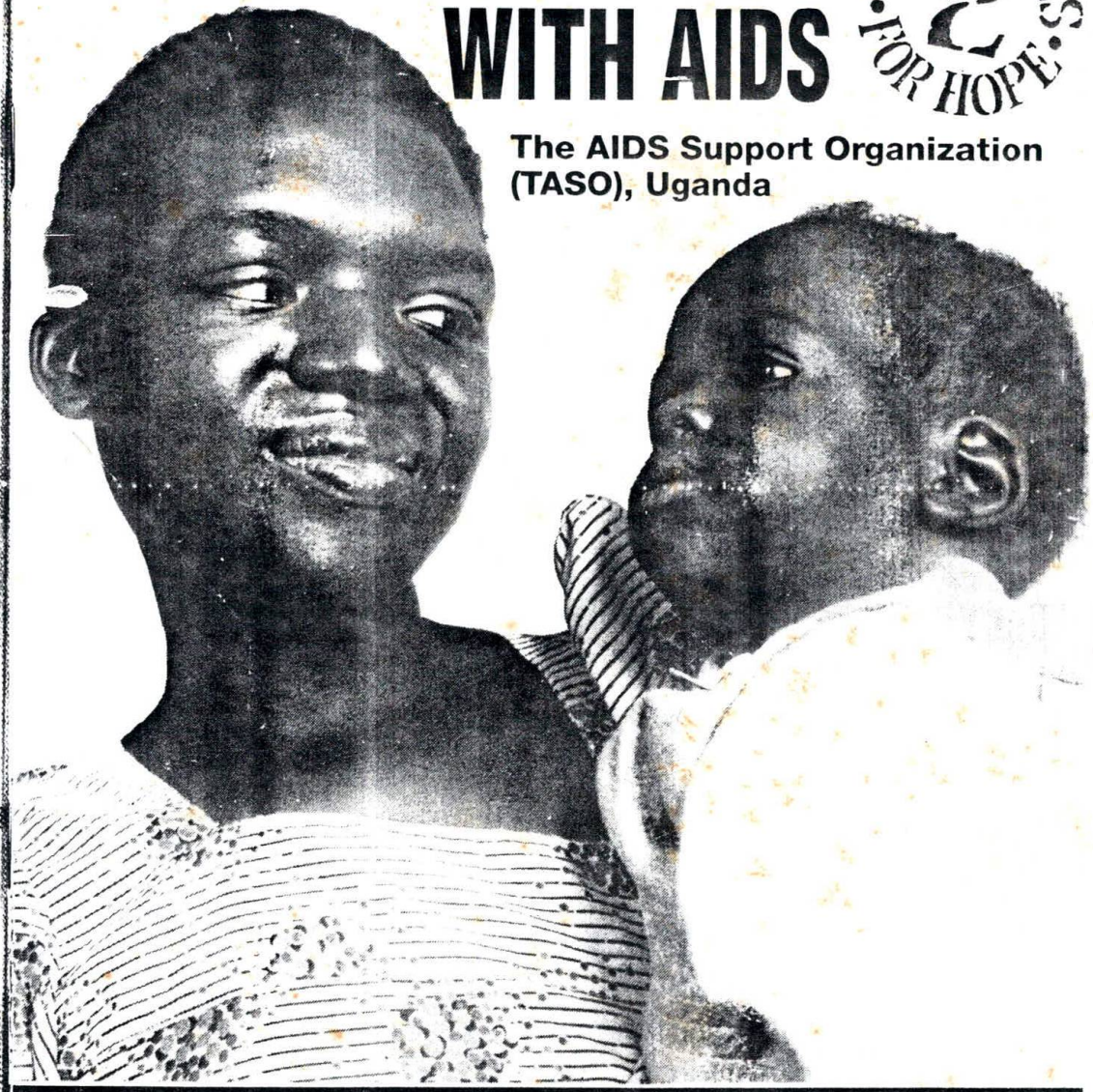
LIVING POSITIVELY WITH AIDS

STRATEGIES FOR HOPE No 2

The AIDS Support Organization (TASO), Uganda



by Janie Hampton

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CONTENTS

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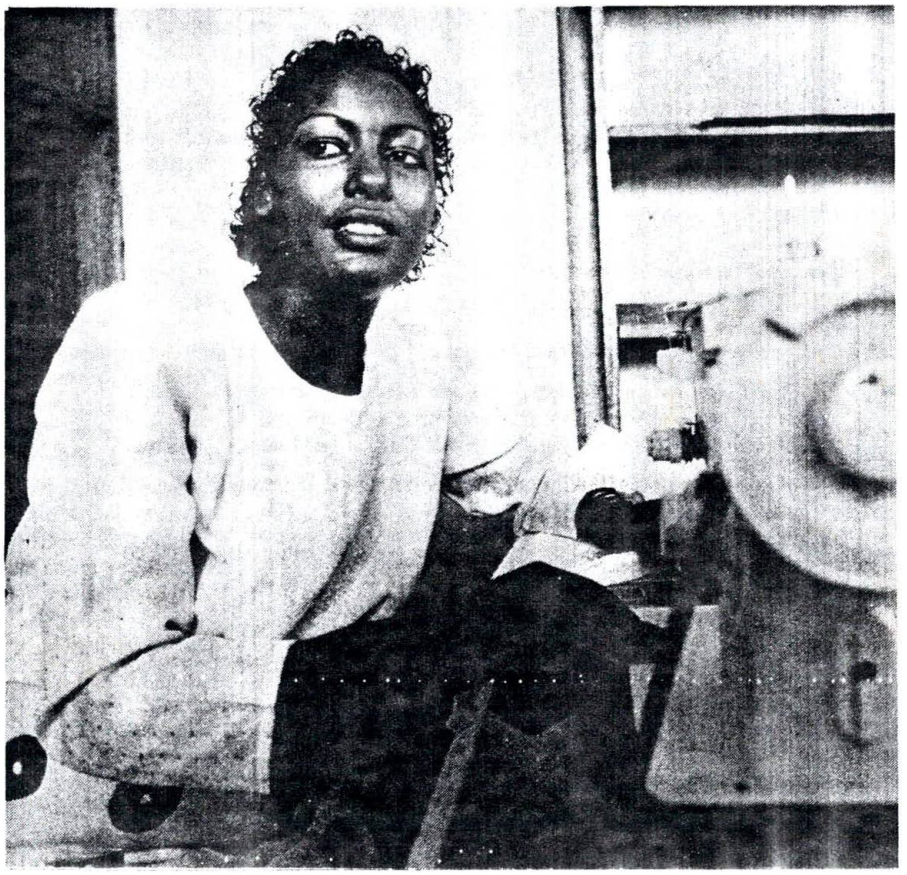
NOTE

The names of all TASO clients mentioned in this book have been changed.



Keeping busy is part of living positively.

Introduction

The AIDS Support Organization (TASO) is the first organized community response to the AIDS epidemic in Uganda. Founded by a group of volunteers in late 1987, TASO now provides over 2,000 people with HIV or AIDS, and their families, with counselling, information, medical and nursing care, and material assistance.

Most TASO workers are themselves people with HIV or AIDS. They know that they may not have long to live. Yet TASO is not pervaded by gloom and despair. On the contrary, it is an organization in which there is an amazing amount of laughter, good humour, and infectious enthusiasm. There is always a sympathetic ear to listen to personal problems and a shoulder to weep on if necessary. But TASO's workers have an overwhelmingly positive approach to life. They embody the organization's commitment to 'living positively with AIDS'.

This book is about that commitment, and how it can be translated into practical action in the face of the prejudice, discrimination and fear that have been generated by the threat of AIDS.

Positive Living

TASO's slogan is 'Positive Living with AIDS'. In practical terms this means:

* Not blaming anyone.

