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CASES IN GLOBAL HEALTH DELIVERY

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The AIDS Support Organization (TASO) of Uganda

In June 2006 Dr. Alex G. Coutinho, executive director of the AIDS Support Organization (TASO), sat at his desk in Uganda contemplating the future of the organization. TASO was founded in 1987 as a small group of volunteers with no formal experience that provided support for people living with HIV/AIDS (PLWHA). In 2001, when Coutinho became executive director, TASO had grown to be an official nonprofit organization with 25,000 HIV positive beneficiaries and 300 staff. In July 2004 TASO began offering antiretroviral therapy (ART) for the first time. TASO emphasized home-based care, adherence monitoring, and individually-tailored social support. By the end of 2006, 9,500 or 94% of the 10,097 clients ever enrolled in ART remained on treatment; an additional 70,000 were in care; the staff had expanded to 1000; and the annual budget was over USD 25 million.[1]

At the time Coutinho had just returned from a trip to Malawi, where he observed a national HIV/AIDS program with a budget comparable to TASO's. Between 2004 and 2006 Malawi's program had enrolled approximately 50,000 PLWHA on ART using a basic, facility-based, public health model, with no CD4 count monitoring and only first-line drug regimens. Retention was 70%; about 35,000 of the original 50,000 enrolled remained on treatment.

TASO's model was expensive, and funding was stabilizing—if not shrinking—over time. In 2006 other organizations whose knowledge and capacities had grown over time were competing for the same limited resources. TASO's slots for ART were filling up while demand was increasing. Coutinho and his staff had to figure out what they could do to maintain their client-centered ethos while delivering services in a more cost-effective way.

Overview of Uganda

Uganda's colonial boundaries encompassed a wide range of ethnic groups with diverse political systems and cultures. When Uganda gained independence from the British in 1962, the cultural and political diversity led to instability for many years. In 1971, Idi Amin took power. He maintained control through a

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combination of military and police terror and intimidation that left an estimated 300,000 Ugandans dead over the course of his eight-year reign, crippling the public sector and civil society.[2] From 1980-1985, under Milton Obote, another 300,000 people were killed during a civil war.

In 1986 President Yoweri Museveni took power and initially restricted the activities of political parties in Uganda in order to reduce sectarian violence. Under Museveni's presidency, "as part of a broader effort to restore state credibility and deepen democracy," the Government of Uganda decentralized many of its political, administrative, and fiscal responsibilities to the district level.[3] This decentralization improved service delivery, increased democratic governance and accountability, heightened awareness, promoted local resource mobilization, and enhanced overall rural development in Uganda.[3, 4, 5] Museveni and the National Resistance Movement government established good relations with the donor community, and Uganda became a pioneer in a variety of innovative development programs. The programs aligned Uganda with the International Monetary Fund (IMF), World Bank, and various donor governments' policies. The poverty strategy (published in 1997 as the Poverty Eradication Action Plan) anticipated policies that became standard for developing nations. Uganda was the first recipient of a World Bank Poverty Reduction Support Credit and in 1998 became the first country to qualify for Heavily Indebted Poor Countries debt relief from the IMF and World Bank, after meeting economic management and performance targets. Of Uganda's USD 3.4 billion debt, about USD 2 billion was relieved by 2000.[6] Nonetheless, Uganda remained highly aid-dependent, with aid averaging 11% of gross domestic product (GDP) and 50% of public expenditure in 2006.[6]

Museveni and his government had largely put an end to institutionalized human rights abuses, liberalized the economy, and increased the openness of the national press. The Lord's Resistance Army continued to wage war against the government in Northern Uganda for close to two decades, however, until a peace process began in 2006. During this war, many civilians were killed or displaced and children were regularly abducted.[7] In July 2005 a constitutional referendum ended the 19-year ban on multi-party politics.[8]

Demographics

Uganda was slightly smaller than the state of Oregon and had approximately 28.8 million people in 2006.[9] Its annual population growth of 3.2% was one of the highest rates in the world.[10] Bordered by the Democratic Republic of Congo, Kenya, Rwanda, Sudan, and Tanzania, Uganda was a landlocked country containing many large lakes and rivers, including the northern part of Lake Victoria and the origin of the Nile River (see **Exhibit 1** for map). In 2006 Uganda was divided into 79 administrative districts spread across four regions—Northern, Eastern, Central, and Western. Each district was divided into sub-districts, counties, sub-counties, parishes, and villages. Four traditional Bantu kingdoms—Toro, Busoga, Bunyoro, and Buganda—remained in Uganda, existing in parallel with the state administration and practicing some degree of cultural autonomy. Twelve percent of the population lived in urban areas while 88% of the population was rural.[9]

