

UNITED AGAINST



AIDS: The Story of TASO



by Peter Kitonsa Ssebbanja

Foreword by Noerine Kaleeba



The **STRATEGIES FOR HOPE TRUST** produces and distributes books and videos that promote good practice in HIV and AIDS work by civil society organisations in developing countries, particularly in sub-Saharan Africa.

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UNITED AGAINST AIDS: The Story of TASO

by Peter Kitonsa Ssebbanja

*United against AIDS
Unite and be safe
Get the facts and get to know
What AIDS is all about.*

Tony Kasule, TASO Mulago Music, Dance and Drama Group

Foreword by Noerine Kaleeba

Edited by Daniel Kalinaki and Glen Williams

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NOTE: The names of TASO clients 'Eddie' (page 13) and 'Susie' (page 20) have
been changed in order to protect their anonymity.

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FOREWORD

As TASO celebrates 20 years of service, people often ask me if I would do things differently if I had the chance. My answer is no. What we did from the start, almost instinctively, without really having any scientific proof of its validity, was to focus our efforts on the person who is infected or affected by HIV. I celebrate the fact that we focused on the quality of life, and on restoring dignity, both in life and in death.

It is easy to look back with hindsight and find some faults with the way TASO evolved, but in fact TASO developed its home-grown philosophy of 'positive living' and exported it to other parts of the world. In addition, long before the principle of GIPA (Greater involvement of people living with HIV and AIDS) became a global rallying call, TASO had instinctively built GIPA into its values and its constitution.

This book captures, in a simple and dignified way, those early days of TASO and what it took to get us off the ground. Twenty years later, TASO has looked after 186,000 HIV-positive people, reaches 56 of the 80 districts of Uganda, has 11 service centres, and has a staff of over 1,000 and an annual budget of over US\$20 million. This book is written to help us understand how it all began, and how TASO today is one of the most widely recognized NGOs in the world. TASO led the call for a dignified life for all and we have continued to combine activism with action – a truly potent synergy for change.

When TASO started, our entry point into the family was the HIV-infected person. We focused on counselling the infected person, and counselling the family to care for the infected person. But this approach had

one major shortcoming, namely, we failed to offer sufficient support to the children of parents living with HIV. In our culture, children are not given explanations: they speak only when spoken to, and don't ask too many questions. I remember how, when we visited our clients in their homes, we would pass the children on the verandah and go and talk to the adults of the family.

I am, however, pleased that TASO is always learning from its experiences, and this book shows how TASO has both grown and adapted to the environment in which it operates. I am particularly delighted with the increased focus in the last three years on children affected by HIV and AIDS. TASO now has 700 children on ARVs, child care facilities and child counsellors at all TASO service centres, in addition to the traditional school fees support for orphans.

Going forward, TASO will need to develop very comprehensive programmes focused on children, not only orphans, but all children affected by the HIV epidemic. Our aim should not be to just provide them with charity, but to ensure that they have well developed survival skills to cope with the tremendous challenges of growing up in a world marked by poverty, violence and conflict. This is a gargantuan task and can only come to fruition if we pull together in partnership and synergy.

It is a sad fact that global efforts to address HIV and AIDS have often failed to transmit lessons and to hold onto them. The response has often happened in a 'pendulum' fashion, swinging from one extreme to another, emphasising one aspect at a time, forgetting that people's lives, needs and environments are different. We have all lost time debating

the focus of our programmes, for example, HIV prevention OR antiretroviral therapy, OR care and support. Condom use OR abstinence and faithfulness! As a country, we in Uganda recently went down the path of promoting mixed and conflicting messages around abstinence and condom use. While those in the two camps were fighting each other, new HIV infections were still occurring.

Nobody should ever say that Uganda reduced its HIV prevalence simply through abstinence or through condoms. It was a combination of both, and much more – including stigma reduction, gender awareness, HIV counselling and testing and the work of TASO and many others – that gave people with HIV a voice and a face. But we still need to go much further. For example, we need to add property rights for women. In our African context, a woman who doesn't have property rights, especially land, or some other source of income, or a good education, has nothing and is therefore very vulnerable.