* Not feeling guilty or ashamed.

* Having a positive attitude towards oneself and others.

* Following medical advice by:

– Seeking medical care quickly when infections such as bronchitis, thrush and skin sores appear. Every time a person with AIDS gets an infection, the body's resistance to AIDS is further lowered.

– Not smoking or drinking alcohol, which lower the body's resistance to disease.

– Eating plenty of food which is rich in proteins, vitamins and carbohydrates.

– Getting enough sleep and not getting overtired.

* Taking enough exercise to keep fit (but no strenuous exercise).

* Continuing to work, if possible.

* Occupying oneself with non-stressful activities such as crafts.

* Receiving both physical and emotional affection.

* Socialising with friends.

* Receiving counselling to maintain a positive attitude and talk about feelings, whether angry, sad, blaming or hopeful.

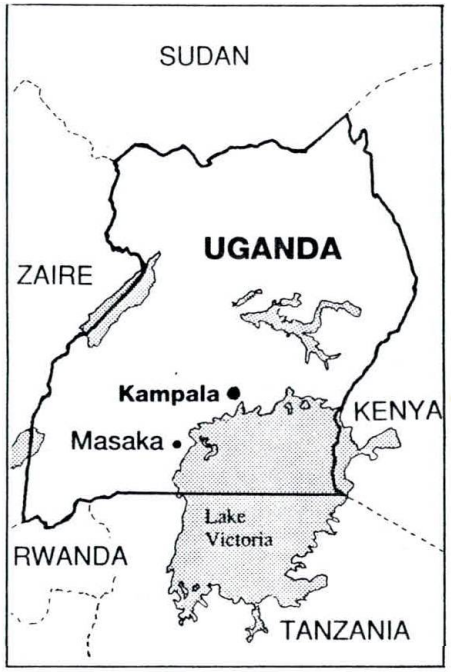
* Always using a condom during sex, even if both partners know they are HIV-positive, in order to prevent pregnancy and avoid catching any other sexually transmitted diseases, which would further lower immunity to disease.

* Avoiding pregnancy because it lowers the body's immunity and can hasten the onset of AIDS in an HIV-positive woman.

AIDS in Uganda

The first cases of acquired immune deficiency syndrome (AIDS) in Uganda were reported in Rakai District, to the west of Lake Victoria, in 1982. Since then the number of cases reported each month nationwide has doubled every six months. By December 1988 over 5,000 cases had been reported to the national AIDS Control Programme, but these are only a small fraction of the total.[1]

The number of people infected with human immunodeficiency virus (HIV) – the virus which causes AIDS – is many times greater than the number of AIDS cases. Surveys in some urban areas of Uganda have found 15-25% of people in the sexually active age group to be infected.[2] At the Mulago Hospital in Kampala, the prevalence of HIV infection among patients admitted for medical treatment increased from 10% in late 1986 to 50% two years later.[3]



In Uganda, as elsewhere in Africa, transmission of HIV is mainly through heterosexual intercourse and from mother to unborn child. Men and women are affected in equal numbers. AIDS in Uganda affects all members of the family – either directly or indirectly. (In the industrialized world, by contrast, AIDS affects mainly single people.) The age of first being diagnosed HIV-positive ranges from around 18 to 30 years for women and from 17 to 37 years for men. The numbers of children born with HIV infection are increasing.

AIDS is an expensive disease. The medicines are costly, and patients are unable to work but need more food. Many Ugandans with AIDS never get to an AIDS clinic because they are too poor or too weak to travel and wait in a long hospital queue. Better-off patients tend to live longer and enjoy a better quality of life because they can afford to buy nutritious food and to pay for medical care and drugs.

For the people of Uganda, AIDS is part of a cumulative catastrophe. The country's economy and social infrastructure are only just beginning to recover from nearly 20 traumatic years of civil war and unrest. The damage has been enormous and recovery is painfully slow. Hospitals and health centres are run-down, and essential drugs and equipment in short supply or non-existent. Many health professionals have either left the country or taken other jobs because their salaries were so low. There are, for example, only five doctors for every 100,000 people.

The Ugandan health services, on their own, cannot possibly cope with the rapidly escalating numbers of people with AIDS who need medical and nursing care, as well as social, psychological, and material support. Government services need to join forces with community organizations in caring for people with AIDS and their families. That is why the emergence of an organization such as TASO is so important.

Origins of TASO

TASO has its origins in a small group of people who began meeting in one anothers' homes in Kampala in October 1986. The group consisted of a truck driver, two soldiers, a veterinarian's assistant, an office boy, an accountant, a physiotherapist, a nurse, a school teacher, and a social scientist. All but one had HIV or AIDS. They met to exchange information, to give one another support and encouragement, and to pray.

In January 1987 one member of the group, Chris Kaleeba, died. His wife Noerine (see **panel**) was devastated:

"I just went to pieces. I knew that Chris was going to die, but when it happened it was just too much. I took my children and left Kampala to go and stay with my parents."

Three months later, when she returned to Kampala, Noerine Kaleeba was determined to do something practical to help people with AIDS and their families. The group which she and Chris had helped to start began meeting once more, and a few new members joined. When TASO was formally established in November 1987, the group consisted of seventeen people, including twelve who had HIV or AIDS (all of whom have since died).

The founding members of TASO had no training in counselling or experience of managing an AIDS support group. There were no precedents for such groups in Africa from which they could learn. They had no office, no transport and no funds. But what they did have was initiative, vision and a deep commitment to practical action on behalf of people with HIV and AIDS, who were being neglected by the health services and ostracized by the rest of society. It was this combination which persuaded two British organizations – ActionAid and World in Need – to provide TASO with the funds to get started.

ActionAid also arranged for two founding members of TASO to participate in a one-week training course for AIDS counsellors in London.

All those involved in starting TASO were practising Christians who regularly prayed together, but they made a conscious decision to make TASO a non-religious organization:

"We want to be open to everyone," says founding Director Noerine Kaleeba. "Everyone should feel equally at home in TASO."

Although TASO is a non-governmental organization, another key factor in its establishment was the open and constructive attitude of the Ugandan Government.

"One cannot rely on government funding, but the government's blessing is necessary," says Noerine Kaleeba. "We have been very fortunate. Uganda's National AIDS Control Programme is run by creative and adaptable people, with a helpful attitude."

Language

At TASO the word 'AIDS' is rarely used. People with HIV or AIDS are described as being 'body positive'. They are referred to as 'clients', never as 'AIDS victims' or 'AIDS sufferers'. The term 'patient' is used only if a client is admitted to hospital.

TASO is also sensitive to words like 'catastrophe', 'plague', and press statements such as 'This person is going to die'.

"We are all going to die sometime, so why pick on a few of us?" said one TASO client. "I have already lived longer than my father, who died of malaria."

Some TASO clients are also annoyed by government slogans such as 'I said NO to AIDS':

"No one has ever said 'Yes to AIDS'," says Susie, a TASO client and counsellor. "None of us have asked for it. Most of us who have it now had never even heard of it when we caught it. You cannot attach blame or assign guilt to anyone. It doesn't matter who was responsible – the husband or the wife or the blood transfusion. The important thing is to think and live positively."

Organization

TASO has two offices – one in Kampala and the other in Masaka, 80 miles to the south-west. These are open from Monday to Friday and clients can come without an appointment. Most counsellors, however, work only part-time for TASO, so clients make an appointment if they want to see a particular counsellor. A file is kept on every client, with details of hospital admissions, medical treatment, material support, visits, and family conditions. Clients are allowed to read their own files.

TASO Kampala's office is a modest,

Noerine Kaleeba Director of TASO

In June 1986 Noerine Kaleeba's husband, Chris, was taken critically ill while studying at Hull University in England.