In the early 2000s Uganda's GDP grew approximately 6% annually, which experts considered a strong performance given that Uganda faced poor international coffee prices, rising oil prices, drought and pestilence.[11] Agriculture was the most important sector of the economy, employing over 80% of the workforce, and coffee accounted for the majority of export revenues. National unemployment was 2%, underemployment was 12%, and urban unemployment was 7%.[12]

Despite economic growth and favorable relationships with donors, Uganda remained profoundly impoverished, with pronounced differences in urban and rural development. A 2002 housing census estimated there were 1.8 million orphans, representing 13% of all children under 18 years and 7% of the total

country population.[10] Twenty percent of these orphans had neither mother nor father.[10] Twelve percent of the urban population lived below the government-defined poverty line compared to 42% of the rural population. Eighty-seven percent of the urban population and 52% of the rural population had access to safe water sources, while 53% of urban residents and 39% of rural residents had access to safe means of sanitation[i].[9] Less than 1% of the rural population of Uganda had access to electricity in 2006.[13] While the government had made strides to improve and maintain roads, access to improved infrastructure varied greatly within the country. [14]

Basic Socioeconomic and Demographic Indicators [ii]

INDICATOR		YEAR
UN Human Development Index ranking	154 out of 177	2005
Population (thousands)	28,699	2005
Urban population (%)	12.6	2005
Drinking water coverage (%)	64	2005
Poverty rate (% living under USD 1.25 per day)	74	2005
Gini index	43	2005
GDP per capita in PPP (constant 2005 international dollar)	966	2006
GDP per capita in constant 2000 USD	312	2006
Literacy (total, female, male)	73.6, 65.6, 81.8	2007

Health in Uganda

Maternal and child health The leading causes of death among children under five were neonatal causes (23.6%), malaria (23.1%), pneumonia (21.1%), diarrheal disease (17.7%), and HIV/AIDS (7.7%).[9] In 2004 the total fertility per woman was 7.1 and the maternal mortality ratio was 550 per 100,000 live births.[9] Ninety percent of rural and 62% of urban women reported serious difficulties in accessing health care when pregnant. Thirty-nine percent of births in 2005 were attended by a skilled health personnel, 37.7% in rural areas, and 80.4% in urban areas.[15]

Nutrition Between 1992 and 2003 the proportion of undernourished people fell from 24% to 19%.[16] During a 2005 study, one million Ugandans were found to be food insecure, living "without the physical, social, and economic access to sufficient safe and nutritious food that meets their dietary needs and food preferences for an active and healthy life;" another 6.75 million were highly vulnerable to food insecurity; and four million were moderately vulnerable. Insecurity was concentrated in the northern regions.[17]

Population health The life expectancy at birth had held steady through the 1980s and 1990s at about 46.5 years, dropping to 41.1 in 2000 before rising to 48 years for males and 51 for females in 2006. The leading causes of death for Ugandans of all ages were HIV/AIDS (9.4%), malaria (4.1%), lower respiratory infections (3.9%), diarrheal diseases (3.0%), and perinatal conditions (1.6%).[9]

[i] Safe (improved) water sources include household connections, public standpipes, boreholes, protected dug wells, protected springs, and rainwater collections. Safe (improved) sanitation facilities include connections to a public sewer, septic systems, pour-flush latrines, simple pit latrines, and ventilated improved pit latrines.

[ii] This data was comprised from the following sources: United Nations (UN); The United Nations Children's Fund (UNICEF); World Bank; United Nations Educational, Scientific, and Cultural Organization (UNESCO).

Health System and Epidemiologic Indicators [iii]

INDICATOR		YEAR
Average life expectancy at birth (total, female, male)	50, 51, 49	2006
Maternal mortality ratio (per 100,000 live births)	550	2005
Under five mortality rate (per 1,000 live births)	143	2005
Infant mortality rate (per 1,000 live births)	89	2005
Vaccination rates (% of DTP3 coverage)	64	2006
Undernourished (%)	15	2005
Adult (15-49 years) HIV prevalence (per 100,000)	6304	2005
HIV antiretroviral therapy coverage (%)	27	2006
Tuberculosis prevalence (per 100,000)	561	2006
DOTS coverage (%)	100	2006
Malaria cases (per 1,000)	355	2006
Government expenditure on health as a % of total government expenditure	8.9	2006
Government expenditure on health per capita (international dollar, USD)	20, 7	2007
Total health expenditure per capita (international dollar, USD)	74, 28	2007
Physician density (per 10,000)	1	2005
Nursing and midwifery density (per 10,000)	13	2005
Number of hospital beds (per 10,000)	11	2006

Health System

Governance Upon independence the government of Uganda was left with a colonial health system centered heavily on hospitals. During the political violence of the 1970s and 1980s, existing physical infrastructure decayed, and health care provision was delivered largely in the form of fragmented humanitarian aid. Uganda's health system was decentralized around 1993 under the first strategic health plan, giving leadership to provincial authorities. The new system was comprised of four levels of care: national referral hospitals, regional referral hospitals, district health services, and sub-district health facilities. Village health teams began to play a role in care through the sub-district health facilities, requiring the construction of village health facilities.[3]

The provision of health services was shared between government-funded facilities (30%), private not-for-profit facilities including church-supported hospitals and clinics (45%), and private or for-profit commercial health units (25%).[18]

Workforce In 2005, only 68% of district level facilities were filled by trained health personnel. There were 2,209 physicians, 16,221 nurses, and 3,104 midwives in the country.[9] Fifty-four percent of the health workforce consisted of nurses and midwives; 6.2% were physicians, and 18.3% served in a management or support capacity. There were nine rural pharmacists and 206 urban pharmacists in 2004.