There is also a huge amount of scope – and an enormous need – for us to do more in the area of HIV prevention. HIV care and prevention are two sides of the same coin. If you have only 30 people to care for, you can provide a high quality service. But if, with the same resources, you have to provide care for 300 people, the quality of your service is sharply reduced. So it's in TASO's interest that fewer people are infected with HIV, so that those who are infected can receive high quality care.

One interesting thing that has happened in TASO in recent years is the growth in the number of discordant couples, that is, those in which one partner is HIV-positive and the other is negative. Discordance is a reality and we need to acknowledge it. Our

message should be that, whether you are in a discordant or a positive relationship, protected sex is the key to health and longer term survival.

I am therefore very pleased to see that TASO in 2007 has focused on 'Scaling up HIV prevention' and has started rolling out the Positive Prevention programme, focusing on safer sex, prevention of mother-to-child transmission, discordance and engaging people with HIV as the voice of HIV prevention, especially for the younger generation, who are most vulnerable.

When we started TASO, we were very clear in our minds that we wanted the organisation to come to an end. We therefore included a dissolution clause in the constitution. Our thinking was that, when the AIDS epidemic came to an end, there would be no further need for TASO. Unfortunately, AIDS is still with us and TASO is still needed. Moreover, the AIDS epidemic is so deeply rooted that in 20 years' time there will still be a need for TASO.

Every day, I ask God to give us a cure – a total cure – for AIDS. I believe that a cure for AIDS is possible, and that eventually we will overcome this epidemic. The ramifications of the AIDS epidemic, however, are far-reaching and will live with us for decades to come.

Let this short history of TASO inspire and invigorate present and future leaders of the struggle against HIV and AIDS, for in the end the story of TASO is the story of how a small band of people did not lie back and wait for others to help them, but instead took up the challenge. Out of the personal loss, pain and confusion of 20 years ago grew TASO - a unique, strong, proud and truly home-grown African institution.

Noerine Kaleeba
Founder and Patron, TASO

TASO SERVICE AND TRAINING CENTRES



CENTRE:

DATE ESTABLISHED:

Mulago [Kampala]	November 1987
Masaka.....	May 1988
Training centre, Kanyanya [Kampala].....	October 1988
Tororo.....	November 1988
Mbarara.....	January 1989
Mbale	March 1990
Jinja.....	March 1991
Entebbe	November 1991
Gulu	January 2004
Rukungiri.....	August 2004
Soroti.....	August 2004
Masindi.....	August 2005

Chapter 1:

Introduction

Early in 1987, I was one of a group of 16 men and women who started meeting in Kampala, the capital of Uganda, to share our experiences of how we were coping with the impact of AIDS on our lives.

Although the first cases of AIDS in Uganda had been identified five years earlier, the epidemic was still shrouded in ignorance. Because of the stigma and fear associated with AIDS, and the myths about how easily it could spread from one person to another, people sought to protect themselves by subjecting those believed to have AIDS to inhumane and degrading forms of discrimination. Traditionally strong family ties, friendships, workplace bonds and community support mechanisms collapsed. Afraid to contract the virus, people refused to shake hands or share plates, cups and other domestic facilities with those living with AIDS. Even people who were not infected with HIV but were affected by having to care for family members and relatives, often suffered from appalling forms of stigma and discrimination.

Our group of 16 individuals who started meeting informally in Kampala in 1987 included both people infected and people affected by HIV. We came together to seek refuge from the stigma and the discrimination we were experiencing, and to find strength in sharing our experiences. We discussed how to care for those living with

AIDS. We shared food and offered what little surplus we had to those who had nothing. We visited one another, in our homes or in hospital, to offer prayer and comfort.

As the number of people to visit grew, a structure and a name gradually emerged from our informal meetings. We called ourselves 'The AIDS Support Organisation' – better known by its acronym, 'TASO'. The organisation encouraged its members to 'live positively'. Those living with AIDS should take care of themselves and those around them, and make the best of whatever time they still had left. They should also make preparations so that they could 'die with dignity'.

Twenty years later, TASO still promotes 'positive living', but now works to keep people living with HIV alive and healthy, rather than resigning themselves to a premature death, whether 'dignified' or not. The organisation has also grown at an amazing rate – way beyond the wildest dreams of the 16 founding members. We now operate 11 large service centres in different parts of Uganda, we employ over 1,000 staff, and we provide services to 80,000 people living with HIV and their families.