"The British Council brought me to be with Chris while he was in hospital for four months. He was the first AIDS patient at Castle Hill Hospital, and the staff were marvellous, so kind and compassionate. I met the 'buddy' group* in Hull and for three weeks Chris, our 'buddy' and I talked of nothing else. It was easier for us because we realized that Chris must have contracted HIV from a blood transfusion after a bus accident in 1983. But whatever the exact cause of HIV transmission, it's the effect that has to be dealt with. There's nothing to be gained from blaming one another or feeling guilty.

Chris wanted to come home to die, so in October 1986 he arrived at Entebbe airport to be greeted by a crowd of family and friends. Most were well-wishers, but some had come only to see what he looked like. He was just strong enough to walk out of the plane.

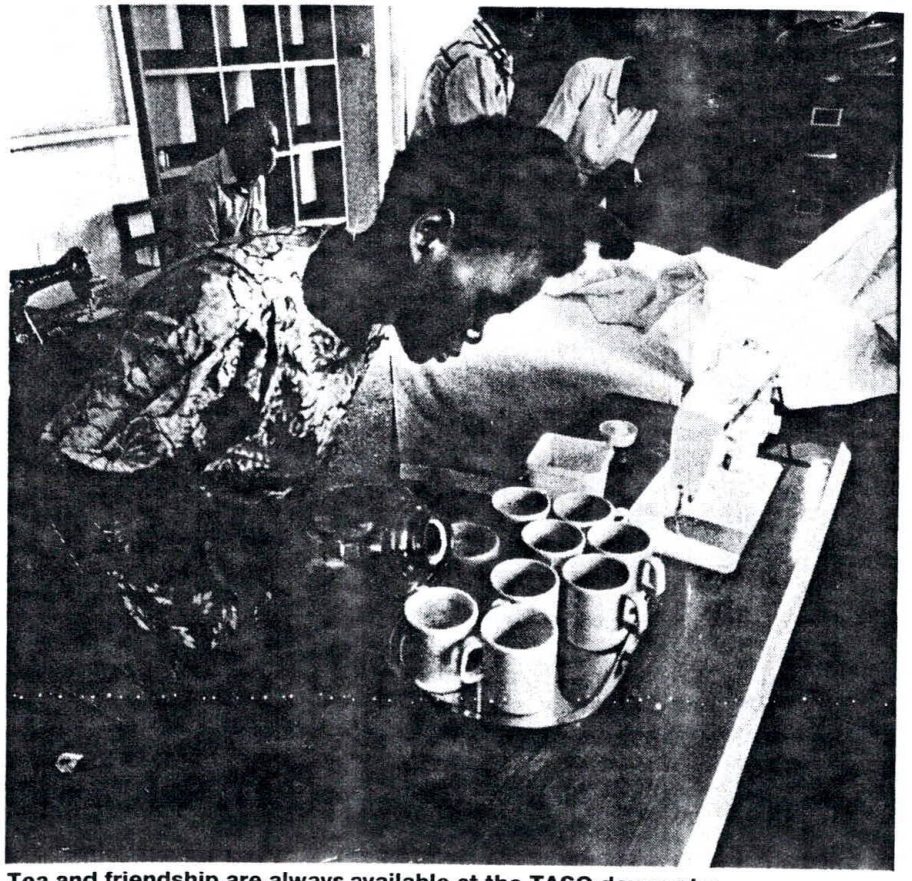
"We tried all the herbal medicines we could find for three weeks. He drank them by the jerry-can full! We never tried witchcraft, which some people suggested. Finally he said: 'Enough, we aren't achieving anything. I'm drinking so much herbal medicine that I have no appetite for food. I must eat good food. Let's plan what to do when I go.'

"There really wasn't much support here in Uganda, except from both sides of the family. But even they didn't fully understand what was happening. They could give emotional support but we were short of medicines and material support. There was stigmatization from friends and neighbours.

"The idea of TASO originated from the example of the doctors and nurses who looked after Chris in Britain – the kindness and care they showed him, despite the fact that he was a foreigner and had AIDS. We were also impressed by what we had seen in Britain of the Terrence Higgins Trust and the 'buddy' system of counselling.

"My Christian faith was strengthened by this experience. Though there have been many times when I have said 'Why me, God?'"

*Volunteers who provide support and counselling to people with HIV/AIDS.



Tea and friendship are always available at the TASO day centre.

unmarked room in Mulago Hospital, a collection of run-down buildings near the centre of the city. A separate building, known as the 'development unit', is used as a training centre and a meeting place. Also in the hospital grounds is a day centre where TASO clients and their families can meet. People come together at the centre to make friends, share information and express their feelings in a safe, friendly atmosphere. Lunch is provided every day for clients, visitors, and any TASO workers who happen to be present. Taking meals together is an important part of demonstrating that HIV is not transmitted by sharing cups, plates and other eating utensils. Every Friday, all TASO workers come to the day centre to share a meal with co-workers and clients, and to exchange ideas and discuss problems.

The day centre is also equipped with four treadle sewing machines which clients use to make clothes and sheets for sale. One client, a talented artist, makes batik hangings which are sold to benefit both the client and TASO.

Places for rest are available for anyone who feels tired and needs to lie down for a short while. Young children are always welcome: their numbers are greatest on Fridays, when the AIDS clinic for children is held at the hospital.

Clients

TASO's clients are people with HIV or AIDS, and their families. In March 1989 there were 140 adult clients registered with TASO Kampala and 85 with TASO Masaka. Some male clients may have wives and families living in distant rural areas who may also be infected with HIV, but are not registered with TASO.

TASO Kampala works within ten miles of the city centre, so their clients are urban and mostly of middle or low socio-economic status. Most are referred to TASO by the two AIDS clinics at Mulago Hospital, and some by other hospitals or private clinics.

TASO Masaka's clients are mostly rural, subsistence farmers referred from the

Eddie
TASO client and counsellor

Eddie is 37, an economics graduate of Makerere University, Kampala. In 1981 he and his wife went to Nairobi for further studies, returning in 1985. A year later his wife had a recurrent fever.

"The fevers subsided for a while, but she kept swelling in different parts of her body. She was admitted to hospital in Kampala with typhoid. Soon after she came out of hospital, still weak, I visited a friend who told me about AIDS. The friend suggested that I should be tested for AIDS. I was found to be HIV-positive.

"I had never heard of AIDS or HIV before, and I didn't know what to do. When I went to the doctor for the results, I couldn't believe it. He just said, 'Well there you are, you're positive. You've got AIDS, so there is nothing I can do. Too bad.' I felt like committing suicide.

"I came home after several hours and during supper I told my wife about the test. After that we cried together. Then she was tested and we found out she had it too. Her relatives wanted to take her to a traditional healer, but we couldn't tell them the truth.

"I was with her all through from the start to the finish. She died a few months ago, at home. I've now lost a lot of weight and my skin is often septic with sores. I am too tired to work. At first I didn't want anyone to know that we had this disease. I even worried about being seen going to the clinic. Then I met two friends there and we talked about it together. Now I don't care who knows. I feel that my experience might help others in showing them that hiding is no use.

"The children are my main worry. They are nine, five, and three years old now. The young one is always sick, she has a fever and diarrhoea a lot. I'm sure she has AIDS too, but I can't bear to get her tested. We are very close to each other. I know now that I will die before I can bring them up, so what will happen to them then?

"I often wonder who brought the disease into the family. I lie awake at night wondering, which of us is to blame? It might have been either of us I suppose. But now I have joined TASO I am trying not to blame anyone, myself or her. OK, I have the disease, but I am going to use my skills and experience to help other people before the disease gets me."

AIDS clinic at Masaka Hospital. Some clients come straight to the TASO office after hearing about the organization from friends, and TASO then refers them to the AIDS clinic in the local government hospital for diagnosis.