[iii] This data was comprised from the following sources: WHO, UNICEF, UN.

Access Only 50% of health units in northern districts were operating in 2002, and a 2004 report found that since that time, more had shut down. Most for-profit facilities and government hospitals were located in urban areas. According to the Uganda Bureau of Statistics, 69.9% of Uganda's population had access to at least one health facility in 2006. The Ministry of Health found that 47% of Ugandans lived within five kilometers of a health facility providing the national minimum health care package.[18]

Financing In 2000, about 70% of total health expenditure was out-of-pocket.[19] In 2001 user fees were eliminated in public government health facilities, but out–of-pocket expenditure remained at 51.8% in 2005. The majority of out-of-pocket expenditure went towards medications. Total public expenditure in 2004 was 2.5% of GDP, and private expenditure was 5.1% of GDP.[20] Between 2000 and 2004 spending on health increased 20%. A credit line system was introduced whereby districts ordered drugs directly from national medical stores, but in 2006, only 35% of all health facilities reported no drug stock outs.[21]

The HIV/AIDS epidemic "imposed a severe and unsustainable burden on the meager health sector resources."[18] HIV infection caused a resurgence of other diseases like tuberculosis, pneumonia, and meningitis.[22] The Uganda AIDS Commission estimated that by 2007, 50-70% of hospital admissions throughout the country were related to HIV/AIDS.[23]

HIV/AIDS in Uganda

Epidemiology

Uganda's first recorded AIDS deaths occurred in 1982. HIV spread quickly along major highways, while heightened mobility and activity by the Ugandan armed forces, insurgents, and rebel groups supported transmission. HIV prevalence likely peaked in the early 1990s, with rates as high as 25-30% in urban areas in 1992. National prevalence was estimated to be 18.3% that year.[24]

In 2003 there were an estimated 530,000 people living with HIV/AIDS in Uganda, and approximately 78,000 died from AIDS-related illnesses, making HIV/AIDS the leading cause of death.[25] In 2005 Uganda's Ministry of Health estimated the national adult prevalence (15-49 years) had fallen to 6.4%,[18] lower than the overall prevalence of 7.5% in sub-Saharan Africa(see **Exhibit 2** for HIV/AIDS prevalence in Uganda over time).[26, 25]

In 2005, 90% of people aged 15-49 had heard of AIDS.[27] Over 28% of women and 35.8% of men (age 15-49) could both identify ways of preventing the sexual transmission of HIV and major misconceptions about HIV transmission.[10] That same year, only 13% of adult Ugandans had tested for HIV; 70% of the estimated one million people infected were unaware of their status.[28]

By the end of 2006, the World Health Organization (WHO) estimated that HIV prevalence in Uganda had stabilized at 6.6%.[9] An estimated one million Ugandans were living with HIV/AIDS, among them 110,000 children. Ninety-one thousand people were dying from AIDS per year.[15] Prevalence was higher in urban areas,[18] in young women, in commercial sex workers, and in military personnel.[29]

In 2006, 42% of new infections were from sex among cohabiting, married, or widowed population groups; 22% were from commercial sex; 21% were through mother-to-child transmission; 14% were from casual sex; and 1% were from medical injections.[10]

Government Response to AIDS

In 1986 President Museveni began a proactive prevention campaign, emphasizing that "fighting AIDS was a patriotic duty requiring openness, communication, and strong leadership at all levels."[30] He started

the National Control Programme for AIDS (NCPA) that included representatives from nongovernmental organizations (NGOs), faith-based organizations (FBOs), and academics, and he created the first HIV/AIDS control plan in sub-Saharan Africa, including policy guidelines, public campaigns for safe sexual behavior and for safe blood transfusions, and programs for care and treatment.[31] The NCPA dissolved after several years and was replaced with the national AIDS Control Program (ACP). The Ministry of Health (MOH) established a national HIV/AIDS surveillance system and coordinated the national control plan which was carried out and financed by local, non-state actors on behalf of the government.[32]

In 1991 Uganda was the first country to offer voluntary counseling and testing (VCT) through the AIDS Information Center (AIC). The government estimated that over 600 non-state groups were involved in AIDS-related activities by 1997, and they remained an integral part of the national response, fulfilling the role of direct service provision. Around that time, many groups felt the government leadership had weakened and that coordination among the players was failing.