Since 2003, TASO has also operated a large antiretroviral therapy (ART) programme in rural and urban areas, as well as in camps for internally displaced people in war-torn northern Uganda. We also train counsellors,

we provide social support to our clients and their families, and we assist community responses to HIV. In addition, we carry out HIV education and we advocate, both nationally and internationally, on behalf of people living with or affected by HIV.

In this book I have tried to tell the story of TASO, from the viewpoint of someone who has worked in the organisation, in many different capacities, since its humble beginnings in 1987. I have tried to identify and describe the key milestones in TASO's journey from a small, informal group of

volunteers to become one of the largest NGOs in the developing world. In doing so, it is not my intention to celebrate TASO in any way, but simply to tell the story of TASO as I see it, as someone who has been privileged to participate in the development of this remarkable organisation.

It is my hope, however, that this book may serve as a learning tool for the thousands of non-governmental and community-based organisations involved in HIV and AIDS care, support, prevention and advocacy throughout the world.

Chapter Two

History of HIV and AIDS in Uganda

The first cases of AIDS in Uganda were identified in 1982. I remember hearing at that time of a strange new illness that was attacking people in the fishing village of Kasensero, on the shores of Lake Victoria, in Rakai district, southern Uganda. The disease soon became known as ‘Slim’ because it would often result in dramatic weight loss and wasting away of the body before causing death. Soon, cases were reported in the neighbouring district of Masaka.

Before many Ugandans became aware of AIDS in their midst, the country had become involved in an intense and bloody civil war, which lasted from 1981 until 1986. This caused enormous insecurity and damaged the country’s economic and social infrastructure, including the health services. The war might also have contributed to the rapid spread of HIV, as soldiers and civilians moved from one place to another.

Between 1982 and 1986, the number of AIDS cases reported increased slowly but steadily, with the largest increases registered in urban areas. The neighbouring countries of Kenya, Tanzania, Rwanda and the Democratic Republic of Congo were also reporting cases of AIDS, with a high concentration of cases along the main highway that connected these countries to one another.

The true extent of the AIDS epidemic in Uganda was unknown until, in the early 1990s, quarterly surveillance reports were produced. In the 1980s, however, people had very little, if any, accurate information about HIV and AIDS. Instead, they heard – and often believed – rumours attributing the origin of the disease to witchcraft, and to ‘God’s punishment’ for sexual promiscuity and infidelity.

I recall how, in 1984 - 1986, when I was working as a physiotherapist at Mulago Hospital in Kampala, we witnessed an increasing number of patients coming in with AIDS-related symptoms. At the time, we used to talk about ‘AIDS’ rather than about HIV, the virus which leads to AIDS. HIV testing was still rare in Uganda, so very few HIV-positive people knew they were living with HIV. By the time a person was diagnosed – generally on the basis of clinical symptoms – as having AIDS, they usually had only a short time to live.

In 1986, soon after coming to power, President Yoweri Museveni’s government publicly announced that there were many people living with AIDS in Uganda, and that the country needed help in addressing the problem. This was a startling declaration at a time when many other national leaders were denying the existence of AIDS in

their countries. In October 1986, an AIDS Control Programme was established under the Ministry of Health to address the AIDS epidemic. It started an intensive health education campaign, targeting in particular the worst-hit districts of Rakai and Masaka.

In Uganda, and throughout sub-Saharan Africa, heterosexual intercourse is the most common form of HIV transmission. The early HIV prevention messages in Uganda therefore advised people to protect themselves by 'loving carefully', which meant either being faithful to one's sexual partner or using condoms. Other messages, reflecting the fact that many people had more than one sexual partner, called for 'zero-grazing'. This was a term borrowed from the common practice of keeping cows tethered to one spot so that they could eat the available grass without wandering off to eat crops. The message was that spouses should remain faithful to one another, rather than seeking sexual partners beyond their homesteads.

As more information about HIV and AIDS became available, more people living with

AIDS came to health units for care and treatment. However, the care provided was inadequate because the medical staff lacked the knowledge and the skills to manage the disease. Morale among medical personnel was also low; health units were understaffed and lacked essential drugs and other basic supplies. In fact many medical staff discriminated against AIDS patients, and left the majority of the nursing, feeding, and cleaning responsibilities to family members, who also knew very little about what to do. Furthermore, in the absence of a cure, many people considered people living with AIDS as 'lost causes' that were 'marked for death', and rejected them.