Some clients want TASO to take over responsibility for everything – finances, food and housing, as well as emotional stress. TASO does not have the resources to do this, and in any case does not want to become simply a 'hand-out' organization.

"The main objective," says TASO Director Noerine Kaleeba, "is to help people to come together and discuss things and feel accepted. The sense of belonging restores their dignity. It's much better if they can come out and have some activities and friends. Otherwise quite a few would just give up."

But not everyone who is offered counselling and other support from TASO takes up the offer. AIDS carries a powerful stigma, fuelled by fear and ignorance, and some people are afraid that TASO will tell their employers, or that their workmates or neighbours may learn that they are HIV-positive. Others fear they will be asked too many questions, or be blamed for contracting the disease. Some try to deny they have AIDS by moving house and changing their jobs, or even their names. (They may then continue to spread the virus through sexual activity.) Others reject the offer of counselling and medical care in the belief that it cannot help them. Some believe they have been bewitched or have not observed the correct rituals, and so seek treatment from 'witch doctors' or traditional healers. Many ignore the problem until they are too ill to make plans for their families.

Confidentiality is of prime importance to all TASO clients. There is no sign outside the TASO office, and only one of the organization's four vehicles is identified as belonging to TASO. Several clients have specifically asked that this vehicle should not come near their homes. Some clients are able to work through the initial fear of being identified as a person with HIV or AIDS. Others, however, risk losing their jobs and homes, or being rejected by their spouses.

Noerine Kaleeba is well-known in Kampala as the Director of TASO, so she reassures new clients and counsellors that, for their own privacy, she will not greet them in public places:

"Everyone knows what I do, so if someone sees me giving you a hug, they may start spreading rumours."

Staff

TASO Kampala employs seven full-time staff and 17 part-time counsellors, trainers and advisors. The full-timers consist of the Director (Noerine Kaleeba), an accountant, a publicity officer, an administrator, a secretary, a driver, and a cook/cleaner. The part-time workers consist of a medical adviser, three counsellor/trainers, 12 counsellors and an honorary legal adviser.

TASO Masaka employs a part-time medical adviser and a full-time office messenger. The 12 part-time counsellors in Masaka include two nurses, a social worker, a medical assistant, a school teacher, and several unemployed people with HIV or AIDS.

TASO follows a policy of actively recruiting people who are HIV-positive, especially as counsellors. Many first come into contact with TASO as clients and then decide to become actively involved in the organization. They fall ill more often than healthy people and several have died since starting work with TASO. This causes a lack of continuity in TASO's work, but Noerine Kaleeba believes that the advantages of employing people with HIV far outweigh the disadvantages:

"People with AIDS are a special asset to TASO as counsellors. They are closer to the clients and make them feel more normal. They can talk from personal experience of the emotions and problems caused by AIDS, and can help people overcome them."

Fred
TASO client and office messenger

Fred is 26 and was a taxi driver. He is married with four children.

"I started to get severe fevers and was admitted to hospital for a week. Eventually I was too weak to drive any more. I suspected I might have AIDS, but I was afraid to find out. Then I came to TASO and they counselled me about the test. So I wasn't so afraid to have my blood taken. When I found out I had the virus, they were very good to me.

Then they employed me as the TASO office messenger. My mother had ten children. I've lost two brothers to this disease, but they did not have any support. They left seven children between them. Two more of us are HIV-positive and we have 16 children between us. I haven't enough money to make sure my children will be OK. There is nothing left to sell. My mother always cries when she sees how thin I'm getting."

Counsellors have about ten clients each, whom they visit at home once every week or fortnight. A counsellor remains with the same client from the diagnosis of HIV infection until death. Even when a client has died, the counsellor remains in touch with the family, which may contain other people with AIDS or orphaned children. Counsellors are accountable to their clients, but also report to the TASO doctors, their supervisors, and the office administration.

All counsellors first have to complete a four-day induction course run by TASO's own training staff (see Appendix). They are paid 1,200 Ugandan shillings (US$4.80) a day, and also receive a free lunch and transport to their clients' homes. Counsellors who are HIV-positive continue to receive material support such as eggs and school fees for their children.

Once a week all counsellors meet for a whole afternoon to discuss the progress of their clients as well as their own problems. The stress of working with terminally ill patients can lead to conflicts requiring quick resolution.

Medical care

Medication is provided free to clients under medical supervision, as long as supplies (or funds to purchase them) are available. The drugs are given out at the TASO office, at the AIDS clinics in hospital, and on home visits. TASO receives some drugs as donations and purchases others locally.

Drug supplies, however, are far from adequate. In 1988, for example, TASO budgeted $5,000 for expenditure on all drugs, but eventually had to spend $8,000 on supplies of a single product, *Nizoral* (for the treatment of oral thrush), which cost 500 Uganda shillings (US$2) per tablet on the open market.

Some TASO clients have reported relief from certain AIDS symptoms after taking herbal medicines, but these have not yet been tested scientifically. Research on

certain herbal preparations, however, is now in progress.

Both TASO branches have a medical adviser who is paid a token sum of 2,000 Shillings (US$8) a month for attending TASO clients two to three mornings a week, and whenever a TASO client needs urgent medical attention. They also run separate HIV/AIDS clinics for adults and children once a week at hospital, seeing up to 45 patients a day.

Dr Elly Katabira, who is the medical adviser to TASO Kampala, also works as a physician at Mulago Hospital and as a Lecturer in Medicine at Makerere University. When he first set up an AIDS clinic at Mulago Hospital in late 1987, many of his colleagues were sceptical:

"Health workers knew there was no cure for AIDS, so they assumed that people with AIDS didn't warrant any medical care. We started the AIDS clinic to show what could be done. We had to demonstrate to patients and health workers alike that people with AIDS who come in very sick can leave the hospital walking."

Dr Katabira's AIDS clinic has been inundated with patients. By February 1989 he had seen a total of 850 adult patients - 55% men and 45% women. The most common symptoms were weight loss, recurrent fevers and diarrhoea.

Dr Sam Kalibala is the medical adviser to TASO Masaka. Since his HIV/AIDS clinic opened in November 1988, the number of new clients has doubled every week. Working with TASO has changed his approach to treating people with HIV/AIDS:

Dr Elly Katabira prescribes medication for a mother and her HIV-positive child.

"I used to see people with AIDS, but before coming into contact with TASO I didn't know what to do. I didn't know what to tell them because I felt I couldn't do much for them. So we were hiding the diagnosis. It was too painful to tell them. But when I heard about positive living with AIDS, I saw there was something that could be done - for example, by counselling people before and after the HIV test."

Patients are usually referred to an AIDS clinic on the basis of their clinical history. The doctor at the clinic takes the patient's history and either makes a clinical diagnosis or offers the patient an HIV test. If the patient agrees to undergo the test – and providing HIV test kits are available at the time - a blood sample is taken. The result is usually available a week later. If the test is negative, a TASO counsellor explains how the patient can avoid becoming infected with HIV. If the patient asks for condoms the counsellor provides some free of charge and also explains how to use them correctly.

If the result is positive, the doctor explains the implications to the patient:

"When I make an AIDS diagnosis," says Dr Katabira, "I have to tell the patient that there is no cure for the virus, but there is a lot that can be done to treat the infections that may come along as a result of HIV infection. The period from HIV infection to death is usually less than two years, but it may be up to five years."

TASO counsellors are also on hand at the clinic to offer clients counselling and other support. Often, however, the clinics are packed and if only one or two counsellors are on hand it is impossible to meet and talk with all potential clients. At the time of the initial diagnosis clients are usually in such a state of shock that in-depth counselling is not possible. Counsellors concentrate on reassuring them that they are not about to die, and arrange to visit them at home within the next week.