Uganda was one of five countries to participate in the Drug Access Initiative sponsored by the Joint United Nations Programme on HIV and AIDS (UNAIDS) from 1998-2000, making it one of the first countries to provide antiretroviral therapy (ART) in a resource-limited setting. It added prevention of mother-to-child transmission (PMTCT) and care and support services to its national strategy as well.[33] The program distributed condoms freely and coordinated classroom curricula on AIDS-related issues.[31] While high-risk sex increased, condom use increased as well (see **Exhibit 3** for sexual behavior survey findings over time). A lack of necessary financial and human capital constrained the government's ability to roll out ART.[29] In 2002 an official strategy to guide the roll out was put in place.

In 2005-2006 about USD 222.1 million were spent on AIDS in Uganda (see **Exhibit 4** for funding sources); USD 93.4 million went towards care and treatment, and USD 49.2 million went towards program management and administration (see **Exhibit 5** for spending allocation).[10] Uganda was the first country in sub-Saharan Africa to register a decline in adult national HIV prevalence,[34] and many regarded the national response as a rare success in the fight against HIV/AIDS despite the setbacks.

Others denied the success for a variety of reasons, including the assertion that the prevalence rate had never been as high as stated.[35] In addition, a study in Rakai, Uganda found there were 70% more deaths annually than there were incident cases, even though incidence among young men had increased.[36] The authors believed the drop in prevalence was due to death rather than declining disease rates. Finally, some claimed that the behavioral changes were not due to successful prevention campaigns but rather due to the sheer scale of the epidemic and the fact that the majority of Ugandans knew someone who had died from AIDS.[37]

ART Provision

By the end of 2003, only about 10,000 Ugandans were receiving ART.[38] Some of them were participating in studies and receiving free treatment; most were paying out of pocket (full price was approximately USD 334 per year). In 2004 The US President's Emergency Plan for AIDS Relief (PEPFAR) began funding private and nonprofit AIDS programs in Uganda. By design a significant proportion of PEPFAR funds did not go to the public sector; when the funding first came in, the MOH did not know which organizations received money. The STD/HIV Control Program Officer and Coordinator of ART Dr. Elizabeth Namagala explained that "with roll-out being so rapid, coordination issues were put aside; especially with PEPFAR money. There was so much pressure from them to meet targets that somehow it became very hard to coordinate all the partners." The MOH formed a National ART Committee to try to coordinate efforts.

In 2004 the WHO estimated that three quarters of the 42,000 Ugandans on treatment were paying for

ART out of pocket, while one quarter got their drugs free from the Ugandan Government and NGOs.[29] The MOH tried to oversee clinics and assisted with coordination. Towards the end of 2004, monthly stakeholder meetings began at several hospitals, with multiple partners, including TASO, MOH, the US Centers for Disease Control (CDC), the Joint Clinical Research Center (JCRC), and others. Stakeholders agreed to set local guidelines together, to share databases for training and for coordination to prevent clients from attending multiple clinics, and to track total numbers on ART. As Namagala explained, "There is a limit to what government facilities can do when it comes to HIV/AIDS especially because of its social consequences… the government can do care and treatment in facilities, but once you move out of the facility, we are not the best at it."

In 2006 there were almost 2,000 indigenous Ugandan NGOs and FBOs contributing to the national response.[28] One hundred percent of donated blood units were screened for HIV; 39% of adults and children with advanced HIV infection were receiving ART; 12% of HIV positive pregnant women received PMTCT; and 15% of primary and secondary schools had trained teachers in HIV education.[10]

Namagala explained, "There are still gaps in our knowledge and leadership. Sometimes we feel like we're not in control, and things would be better if we were." TASO Director Coutinho's perception of the general relationships between the major players was "Cordial. Respectful. Distant." He explained, "It takes a lot of energy to collaborate, especially when you're in the midst of scaling up and doing your thing and moving fast, and people are trying to slow down with coordinating."

Select HIV/AIDS Organizations in Uganda

Joint Clinical Research Centre

JCRC was founded in 1991 "to serve as a national AIDS Research Centre" by the government as a collaboration between the Ministry of Health, the Ministry of Education, and the Ministry of Defense.[39] In addition to serving as a research center, JCRC provided support for the Army. The center pioneered the use of ART in 1996 among patients who could pay for medication out of pocket. Among 577 patients enrolled between January 1998 and June 2001, 39% returned for a second visit. Of those who returned at least once, around 56% were characterized as adherent based on self report.[40] Many patients interrupted therapy in 1999 due to currency devaluation that year.[41]