As a young physiotherapist at Mulago Hospital, I regularly tuned into the British Broadcasting Corporation's *Focus on Africa* programme, which often discussed HIV and AIDS. I followed the broadcasts with keen interest to learn more about this mysterious new disease. What I didn't know at the time was that I would spend more than 20 years of my life trying to contain the spread of AIDS and endeavouring to give a better and more dignified life to those whom it affected.

Chapter Three

The beginnings of TASO

In June 1986, Noerine Kaleeba, who was Principal of the School of Physiotherapy at Mulago Hospital, where I also taught, flew to England to visit her husband, Christopher, who was studying at Hull University. Christopher had been admitted to Castle Hill Hospital, where he had been diagnosed as having AIDS.

At the time, I did not know about Christopher's condition. But one day, Mary Kakeeto Lukubo, a friend and fellow tutor at the School of Physiotherapy, who was a close friend of Noerine, whispered to me that Christopher had been diagnosed with AIDS. Mary insisted, however, that I should not tell anyone else about it. I was shocked and speechless. Later I plucked up the courage to ask: "What about Noerine?" Mary answered: "I don't know."

I had met Christopher at Mulago Hospital, where he worked as a radiographer before going to Hull University. Although not close friends, he and I had always got on well. Noerine stayed with Christopher in Hull for several weeks, until he himself decided he wanted to return home to Uganda, because he was missing his family so much. Christopher returned to Kampala towards the end of 1986, and continued receiving medical care at Mulago hospital. Mary and I regularly visited him on the ward to

offer him our moral support and to show solidarity with him and the entire family. Christopher passed away on 23 January 1987.

While Christopher was hospitalised in Kampala, Noerine, who had tested HIV-negative while in England, and the rest of her family experienced the stigma that was routinely directed at people with AIDS and their families at the time. This was in stark contrast to their experience while Christopher was in hospital in Hull, where Noerine and Christopher had received counselling and information about HIV and AIDS from a local support group. While taking care of Christopher in Mulago Hospital, Noerine sorely missed this kind of support. None of the other people living with AIDS patients in Mulago Hospital were receiving such support either.

Before Christopher's death, Noerine started reaching out to some other patients with AIDS in the hospital, and to their families. She brought together a few people who later became founding members of TASO. After Chris died, she asked several friends, including Mary Kakeeto, Jane Mulemwa and me, whether we would join with her in forming a support group.

I was not yet affected – either directly or indirectly – by AIDS, but I had developed

an interest in the disease through listening to broadcasts about it on the BBC, and I had also felt very moved whenever I visited Christopher in hospital. So I did not hesitate when Noerine invited me to join the group – I said ‘yes’ straight away. I told my wife, Josephine, about my decision to join this new group. She told me that many people with AIDS were coming to the clinic where she worked as a nurse, and she agreed with me that they needed much better care and support.

In April 1987, Dr Elly Katabira started the first AIDS clinic in Uganda at Mulago Hospital, and most of the members of our informal support group were connected with this clinic in some way. The group consisted of Noerine Kaleeba, Dr Elly Katabira, Colin Williams, Rose Ojamuge, Jason Bazebulala, Chanda Williams, Jane Mulemwa, Daniel Etole, Lydia Tamale, Mary Kakeeto, David Lule, Nestor Banyenzaki, Nampologoma, Charles Sentamu and myself. Seven of the members were themselves living with AIDS and were being treated for opportunistic infections at Dr Katabira’s clinic.

The group was completely informal, with no name. We came together in solidarity to share information about AIDS and how it was affecting us and our families. We wanted to dramatically reduce the terrible fear, stigma and discrimination that surrounded the disease, which we were seeing daily in the hospital and in the homes of some members of the group. We also took advantage of Dr Katabira’s clinic to talk with and comfort those recently diagnosed with AIDS.

The work of our small group soon began to draw attention. Colin Williams, the

Country Director of the British development agency ActionAid, arranged for Noerine and Dr Katabira to attend a two-week course in AIDS counselling in the UK. They were also able to visit some of the NGOs and institutions providing HIV and AIDS services in the UK. On their return, Noerine and Dr Katabira shared with the rest of us what they had learned, particularly about counselling.