Children's clinic

An AIDS clinic for children is held every Friday morning at Mulago hospital in Kampala. Over 140 children with HIV/AIDS are registered with the clinic, and more than 30 are brought for diagnosis or treatment every week.

Most of the children are babies or toddlers. Babies infected with HIV develop AIDS more quickly than adults. Few survive beyond the age of two years, and many die before being diagnosed as having AIDS. Most die within a year of birth, often of dehydration or malnutrition due to repeated diarrhoea and other infections. Many are not brought to the AIDS clinic until they are already close to death.

TASO counsellors talk with mothers as they sit on a low wall, suckling their babies before seeing the doctor. The nurse calls the mothers into a small room where Doctor Laura Guay sits close to them, clicking and smiling at the babies. She asks the mother how the baby is this week and examines the baby gently, feeling for swollen lymph nodes, listening to the chest, and looking in the mouth for thrush. Many babies require ampicillin for chest infections, others are given oral rehydration salts for diarrhoea. Whenever the drugs run out TASO provides whatever it can until the hospital's supplies are replenished.

Blood tests are usually necessary to diagnose HIV infection in babies and young children because the symptoms of AIDS in young children are similar to many other children's diseases. But taking blood often involves a struggle. Doctors and nurses may have to take blood without the protection of rubber gloves simply because there are not enough gloves available. Inevitably, blood is spilt from time to time. Dr Katabira insists that the safety risk is negligible:

"It's quite safe as long as you wash your hands well with soap and water afterwards.

Susie
TASO client and counsellor

Susie, 24, took 'O' Levels at school and then got married. By 1986 she had two children. Her third child died a few days after a premature birth. During her fourth pregnancy she was sick a lot. The baby was born at full term but became sick after a week. Susie was also ill and they were both admitted to hospital. Sickle cell disease was diagnosed shortly before the baby died. Susie recovered but was then readmitted to hospital with typhoid.

"When I found I was HIV-positive, I did not know what to do. My neighbour got AIDS and she tried to kill herself and her children. I too felt like taking poison. I looked so ill. I couldn't walk or do anything. Then I heard about TASO and since then everything has changed. I feel much better now. When I am sick they support me and are kind. They give me medicines and some food. The counsellors never neglect you, they support you through everything. My children are my main worry, the school fees are so high. I am hoping that TASO can help with that. My relatives could look after them, but they need help with food and school fees.

"My husband has gone now, I don't know where. When he knew that both my co-wife and I had AIDS, he just went. He must have it too. I still live together with my co-wife and her children. She has two children alive. Three others died.

"Up to now, my parents don't know. I will go and tell them myself soon. I don't want them to find out from someone else, but I have to be strong enough to cope for them as well as for myself. They have paid out so much for me, but now they will get nothing back. I cannot help them in their old age. The people we share a house with wouldn't let us live there if they knew. They have said in front of us 'If anyone had AIDS, we would throw them out'. So we can't tell them, but they will suspect eventually. I hope that TASO will help them to realise that it is not a threat. We are suffering more from this disease because of people's ignorance. It is bad enough without ignorance as well. But we have to fight the virus, so we can live longer."

Susie attends the day centre most days, but sometimes she is too weak to work as a counsellor. She has been coughing for three months and frequently has diarrhoea and vomiting with headaches.

The main danger of infection is not from HIV but from diseases such as TB, hepatitis or typhoid."

All the mothers of babies and young children with AIDS are themselves HIV-positive. They may discover this only when their babies are diagnosed.

Hospital admissions

People with AIDS are admitted to hospital whenever they require in-patient treatment, which is given free of charge. Severe dehydration after diarrhoea or vomiting is the most common reason for admission. Most diseases associated with AIDS are treatable. Surgery, however, is used only very sparingly because of the risk of precipitating AIDS in a person with HIV infection by further weakening the body's immune system.

Mulago Hospital does not systematically test in-patients for HIV infection. However desirable it might be to do so, there are simply not enough AIDS testing kits available. Diagnosis is usually done on the basis of a physical examination. Many hospital patients are admitted, treated and discharged without the staff knowing that they are infected with HIV. Nurses are not issued with gloves for general nursing care, but are taught to be careful and to wash their hands thoroughly after contact with patients.

The hospital does not have a special AIDS ward. Dr Katabira believes that such a ward is not justifiable and could lead to other problems:

"A special AIDS ward would increase the stigmatization of people with AIDS.

Noerine Kaleeba counsels a mother at the children's clinic.

A Hospital Visit

Sally lies in her bed in the passage of the mixed medical ward. She has no sheets and the mattress is stained and worn. A thin blanket covers her emaciated body. Most of the other patients have a relative sleeping under the bed, their cooking pots and blankets piled around them. Sally has no-one. Her relatives simply brought her to hospital and left her.

Mary, a TASO counsellor, brings her eggs and some anti-lice shampoo. "These mattresses are full of insects," she explains.

Sally receives free medical care, but TASO has to pay a hospital orderly to make up a flask of tea every morning and wash her. She can barely raise her head to sip the tea.

"We used to see a lot more like her," says Mary, "but now relatives are learning that there is no danger in caring for people with AIDS. Many relatives are a lot more caring than some health workers."

In the next ward lies Rejoice, aged 18. As Mary approaches she tugs her blouse over her bare chest, but there is nothing to hide. Her ribs stick out through the sagging skin and her breasts have withered away, leaving just flat nipples. She can't sit up, but smiles with pleasure to see Mary. Rejoice's mother takes the bag of eggs, milk powder and soap. She has already lost one daughter to AIDS, and has been with Rejoice ever since she was admitted to hospital. Rejoice's 12 year-old brother comes in smiling, carrying the day's shopping and clean bedding. He will sit and read to his sister while their mother takes the bedding home to wash.

The children's ward smells strongly of urine and the noise is deafening. The mothers are lining up with their babies and children for injections. Some are so thin there is barely enough flesh for a needle to penetrate. By the window lies Karen, aged 14 months, a tiny body in a large metal cot. Karen is dying of AIDS. She weighs a mere 6.5 kilos – the weight of a normal 3 month-old baby. Her mother sits beside her, their belongings under the bed. Six weeks ago Karen was well and just beginning to walk. Then she had a fever, diarrhoea and vomiting. Now she can't even sit up, let alone crawl. A tube is taped across her face, leading into her nose and down to her stomach. Karen's mother expresses breastmilk into a cup and feeds her through the tube.

Karen's mother knows that she must be HIV-positive too, though she is not yet ill. She is already concerned about the future for her other two children after she dies. Mary reassures her that she is not going to die soon, but TASO will help with the other children if the need arises in the future, as long as the children can stay with relatives.

These patients are no more of a risk in a general ward than other patients. We believe that all patients should be nursed and managed in the same way, as if they were all HIV-positive."

In any case the problem of AIDS is already too enormous to be dealt with by separating AIDS patients into a single hospital ward. In Kampala alone it would be necessary to allocate up to half of all hospital wards to AIDS patients, and there are no valid medical grounds for doing this.

"Every AIDS patient," says Dr Katabira, "is admitted with a different problem. They cannot all be lumped together."

Home care

TASO counsellors try to visit clients once a week at home, unless clients prefer to come to the TASO office. Counselling is done in the local language whenever possible. TASO counsellors spend a great deal of time listening to clients and their families talk about their problems. Rather than prescribing solutions, they aim to provide their clients with information about how they can look after themselves and lead positive lives. Noerine Kaleeba is convinced that this approach is effective:

"People with HIV can live positively by gaining morale, rather than giving up. They can choose to eat good nutritious foods, and not to smoke or drink alcohol. They can get immediate medical care for every infection. Through positive living, people with HIV can make the most of their remaining time and even extend it."