In 1999 JCRC opened its first general inpatient observation ward. As one source explained, "you could go to JCRC and get first-class care; you make an appointment for any time, even in the evening, because you were paying." Though critics accused JCRC of catering to the rich, JCRC was a nonprofit and explained that there was no other way to get the program off the ground and maintain financial independence.[42] JCRC began affiliating with clinics around the country and providing cyber training through satellites. In July 2002 about 180 patients were on ART.[41] The clinic prescribed up to three drugs per month, costing USD 92.[41] In 33% of non-adherence cases, finances were determined to be the barrier. Fewer than 30% of clients could afford to pay for CD4 and viral load monitoring.[41]

With support from PEPFAR and the United States Agency for International Development (USAID) in 2004, the number of JCRC patients grew rapidly. Within 18 months of receiving PEPFAR funding, JCRC had over 19,000 clients and had expanded nationally to more than 30 clinics. The majority of clinics were in public (government) health facilities.[43] JCRC procured generic drugs that patients purchased; the cheapest regimen was USD 16 per month. JCRC expanded to 42 treatment sites across the country (see **Exhibit 6** for coverage map) and later provided free drugs for orphans and vulnerable children, pregnant women, and other poor women. JCRC provided 2,000 people with free ART and treated over 25,000 by 2005. JCRC

counseled patients on adherence upon treatment initiation and began adding strategies such as home visits for patients with risk factors for poor adherence.

JCRC had five Regional Centres of Excellence in Mbale, Fort-Portal, Mbarara, Kabale, Gulu, and Kakira, plus a main Centre at Mengo in Kampala. All centers had state-of-the-art lab capabilities and did research, treatment, testing, diagnostics, and training.

Infectious Diseases Institute (IDI), Makerere University

IDI was founded as a part of Makerere University in 2004 by a group of infectious diseases experts from North America and Uganda. Its goal was to build HIV/AIDS capacity in Africa. International donors including Pfizer Inc, PEPFAR, the Global Fund, and the Government of Uganda supported IDI in building upon the clinical services offered in the Adult Infectious Diseases Clinic and the Pediatric Infectious Diseases Clinic at Mulago Hospital – the national, public referral hospital in Kampala. IDI aimed to provide quality care by increasing consistency in staffing, improving patient flow through scheduled appointments, providing free laboratory test monitoring, expanding the drug formulary of free medications, and introducing a sustainable medical records system. IDI was a national referral center for complicated HIV cases requiring second-line treatment and had three core programs: Prevention, Care and Treatment; Training; and Research.

Patients at IDI worked with volunteers in the waiting room to develop creative ways to occupy, entertain, console, and educate others through music, dance, drama, indoor games, and art and craft and they formed groups on entrepreneurship and life skills. At IDI's clinic in Kampala, almost 9,000 adults were receiving free HIV care as of 2006; 4,087 of those patients were on ART. An additional 1,500 children received ART through the pediatric clinic. IDI had a facility for trainee accommodation and one for short-term visitor lodging, as well as four urban outreach clinics in Kampala where another 3,000 people were receiving care (1,339 on ART).

A study enrolling 1,047 patients between April 2004 and April 2005 had retained 946 patients (90%) by August 2006. Nineteen of the patients were lost to follow-up and 80 had died. Of the patients retained, 69.5% had completed at least six months of follow up, and 95% reported 100% adherence within the last seven days.[44] By 2006 IDI had trained 1,017 course participants from 13 African countries in the areas of HIV/AIDS, malaria, pharmacy, laboratory, and data management. The core laboratory at IDI conducted approximately 180,000 tests in 2006 alone, and it served 80 research and clinical projects throughout Uganda.

The AIDS Support Organization (TASO)

The Beginning

When Noerine Kaleeba's husband faced discrimination and poor treatment in the Mulago Hospital before dying from AIDS in 1986, Kaleeba began reaching out to other AIDS patients and their families. The first AIDS clinic in Uganda, opened at Mulago Hospital in April 1987, became a meeting place for people infected and affected by HIV/AIDS. The group soon came to be known as "the AIDS Support Organization," or "TASO."

The TASO philosophy revolved around "living positively with HIV/AIDS" and "dying with dignity."[45] TASO's mission was to contribute to the process of preventing HIV infection, restoring hope, and improving the quality of life of persons, families, and communities affected by HIV infection and disease. In the words

of co-founding member Peter Ssebbanja, "We regarded our clients as fellow members of the TASO family. … At a time when many were shunned by friends and family, they were welcomed to TASO with smiles, handshakes and hugs."[45] Along with counseling and social support, TASO soon provided food, soap, blankets, and clothes for clients as well as money for school fees, uniforms, and scholastic materials for their children.