Noerine kept the group together by holding meetings at her home and in the Department of Physiotherapy at Mulago Hospital. We also visited the sick in their homes and talked to their relatives about how they could offer them better care and support. Soon, the AIDS clinic at Mulago Hospital, which ran once a week on Friday mornings, became the central meeting place for people living with or personally affected by AIDS.

When we started, the group had no name, no organisational structure and no funds. We were just a small group of concerned individuals doing our best to support one another and others in need of help because of the impact of AIDS on our lives. This was our mission, though we did not record it on paper at the time. We had all experienced or observed the rejection and discrimination faced by people living with AIDS and their families. We grew closer, united in the belief that a person with AIDS should receive treatment, care and support, like a person suffering from any other disease. The group stood together against AIDS-related discrimination and stigma, and worked hard to demonstrate to medical staff, the relatives of patients and other community members the kind of compassionate care



Christopher Kaleeba (second, left) is greeted by his wife, Noerine (on left) and relatives on returning to Uganda from the U.K.



Dr Elly Katabira, TASO's first medical adviser, prescribes medication for a mother and her child in 1989.



TASO co-founder members Peter Ssebhanja and Colin Williams.



The room in the former polio clinic building, where TASO had its first office.

and treatment which all patients need and deserve.

On 11 November 1987, we decided to give the group a name – ‘The AIDS Support Organisation’, or ‘TASO’ for short. We also started looking for an office where people living with AIDS could receive counselling confidentially. The Medical Superintendent of Mulago Hospital, Dr Edward Kigonya, together with Dr Stella Tibumanywa, who was Deputy Medical Superintendent, responded to our request and allocated a room to TASO in the former polio clinic building, which we used for counselling and as our office.

The ‘TASO family spirit’

At first everyone working for TASO did so on a part-time, voluntary basis. We all had jobs elsewhere. As the organisation took shape, however, it became clear that we needed to have a full-time person in the office, in order to meet and talk to the new clients who were coming in for assistance. We chose Jason Bazelulala, one of the founder members, as TASO’s first administrator. Noerine Kaleeba was assigned the post of secretary, David Lule became treasurer and I was put in charge of sensitisation workshops and training of new volunteers. Despite these titles and responsibilities, we were all still volunteers, with no formal job descriptions, but we carried out our tasks in a timely manner and in a heart-warming team spirit.

We made decisions quickly, after minimum debate, aware that time was precious. This was especially the case for the people living with AIDS who came to us for help, whom we decided to refer to as our

‘clients’ rather than ‘AIDS patients’ – a term we considered stigmatising. In fact, most people were scared of the term ‘AIDS’, so we felt that using it would lead to people with AIDS suffering even more discrimination. We were all committed to doing our best to assist whoever needed help: one of us could offer counselling; someone else would supply a car to drive the client home; others – sometimes as many as three of us – would escort a client home.

This personal sacrifice and human warmth developed into a culture that would later become better known as the ‘TASO family spirit’. We saw the problem of HIV and AIDS as ‘our’ problem and we regarded one another as ‘fellow fighters’ in the battle against the epidemic. We all spoke openly about this ‘helping culture’, and there was always mutual support and a show of solidarity in accomplishing tasks. We regarded our clients as fellow members of the TASO family, and as such they deserved maximum compassion and empathy. We often prayed together, following the biblical saying that a family that prays together stays together. Above all, we were trying to help people living with AIDS to either maintain or to regain their human dignity. Noerine Kaleeba summed it up once:

“We encourage dignity both in life and in death. We encourage living positively and dying with dignity.”

‘Positive Living’

At first there were clients who were rejected by their families because AIDS-related stigma, based largely on ignorance about the disease, was very high. We welcomed

them into the TASO family, where there was no stigma and no discrimination. While we observed confidentiality with regard to the HIV-positive status of our clients, we strongly rejected stigma against them.

The demand for TASO's counselling and support services increased rapidly. In addition to his Friday morning clinic, Dr Katabira volunteered to run a half-day clinic in the TASO office every Thursday. As the number of our clients increased, we requested – and received – a second room. By then about 30 clients had registered with TASO, and we were starting to realise that TASO might develop into something much larger than we, its founders, had ever imagined. I remember vividly the late David Lule saying to me one day: "Peter, we all have to work very hard because this organisation will help many people". And in the end, that is exactly what has happened.