Home care has many advantages over hospital care. It enables the counsellor to assess the client's social and economic situation. It also helps to break down or prevent the sense of isolation experienced by many people with HIV and AIDS. Home care also brings the counsellor into contact with other members of the client's family.

Home Visits (morning)

Godfrey's first home visit of the day takes him to a township on the outskirts of Kampala. The TASO vehicle stops under a banana tree. Godfrey and the driver, Sam, climb out and walk past a patch of sweet potatoes to Sandra's house. There are six outside doors, each one leading into a dark, windowless room with an earth floor and bare mud walls.

Sandra appears from behind the house, where she has been tending the cooking fire. She is tall and very thin. Her face is so wizened she could be any age. Her prominent cheekbones emphasize the depth of her eyesockets. She has only one child, four year-old Rosie.

After the formal greetings, Sam sits under a tree and plays with Rosie and her cousins, while Godfrey goes inside the house with Sandra. She shares a room with Rosie and a young niece. There are 22 members of this extended family, ranging from a six day-old baby to two grandmothers in their seventies. Godfrey gives Sandra eggs, milk powder and a bag of clothes for Rosie.

Sandra and Rosie were living in a rural area until they were called to Kampala because her husband was sick. By the time they arrived, he had died of 'unknown causes'. Soon afterwards Sandra fell sick, and was too weak to go back home. By this time the family suspected that her husband had died of AIDS. Afraid that they would catch it too, they isolated Sandra. She had to stay in one room, with her food left at the door. No-one spoke to her. She lay on the floor, with diarrhoea, vomiting and headaches. One day she was so bad that her relatives carried her to the main road and took her by bus to the hospital. She was admitted and the doctor diagnosed HIV infection. A week later, when she was feeling much better, she learned about TASO through Godfrey, who had been appointed her counsellor. He realised that his first task was to counsel the family and show them that there was no risk to themselves. As a result, Sandra now shares their food, and sits and talks with them. Now that she receives medical treatment as soon as she is sick, Sandra feels well most of the time. She often goes to the TASO day centre and sews hospital sheets. She has been admitted twice more to hospital, and although she gets thinner and a bit weaker each time, her spirit remains strong.

Rosie has been tested and is free from HIV. When her mother dies she will not have the additional stress of moving elsewhere. She already has a home and a family who care for her, with aunts young enough to be around until she grows up.

During a home visit a TASO counsellor explains that AIDS is not transmitted through clothes or food.

Home Visits (afternoon)

After lunch Godfrey visits a block of flats near the centre of Kampala. Michael lives here in two small rooms with his wife, six children (aged from four months to 12 years), his sister and her three children. There is no electricity and the nearest water is a tap in the next street.

Until a year ago Michael worked in a factory and the family lived in a better home. But when he started to become ill he lost his job and he fell behind with the rent. When they were thrown out he had no choice but to move in with his widowed sister. She is a market vendor, selling cakes which she makes on a charcoal burner in the street outside.

The children run in and take Godfrey's hand while he talks to Michael and his wife, Franny. Franny feeds the baby, who is bouncy and chuckly, even though she is HIV-positive. So is two year-old Henry. The other four children are free of the virus.

Michael is worried because the shingles have returned on his body. The rash itches all the time and he can't sleep at night.

"Are you both eating well?" Godfrey asks.

"We try to, but with twelve mouths and only the cake money, there isn't much to go round."

Godfrey says he will bring more food on his next visit, but meanwhile Michael should come to see Dr Katabira for some medication for the skin rash.

Franny offers Godfrey some tea, but he has other visits to make and leaves, the children all laughing and shouting goodbye.

Further down the dirt road lives Mrs Owagi in a small earth house. A year ago her widowed daughter died of AIDS, leaving two children aged four and five. Her daughter was a TASO client, so TASO now pays the children's school fees and also brings them soap, eggs, milk and clothing. Mrs Owagi does not know how old she is, but her bones ache, especially when the rain pours down and water rushes straight off the road into her house. Whenever she wants drinking water she has to buy it from a water carrier or fetch it herself.

"I don't know what we would have done without TASO," she says. "But even so I worry about when I go. The children are so young."

Ugandan families have been caring for their sick relatives for generations. There is a great deal that family members can do to protect the health and prolong the lives of their loved ones with HIV/AIDS. By adopting a loving, positive attitude, they can help to maintain the person's morale. They can also make sure that the person eats well and gets prompt treatment for infections.

First, however, family members need to be reassured that they are not at risk of contracting AIDS through casual contact with the infected person. The TASO counsellor demonstrates this in practical ways – for example by sharing cups, eating utensils and food with the client. Relatives may also be worried about bedding and clothes which become soiled with faeces or blood. The counsellor demonstrates how to make these items safe by soaking them in a bleach solution or simply washing them with soap and hot water and drying them in the sun. Both methods kill the virus.

Material Assistance

Each TASO client receives free of charge 30 eggs a month and four kilos of milk powder. Other foods such as cocoa-mix, baby porridge and flavoured drink powder are handed out as and when TASO receives them. This is not entirely satisfactory as the

supply is erratic and the food is not all nutritionally sound.

Second-hand clothes, whenever available, are also given to families according to need. Condoms supplied by USAID are provided free. TASO has also produced a leaflet in Luganda (the main local language) about the use of condoms.[4]

School fees are paid for some children of TASO clients or deceased clients. Every effort is made to keep children at the same school, unless the cost is prohibitive or the child has to move to relatives in another area.

Orphans

One of the most agonizing worries of people with AIDS is the fate of their children after they die. In Uganda it is traditional for relatives to adopt children whose parents have both died. In recent years, however, some relatives have rejected children orphaned by AIDS because they do not understand how the disease is spread and are afraid of contracting it themselves. In some communities the traditional system of adoption has broken down because so many adults have died that the few surviving relatives are simply unable to bear the burden of caring for large numbers of young children.

TASO believes that orphaned children are best cared for within families rather than in orphanages. If no relatives are available, every effort should be made to place the child with friends of the deceased parents. In order to overcome prejudice against children whose parents have both died of AIDS, TASO helps clients to identify relatives or friends who can adopt their children after both parents have died. TASO counsellors also explain to potential foster parents how AIDS is spread in order to dispel misconceptions and overcome the powerful stigma associated with the disease. Together with the Save the Children Fund, TASO also provides foster parents with food, clothing and financial support to enable children orphaned by AIDS to attend school.

TASO helps parents with AIDS to plan for their children's future.

Nurses discuss their feelings about AIDS during an orientation workshop.

Training

All TASO workers – including drivers and cleaners – attend a four-day induction course which covers the basic facts about HIV and AIDS, explores the emotions of people diagnosed as being HIV-positive, and imparts basic counselling skills (see Appendix). Trainee counsellors start by watching experienced counsellors at work in the AIDS clinics for children and adults, and later are allocated their own clients.

This course is also open to health professionals, social workers, and religious leaders. (Twenty nuns, three Catholic priests, one Protestant pastor and one Islamic leader have so far completed the course.) Visiting journalists who wish to film or write about TASO's work are politely but firmly requested to participate in this course before interviewing TASO workers or clients.

TASO also offers a 20-week half-time certificate course in advanced AIDS counselling for counsellors who already have some training and experience.

In addition, TASO organizes orientation AIDS workshops of one-to-three days

courses for various types of health and social workers, as well as community and religious leaders. About 150 Catholic and Protestant leaders, for example, have so far taken part in these workshops.

Counselling the counsellors

Counselling people with AIDS is very stressful and places the counsellors themselves under a great deal of strain. All have families of their own to care for and most have difficulties in making ends meet. However much they try to encourage their clients to live positively, the fact remains that everyone with AIDS is going to die prematurely. For those counsellors who are HIV-positive the strain is even greater. Yet the pressures on them – from clients and family members alike – are enormous and unrelenting. Inevitably there are times when the stress becomes too great. One sign of excess stress is when counsellors feel that no-one appreciates their work and there is no point in carrying on. Stress may also come to the surface in arguments about management issues, or how supplies should be distributed. When everyone is under stress people do not notice when others are as well. Counsellors need to feel that their work is appreciated. They also need opportunities to share their feelings and frustrations.