Becoming Official

The organization became an established NGO in 1991; an office in Kampala was created, and hospitals and medical NGOs reached out to TASO for assistance training medical personnel in HIV counseling. The Ugandan government requested that TASO set up additional clinics to strengthen the national response as well. TASO set up clinics within or alongside government facilities (see **Exhibits 7 and 8** for map of clinic sites and dates of their opening), where they often referred clients for problems beyond their scope. A day center set up at Mulago Hospital provided a place for clients and families to come relax, socialize, share meals, and participate in yoga classes. TASO's complete offering of services by 2001 included training, social support, counseling, limited medical care, community mobilizing, advocacy, and networking (see **Exhibit 9** for photo of TASO-Mulago center).

Between 1996 and 2001 the number of clients had more than doubled. As the then Head of Monitoring and Evaluation Robert Ochai said:

> We at TASO end up seeing the poorest of the poor. There are people—the middle-income—that don't want to come sit here, and maybe they are working somewhere, so because they can pay, they attach to a different place. In general, if people had a lot of money, they went to JCRC; if they had a little money, they went to MM [Mild May, a Christian organization from the UK working 12km south of Kampala] and paid half; if they had no money, they came to us.

TASO did not provide antiretroviral therapies, and the average client lived only one year.[46]

Alex G. Coutinho

Coutinho, a Ugandan graduate of Makerere University who had been working as a medical director for a sugar cane company in Swaziland, took over the directorship of TASO in 2001. Bringing management skills from the private sector, Coutinho was committed to "professionalizing the way TASO programs were planned, implemented and evaluated," and to "implementing changes to help the organization perform to its potential."[45]

Coutinho immediately began streamlining administrative structures, growing the workforce, and mobilizing resources. Physicians were hired on a full-time basis, and TASO medical services were "transformed from symptomatic nursing care to precise, professional diagnosis, care, and treatment," according to one of TASO's first full-time physicians.

Client Involvement

In Coutinho's words, "HIV-positive people continue[d] to be the center of existence of TASO." Each of TASO's 11 centers had a Client Council (CC), composed of 10 to 15 clients who were elected by the other clients to represent them to the day center supervisor and to support and talk with other clients. One male and one female client were elected to sit on the Center Advisory Committees (CACs) to guide each center's manager. Two CC members were elected to meet with the executive director of TASO every six months, and two clients were elected by all of TASO's clients each year at the Annual General Meeting to sit on the TASO

Board of Trustees.

TASO clients also helped community mobilization and sensitization through a drama group. The group did performances and gave testimonies about their lives with HIV to community groups, churches, schools, government organizations, NGOs, and institutions of bankers.

The number of new clients registered with TASO increased annually. While 4,767 new clients registered in 1997, 8,701 registered in 2001, and 15,934 registered in 2003 (see **Exhibit 10** for graph of clients registered with TASO over time).[47] TASO had become "the largest NGO care and support organization in Africa." Ninety percent of TASO's clients were rural-dwelling, 90% were at or below the poverty line, 64% were women, about half were widowed, and most were illiterate. TASO's HIV prevention and care activities included counseling to help clients assess their risk of transmission. Counseling sessions focused on the four main types of transmission (intercourse, MTCT, blood transfusions, and sharing needles) and were an opportunity to discuss and reinforce safe sexual behaviors such as condom use, abstinence, and monogamy. Some community members urged TASO to develop public education programs rather than waiting to counsel clients after they are infected.[48]

Expanding Services

The organization gradually began decentralizing its services and management to four regional service centers and 10 service delivery centers outside Kampala. "The aim was to improve the performance, efficiency and cost-effectiveness of each centre, allowing the head office to concentrate on policy formulation, guidance, standards, monitoring activities, and fund-raising."[45] Regional managers were hired from among the initial staff. In each regional office, there were six people: the manager, a project officer, two trainers, an accountant, and a secretary. Regional offices aimed to increase access to services in places where there were no TASO services by providing grants and sub-grants to other district players. They supported other community based organizations (CBOs) and NGOs through capacity-building and training.

TASO worked with the World Food Program (WFP) to begin offering nutritional support for some of its clients starting in January of 2002.[49] Through food distribution points TASO distributed maize, rice, cowpea, soybean, and vegetable oil – an average of 1,293 calories per person per day—to 9,876 PLWHA and up to four of their family members.[50, 51] In just over two years, 35,549 people had benefitted from the program.[49] The WFP supported 46,200 beneficiaries over a three-year period. Counselors and a selection committee helped determine who was eligible, giving priority to children, orphans of late clients, and clients with tuberculosis. The committee reviewed clients' status regularly. After some time, services were expanded to provide food for up to seven people per household. USD 4,500 worth of food was distributed per month.[50, 51] Clients with food support were able to save money, become more economically productive, and provide better care for their children and themselves.[49]

Soon, clients began demanding ART. Michael Etukoit, a center manager at the time, explained:

> Everyone was wondering 'when are you making this available to us?' because they started to hear about the drugs that could treat HIV. Our clients were saying, 'if you can provide everything else for us for free, then why can't you provide us ARVs for free?' At the time, we were constrained by the cost of the ARV drugs.