One of the most important contributions which TASO has made to improving the situation of people living with HIV is the message of 'living positively' (see box opposite). Originally the message was 'Living positively with AIDS'; these days we say 'Living positively with HIV'. This simple message has given hope, purpose and self-respect to many people living with HIV, and to their family members. As this message reached patients and families who, up until then, had been suffering alone and in silence, more and more people started coming to TASO to seek more information and support, and to learn how they too could 'live positively'.

Many people were encouraged by the warm and unique welcome we gave them. At a time when many were shunned by

friends and family, they were welcomed to TASO with smiles, handshakes and hugs. Tea and food were provided. Each new member was encouraged to say something about themselves. I remember one early client saying "I feel good when I am with you". Another one said "You are truly a caring family". Some clients did not open up right away, but as they saw the non-judgemental care and support available within the TASO family, they started sharing their experiences, and later they brought friends and relatives who were also living with AIDS.

Home visits

From the beginning, TASO members understood that reaching out and providing home care to people living with HIV and AIDS was essential to fulfilling the group's mission. Home visits by TASO volunteers made a tremendous difference to the lives of individuals and families who could not afford transport costs for frequent hospital visits and admission expenses. It also allowed relatives to stay at home and continue to earn a living to support their patients and families.¹

Initially we used a car belonging to a TASO volunteer and founder member, David Lule, who was himself HIV-positive, to visit patients in their homes. The TASO volunteers, who were still not being paid for their work, contributed from their meagre resources to buy fuel for the car.

In April 1988, as TASO became busier

¹ In Uganda, as in many other African countries, it is common for hospital patients to be accompanied by relatives, who provide for their physical and material needs.

The tenets of 'Positive Living'

1. Maintain a positive attitude towards yourself and others.
2. Do not blame others.
3. Do not feel guilty or ashamed.
4. Share your diagnosis with a few significant people.
5. Follow medical advice; seek medical care quickly when attacked by infections.
6. Take medicines regularly as prescribed.
7. Eat plenty of food which is rich in proteins, vitamins and carbohydrates.
8. Get enough sleep and do not get over-tired.
9. Do not smoke or drink alcohol which further lower the body's resistance to disease.
10. Take enough exercise to keep fit (but not strenuous exercise).
11. Continue to work if possible.
12. Occupy yourself with non-stressful activities such as making crafts.
13. Accept both physical and emotional affection.
14. Socialise with your family and friends.
15. Seek counselling to maintain a positive attitude and talk about your feelings, whether angry, sad, blaming or hopeful.
16. Always use a condom during sex. Even if both partners know they are HIV-positive, using a condom prevents pregnancy and avoids passing on other sexually transmitted diseases, which would further lower immunity to disease.
17. Avoid pregnancy. It may lower the body's immunity and can hasten the onset of AIDS in an HIV positive woman. **(Note: This advice was given before antiretroviral therapy became available. TASO now advises couples where at least one is HIV-positive on how to have children with very low risk of passing HIV on to the child or the uninfected partner.)**

with home visits and volunteers began to feel the pinch of fuelling the car from their own pockets, ActionAid Uganda stepped in and provided a small Suzuki car, and money to pay for running costs. Using the Suzuki

within local communities, however, really opened our eyes to the enormous intensity of the stigma attached to AIDS within local the communities.

Initially, many clients were attracted

to TASO because of our sensitivity in handling confidentiality about their HIV-positive status. We fully understood that our clients could not feel free to disclose their HIV status to communities that were not supportive, or were, in some cases, hostile. At the same time, however, we actively and publicly promoted acceptance, care and support for people living with HIV and AIDS, and we felt it was our duty to spread this message in the communities. It became clear to us that two conflicting principles were at work: on the one hand, confidentiality about a person's HIV-positive status, and on the other, the need for much more openness about HIV and AIDS, so that families and communities could offer the required care and support to those infected and affected by HIV.

Matters came to a head over the issue of whether our Suzuki car should be labelled as belonging to TASO or not. Doing so would clearly breach patient confidentiality whenever counsellors went on home visits. Not doing so would mean missing an opportunity to promote greater openness and honesty about HIV and AIDS at community level. We decided to label the vehicle 'TASO COUNSELLING SERVICES', which led to protests from a number of clients, who insisted that we should park the vehicle as far as possible from their homes. Reprieve came in 1989, when we acquired two additional vehicles which we left unmarked; these were used to visit those clients who felt uncomfortable with the labelled car.