When several counsellors were nearing the point of 'burn out' TASO organised a Quilt Day. Clients and workers (there is no distinction in the way they are treated) gathered at the TASO development unit with pieces of cloth and began to make a colourful patchwork quilt. Six foot long and three feet wide, the quilt was to be sent to 'The Names Project', which commemorates people who have died of AIDS all over the United States. The TASO quilt is the first to be made in Africa, sewn by people with AIDS as their own memorial.

Keith
TASO client and trainee counsellor

Keith was a primary school teacher for 20 years in Rakai District, the area in Uganda first affected by AIDS.

"I saw and heard stories of people suffering for several months with diarrhoea. We thought, 'This is witchcraft, it won't affect us. It has come with the smugglers from Tanzania. They have been bewitched for not paying their debts.'

"Early in 1986 my wife had some of the symptoms, so I wanted to know more about the disease. Then I started to get sick from time to time. My best friend called me to Kampala and he died of AIDS a few days after I arrived. But before he died he told me about TASO. At first I was afraid to go there, because I had heard that some places were killing people with this disease. We decided that they had a Christian heart, so they couldn't want to kill us. I went to their office and now I'm training to be a counsellor. I was greatly impressed by the people there. They were open, friendly and easy to talk to. They showed me not to be afraid that we are going to die.

"But I am still afraid for our people because there is no cure. Friends may run away and abandon you. If they see anyone who might be sick, for whatever reason, the people in the market say 'Yes, that one is going. He'll be dead soon, you'll see.' If someone has any slight fever, they say, 'That one may now have the insect (virus). Who is she loving?'"

The TASO vehicle delivers food, medication and clothing to clients' homes.

Funding

Since the establishment of TASO in November 1987, two British organizations – ActionAid and World in Need – have paid TASO's running costs (salaries, drugs, supplies, transport, office administration) and capital expenditure. In 1988, for example, the budget was $140,000, of which $40,000 was capital expenditure, mainly for the purchase of three four-wheeled drive vehicles. In 1989 TASO expects to spend approximately $300,000 on running costs and capital expenditure.

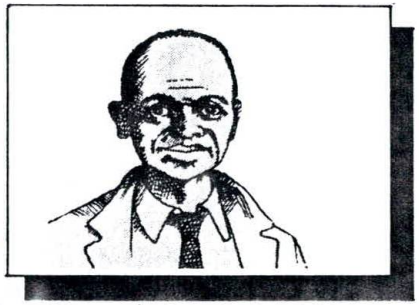
Two US organizations – Experiment in International Living and USAID – have contributed funds for training and equipment. In addition, Voluntary Service Overseas (UK) has provided a trainer of counsellors for two years. The Danish Red Cross, the German Emergency Doctor Service, and the Pentecostal Church have

Role play teaches counsellors how to listen effectively.

Bill
TASO counsellor

Bill has been a medical assistant in Rakai District for 28 years. He has ten children.

"Since the early 1980s we have been seeing this disease, but at that time it had no name. We thought it was only smugglers from Tanzania who got it, because they were bewitched. But since we medical people don't believe in witchcraft, we were puzzled. Then we saw people affected who were certainly not smugglers, and who didn't move about anywhere. I tried using strong drugs, but it still reoccurred and people died. As time went on, there were so many. It was such a worry, how to cope with them all. You lose credit because your patients don't get better and die. Some doctors won't even treat patients they suspect have AIDS. I've also seen many cases wrongly diagnosed - sometimes it's just a curable disease, but they stop the treatment because they think it's AIDS.



"Before TASO started coming to the AIDS clinics there was no support given to the patients after they were told they had AIDS. Many of them were very upset and they just got up and left the hospital. The hospital staff also used to be afraid of people with AIDS and either sent them away or isolated them. Now they are cared for just like other patients.

"Whenever I go home, I get so many people approaching me for advice. Many of my people are getting wrong information, especially from the witch doctors. When I retire in a few months time I want to help the people at home. I lost a brother and friends through AIDS so I really want to do something about this great problem."

also provided assistance, and local voluntary organizations have held fund-raising events for TASO.

The future

In the immediate future TASO aims to train more counsellors to meet the rapidly growing needs in Kampala and Masaka. TASO also plans to help establish AIDS support groups in other parts of the country. Says Noerine Kaleeba:

"These groups must be initiated by committed local people. We can show them what we have done and give them training, but it is up to each group to run itself independently. All you need is a willing doctor, counsellors and commitment."

Orientation workshops will also be organized for health professionals – from orderlies through to senior consultants – at all hospitals throughout the country, starting with Mulago Hospital in Kampala.

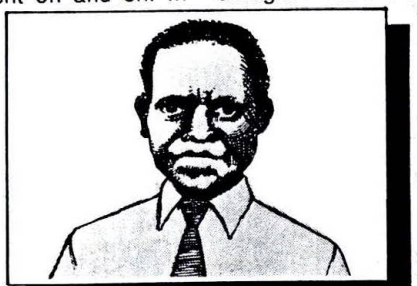
TASO workers are also writing a booklet on positive living with AIDS, based on their personal experiences. Also in preparation is a broadsheet explaining the aims and work of the organization, to be distributed at AIDS clinics throughout the country.

The growing demands on TASO's services also mean that there is a need for more

Gilbert
TASO client and counsellor

Gilbert, 36, was working as a civil servant until a year ago.

"I kept falling sick, having fevers and diarrhoea which went on and on. In December 1987 I learned I was HIV-positive. My sister is a nurse and she realised what was wrong with me. At first she didn't want to tell me, she was afraid of my reaction to the news. She introduced me to Noerine, who invited me to visit TASO. There I met other people in the same position. They all looked fine and healthy, but we all had the same problem.



"Work was getting too difficult and tiresome and I asked if I could become a TASO volunteer. After three months TASO started to pay me as a counsellor. As an HIV-positive person myself I can talk to doctors and tell them what our concerns and feelings and needs are. Doctors or other people without personal experience don't really understand, however hard they try. It is easier too when counselling other people. It helps them when they know that I have it too.

"I have to accept that this is a disease that cannot be cured. It is fatal, but in the meantime I can do most things normally, although I sometimes have to spend a few days in bed. I'm glad I landed in TASO. If I hadn't been here I would have thought I was the only person like this. They understand here, so the work isn't too taxing. I do get annoyed very easily, perhaps because I get tired. The major thing that keeps me going is the positive feeling I have."

Gilbert's wife and three children have moved into a small house near the TASO office, so Gilbert can go home whenever he feels tired. He can also see a lot more of his children, who are at primary school nearby.

"As a father I feel much closer to my children. I have made every effort to get them here with me and now I want to spend as much time as possible with them. I must be with my family and help them while I'm here. When I'm ill, my wife and children can care for me much better than anyone else.

"Being HIV-positive is like being sentenced to death. Some people get stuck in the condemned cell and they can't see their way out of it. But we are free to leave the cell and to live a good life until the end."

vehicles, drugs, equipment, and physical facilities. The hired buildings currently used by TASO in Kampala are already totally inadequate, and ActionAid has pledged support for a new building which will have three offices and counselling rooms, a kitchen, toilets, a day centre and a garage. This building will also be sited within the Mulago Hospital, which provides TASO's clients with a degree of anonymity and is easily accessible.

As TASO continues to expand in response to growing needs, it will inevitably encounter management and personnel problems. As in the past, the organization's staff and volunteers will identify and tackle each problem with ingenuity, commitment and good humour.