Prior to joining TASO in February 2001, Coutinho attended a World Health Organization (WHO) meeting on rapidly increasing access to ART in Africa. He knew that "it was not a question of *if*; it was a question of *when* treatment would become available in Uganda on a large scale." Coutinho knew that even if ARV prices dropped, incorporating ART into the TASO service package would be immensely challenging and expensive, yet he convinced his staff that it was a necessary next step. "Everyone believed that we

couldn't do ART," one staff member said. On the international scene, there were arguments that making ART accessible in resource-limited settings would only intensify the HIV epidemic, creating resistance when people did not adhere to their strict drug regimens, and the TASO staff was concerned about worsening the problem.

Coutinho took a team of people who would be involved in treatment scale-up at TASO on a trip to Swaziland and Botswana where they observed treatment programs and spoke with the front-line managers about the issues involved. "Learning from what others had done was a very important part of the process for us," Coutinho said. "It gave the team the confidence that this could be done."

TASO began by providing ART for small groups of clients with various funding sources at four sites in 2003. TASO-Tororo participated in the Home-Based AIDS Care (HBAC) research project with the CDC that provided ARVs to 600 TASO clients to assess whether it was possible to maintain high levels of adherence among people in poor communities. CDC selected TASO believing that the organization's psychosocial services would support adherence. TASO-Entebbe initiated close to 400 clients on ART under the DART trial; approximately 40 TASO clients in Masaka gained access to ART funded by Uganda Cares; and the drama group members of TASO-Mulago got ART through a personal donation from Bono who saw them perform.[47]

Global Health Initiatives Make Treatment a Possibility

In 2003 a number of global health initiatives pushing for increased access to HIV treatment in developing countries began to support TASO (see **Exhibit 11** for TASO income statements). WHO and UNAIDS through the "3 x 5 Initiative" encouraged TASO to set a goal of having 20,000 clients—representing 40% of those who needed ART within TASO—on ART by 2007.[27] PEPFAR made funding available to TASO through the CDC and USAID. CDC offered about USD 4.6 million for treating 7,000 clients in 2004.[52] The Global Fund to Fight AIDS, Tuberculosis, and Malaria (Global Fund) pledged about USD 194,000 to TASO that year as well. There were 60,000 PLWHA in the TASO database and 35-40% needed ART. "At that point, money was not the limiting factor—it was capacity. You couldn't even absorb all the money at that time," Coutinho explained (see **Exhibit 12** for TASO expenditure statements).

The Planning Stage

In 2003 TASO began making preparations for ART provision. "Adherence was at the center of the decision around the program model," Etukoit, who became ART coordinator, said. At TASO Headquarters a technical team was formed to lead the organization in thinking through the issues and creating an effective model. This team was composed of representatives from a variety of issue-specific sub-committees, including medical, psychosocial, data, logistics, supply chain, laboratory, and informatics. Each center soon had an ART team leader who participated in the strategic planning and disseminated information to the staff at the centers.

TASO expanded its internal capacity by recruiting and hiring 18 new counselors and 19 new nurses, clinical officers, and physicians.[47] Coutinho explained, "I got a bunch of really motivated, generally youngish (30- to 35-year-old) physicians and nurses, and enthused them. I delegated to them the responsibilities, and I took on a management style of a cheerleader more than anything else, really."

The technical team helped implement a training program for all staff members at all levels of the organization. "We set up a training wing to quickly build the capacity of 3,000 TASO staff and volunteers in the roll-out of drugs," Coutinho said. Courses were taught at different levels of specialization in 52 different languages. Next, TASO trained every client, regardless of whether he qualified for treatment, on ART issues,

emphasizing that it was a treatment not a cure. TASO also sensitized community leaders, especially religious leaders.

In 2003 TASO handled 163,436 medical sessions, a 40% increase from 2002.[47] The organization increased its laboratory facilities, hired new technicians, and improved the equipment. TASO expanded the operational radius, or catchment area, of each center from 35km to 75km. The organization recruited retired health professionals, especially comprehensive nurses and medical assistants, to work as volunteer AIDS community workers, identifying and supporting PLWHA in their communities. TASO provided the medications, transportation, technical support, and supervision, while the volunteer community workers provided support and care in the field. If a client's illness was beyond the volunteer's capacity, she referred the client to a government health unit or to TASO. TASO also trained 150 PLWHA in basic counseling and home care skills in 2003; they became TASO's "expert clients."[47]

Coordination with the Ministry of Health

One of TASO's greatest challenges was convincing the MOH that it was qualified and had the capacity to deliver treatment to its clients. Many from the MOH argued that TASO should continue doing what it did best—delivering counseling and social support services to PLWHAs. "There was almost a scarcity mentality," Coutinho said, "that there was only going to be so many slots for treatment, so let's keep it with the organizations that know how to do it." Senior MOH officials told Coutinho that if TASO accessed funding for treatment, the MOH would require that it complied with certain guidelines:

> It became apparent to me that what the Ministry was looking for was two things: wording to the effect that a particular hospital would be running one particular program; although there could be sub-programs in the hospital, they were supervised by the hospital. So if we accepted that we could run a sub-program of the hospital, supervised by the hospital, providing credit to the hospital and the MOH, then this proposal would be accepted. Two is that we would be prepared to share resources.