Nevertheless, the labelled car that took volunteers on home care visits to the

communities informed more people about our services. This meant that an HIV-positive diagnosis was not totally confidential to the person concerned, the clinician and the TASO counsellor. It was, in effect, a statement that a person was living with HIV and might be in need of understanding, help and support from family members and others in the community.

In fact sometimes, when people saw TASO volunteers in the labelled vehicle, they would stop it and tell them that there was someone in the community who was unwell and needed assistance. Sometimes we were stopped and directed to the homes of people who were suspected of living with AIDS but who were hiding in their houses. We interpreted this as an indicator that people recognised the need to provide care and support to members of their community who were living with AIDS. Our volunteers were always ready to approach those suspected to be living with AIDS and to explain the care and support that TASO could provide. Nevertheless, stigma and denial continued to thrive in the communities and within families and individuals.

After increasing community sensitisation activities, our desire to let the public know and get involved in AIDS care and support overtook the fear of stigmatisation. Eventually, all TASO cars were labelled as such. They became, in effect, another means of informing people about the availability of TASO services and of encouraging them to come, or to encourage their loved ones and friends to do so, if they knew or suspected that they were living with HIV.



Eddie:

TASO client

(From: *Living Positively with AIDS. The AIDS Support Organization (TASO), Uganda*, by Janie Hampton, Strategies for Hope no. 2, ActionAid, 1990.)



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

"The fevers subsided for a while, but she kept sweating 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's 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 that 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 the 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 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 one 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."

The need to inform other people, in order to create a support network, led us to adopt the principle of ‘shared confidentiality’, which we borrowed from the Salvation Army Hospital at Chikankata, Zambia, where Noerine Kaleeba had attended a meeting to share experiences of community-based HIV and AIDS work².

The principle of ‘shared confidentiality’ was meant to help people living with HIV to get the right help by enabling some significant people – especially spouses and other family members – to learn more about HIV and AIDS, and how to care for those who were living with HIV.

As TASO volunteers, we also faced stigma. Many people thought that everyone in TASO was living with AIDS. I used to hear whispers behind me while getting out of the TASO car: “Oh! Look at him; he looks healthy but he must be having the virus”. Some people would not even accept a lift in a TASO car. I did not greatly mind their funny comments about me and the other volunteers, because I knew that many people still had inadequate information about AIDS. Nevertheless, I sometimes thought strongly about taking an HIV test myself, just to be sure.

It took me a long time, I must admit, to gather the courage to take the HIV test. There was a fear, naturally, that I could be infected, even though I knew that the risk of being so was low. But the virus had spread out very fast in our communities, and one could not say for sure who was infected and who was not. With the philosophy of positive

living, through which we encouraged people living with HIV and AIDS to lead as normal a life as possible, it felt as if anyone and everyone could have HIV. In fact, the volunteers who joined us later did not take HIV tests because it was practically assumed that anyone could have HIV. We also had some fear of finding out the result, even though we were encouraging other people to take the plunge.

It was not until August 1997, therefore, that I finally took the HIV test when, following the death of my first wife, Josephine, on 22 November 1994, I decided to remarry. By then I had enough information about HIV and AIDS, and had found the courage to accept any result. As it turned out, the result was HIV-negative.

Poverty and AIDS

Based on the intensive nature of our interaction with our clients, TASO volunteers were faced with a multitude of issues, many of which we felt almost overwhelmed by. We were worried, for example, by the rapidly growing number of people with AIDS in Uganda, and the poor quality of medical care available to them in our hospitals. Stigma and discrimination continued to be massive problems. AIDS was impoverishing many families. When one or both parents were chronically ill and unable to work regularly, the whole family suffered from lack of income. Parents were unable to pay their children’s school fees, so their children dropped out of school. They could not afford the cost of medical treatment, or even basic needs such as food and other basic needs.

² See also *From Fear to Hope and AIDS Management*, nos. 1 and 3 in the *Strategies for Hope* series.



At a time when many people with HIV and AIDS were shunned by friends and family, TASO welcomed them with smiles, handshakes and hugs.



TASO's first Suzuki vehicle, donated by ActionAid in 1988.