Conclusion

TASO has provided hundreds of people with HIV/AIDS, and their families, with invaluable information, medical care and material support. Perhaps even more importantly, it has helped people with HIV/AIDS regain their self-respect through playing socially useful lives within their families and communities. It has also helped change the attitudes of many health workers and community leaders towards people with HIV/AIDS.

But TASO is only one small organization within a vast sea of need. Uganda needs AIDS support groups in every town and rural district. Many other countries in Africa also need community organizations of this kind.

TASO has demonstrated that a small group of people, with some external assistance but with no previous experience, training, or institutional support, can establish an effective organization within a matter of months. What is needed, above all, is a combination of initiative, commitment, and a vision of a future in which people with HIV/AIDS will be treated with compassion and respect rather than prejudice, ignorance and fear.

APPENDIX: TRAINING COURSES

TASO's training courses present the basic facts on HIV and AIDS, explore the emotions experienced by people diagnosed as HIV-positive, and also impart basic counselling skills.

The induction course for TASO counsellors, for example, lasts four days – either consecutively or once a week over four weeks. It has been found to work best with a maximum of eight participants. The health workers' training workshop, with up to 25 participants, usually lasts three days.

The courses have similar subject matter, but their length can be adjusted to the needs and background of the participants.

COURSE OBJECTIVES

1. To show why the course is necessary.

2. To share experiences of HIV and to break down barriers between people.

3. To build trust among prospective counsellors.

4. To examine the objectives of TASO.

5. To examine the emotional feelings surrounding HIV diagnosis at a personal level, in society and in the media.

6. To provide basic information about HIV and AIDS.

7. To introduce counselling skills.

8. To emphasize the importance of confidentiality between counsellor and client.

CONTENTS

6. Thinks about non-verbal communication: takes account, for example, of the client's body language.

7. Relaxes, so that the client finds it easier to relax too.

8. Thinks about sitting positions. A desk forms a barrier between client and counsellor. Put two chairs close together, or sit on a sofa or the floor next to each other. Do not sit on the far side of the room.

9. Keeps eye contact, to establish and maintain communication.

10. Makes a client feel comfortable. Touching is important for warmth and comfort, especially when people with AIDS feel contaminated or isolated. Hold hands or put hand on shoulder.

11. 'Reflects back' what the client has said. Doing this ensures the counsellor has heard correctly, and helps the client think calmly about the situation. "I understand you said. . . ." "So, you are worried you may have AIDS. Why is that?"

12. Helps the client look at new possibilities by providing information and talking about the problem.

13. Helps the client to tell his/her story. "Can you tell me what happened/how you feel/who you are?" Remember that every client is unique, with different problems and different stories.

14. Asks only relevant questions which lead to as much information as possible. 'Closed' questions only receive 'Yes' or 'No' answers. Open questions yield more information and may lead on to other topics.

15. Helps the client make a Family Plan by responding to the following questions:

"What do you need to do?"
"What will you do first?"
"How will you do this?"
"Who might help you?"

Guidelines for responding to clients' questions

1. Give information, not advice. Information allows a person to make an informed choice of their own. Advice tells people what to do. For example, tell clients when the AIDS clinic is held. Don't say "You ought to go to the AIDS clinic."

2. Ensure that the correct amount of information is given in non-frightening terms. For example, warning a client too strongly about the dangers of injections or blood transfusions could frighten the client into never accepting either again.

3. Before giving information, find out what the client already knows, then correct any errors.

4. Only give accurate and relevant information.

5. Be honest. It is better to say "I don't know" than to invent an answer. If asked "How can I be cured of AIDS?" say "You can't be cured, but if you eat well, get infections treated quickly and reduce stress, you can live for several years."

6. For some questions there are no 'right' answers. Remember that every client is different.

7. Look for underlying questions. Clients often 'present' a simple problem behind which a much greater one is hiding.

8. Use simple language, not medical jargon.

Counselling role-play

This exercise is useful at the end of each workshop session. Participants can learn from each other by watching and discussing one anothers' performances. Trainers can check that participants have understood the lesson correctly.

Participants get into pairs, as 'client' and 'counsellor'. The 'client' is given a card with a typical question on it, e.g.

"What causes AIDS?"
"Can babies catch AIDS?"
"Should we share household articles?"

After five minutes of role-play the pairs give a demonstration to the group. Trainers and participants then discuss the performance in a constructive manner, noting the following:

* How the client was welcomed. Did the counsellor look relaxed and ready to help?

*The sitting positions. Were they close together?

* Was the client comfortable?

* Did the counsellor touch the client in a gentle, reassuring way?

* Was the client assured of confidentiality? This is especially important if the client already knows the counsellor.

* Has the counsellor ensured that the client has really understood the information given?

* Was the counsellor listening?

* Was the counsellor giving information or advice?

'ROLES'

The word 'ROLES' is used to help participants remember the most important points about counselling:

Relax
Open
Lean forward
Eye contact
Sitting in a helpful way

FURTHER READING

1. **'AIDS Action'**, an international newsletter for information exchange on AIDS prevention and control. Distributed free to readers in developing countries. Available from AHRTAG, 1 London Bridge Street, London SE1 9SG, U.K.

2. **'WorldAIDS'**, a news magazine reporting on AIDS and development. Distributed free to readers in developing countries. Available from The Panos Institute, 8 Alfred Place, London WC1E 7EB, U.K.

3. **'AIDS Newsletter'**, a digest of recent developments in AIDS research, education, clinical care, counselling, and official policies worldwide. Available from Bureau of Hygiene and Tropical Diseases, Keppel Street, London WC1E 7HT, UK.

4. UNICEF Kampala, **Our Children and AIDS. A Guide to Child Survival**, 1988. Available from UNICEF, P.O. Box 7047, Kampala, Uganda.

5. Gill Gordon and Tony Klouda, **Talking AIDS. A Guide for Community Work**, International Planned Parenthood Federation and Macmillan, 1988. Available from IPPF, P.O. Box 759, Inner Circle, Regent's Park, London NW1 4LQ, U.K.

6. Gill Gordon and Tony Klouda, **Preventing a Crisis. AIDS and Family Planning Work**, IPPF and Macmillan, 1988.

7. Gill Gordon, **AIDS and Family Planning**, flannelgraph and book, Teaching Aids at Low Cost (TALC), 1988. Available from TALC, P.O. Box 49, St Albans, Herts AL1 4AX, U.K.

8. Wendy Holmes and Felicity Savage, **HIV Infection - Virology and Transmission**, slide set and script, TALC, 1988.

9. Wendy Holmes and Felicity Savage, **HIV Infection - Clinical Manifestations**, slide set and script, TALC, 1988.

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1. Uganda AIDS Control Programme, 'Review of Uganda AIDS Control Programme', December 1988.

2. Ibid.

3. Elly Katabira, 'Two years experience in the AIDS Clinic in Uganda', paper presented at 'Integrated AIDS Management: a Conference for Field Workers', Nairobi, 21-24 May 1989.

4. The text of this leaflet is based on *Body Positive*, a pamphlet published by the Terrence Higgins Trust in the United Kingdom.

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STRATEGIES FOR HOPE aims to promote informed, positive thinking and practical action, by all sections of society, in dealing with AIDS.

Non-governmental organizations have a front-line role to play in AIDS control and prevention. In some developing countries, NGOs have already developed new, community-based forms of care, counselling and support for people with AIDS and their families. NGOs are also involved in educating communities about AIDS.

STRATEGIES FOR HOPE describes these pioneering experiences, initially in several African countries, in a series of case study booklets and video programmes. These materials are being distributed with the support of the World Health Organization's Global Programme on AIDS, and in cooperation with national AIDS control programmes.

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