Coutinho used a variety of techniques to convince the MOH that not only was TASO capable of treating its clients, but the organization's participation in the nation-wide scale-up of treatment was critical to the country's ability to reach its 2005 targets. Using a strategy of "quiet diplomacy," Coutinho privately lobbied officials in the MOH, the US Ambassador, and key HIV-positive people in Uganda, and eventually the MOH conceded.

The next issue to hash out with the MOH became how to determine who would get treatment. Countinho explained:

> Because we were rationing and playing God, we had to find a set of rules. We had set up a system of equity, that those who were registered first in TASO had first go at treatment-- first in, first out. We were calling on the radio for people to come if they had registered; but, the Ministry said "no, it's first come, first serve. As the government, we have the right to treat every citizen." We said, "But you know, this whole treatment scale-up has been a result of activism and people who've disclosed. Surely they deserve this one small reward by being given priority over those who for whatever reason kept quiet."
>
> Well, the Ministry didn't want that, but we found wording to say that within hospitals, we would work closely with the teams to determine a system that would work. The strategy that I used was to negotiate so that most of the decision-making would be decentralized, at the hospitals themselves, because the TASO centers had excellent relationships with the hospitals.

Rolling out Treatment

TASO had learned through its experience with the CDC's HBAC study at Tororo that a model which

combined home- and clinic-based management of clients on ART would be optimal in terms of maintaining high adherence levels. This hybrid facility- and home-based care model was rolled out at TASO-Mulago for a one-month trial period; other center directors learned from the experience; it was then scaled to the other TASO centers, three or four centers at a time, and completed by the third quarter of 2006. Dr. Christine Nabiryo, deputy executive director of program management, explained the process before each roll out:

> We would train all the teams, and then they would have to go through kind of a mock-run of how they would do everything-- like a simulation. Then, they would do the real thing. Having it piloted somewhere else helped to build up confidence and to provide lessons and recommendations for modifications. It was sort of an operational research methodology without the formal structure.

During the first 18 months of funding, TASO started around 2,500 clients on ARVs. "The key was to get the capacity right, get going, and then once you have the confidence that you can do it, you start fiddling with it to improve it. That's an important lesson in any model: starting is more important than how you start." Coutinho recalled a friend's advice: "You're going to make mistakes anyway, so you might as well start all of the sites simultaneously. You'll save more lives that way, whereas if you're doing it one after another, by the time you get to the last one, too many people will have died."

The TASO Treatment Model

With the hybrid model all clients who initiated ART had to initiate their treatment from the clinic (see **Exhibit 13** for TASO ART care pathway). The preparation period required clients to come for two visits at the centre before starting the treatment. The first visit could last several hours. It entailed participating in a health talk with a counselor and then a supervisor who registered the client and verified information. Clients then moved into a counseling and information session with 8 to 10 other patients who shared a language. An individual pre-test session followed in which clients consented to the test and verified their identity. They participated in a discussion about the definition of HIV, AIDS, and the differences between the two; modes of transmission of HIV and strategies for prevention; and the meaning of test results and implications of these results. After the test a post-test counseling group was held. Patients who needed TB or other treatments were referred for clinical evaluation before enrolling in ART. For tough cases a case conference was held after the first visit to make a decision collectively. The medical officer, counseling officer, and often the clients themselves would participate.

On the second visit, also lasting several hours, clients participated in pre-result counseling to learn about CD4 counts, the benefits of ART, possible side effects, and the dangers of drug sharing. They received a clinical evaluation regardless of their status. When their CD4 counts were over 200, they were told to return for periodic checks. They also received a basic care package that included: Septrin (co-trimoxazole) to prevent opportunistic infections (OIs), a plastic vessel for storing drinking water hygienically, water purification solution, condoms, two insecticide-impregnated mosquito nets to protect against Malaria, and health education materials on use of the basic care kit. If their CD4 was under 200, they received individual counseling to consent to ART and monitoring, to determine the regimen, and to arrange a home visit. They also received the basic care package.

The home visit involved disclosing a client's HIV status to the family through "supported disclosure." If patients did not agree to this, they were not eligible for home-based care. Home visits were also used to conduct a psychosocial assessment, to identify a medicine companion who would help the client with adherence and be trained in social support, to introduce the TASO field officers (FOs) to the family, to inform household members of the home-based voluntary counseling and testing (HBVCT) available to family members, and to schedule a follow-up. HBVCT enabled TASO to avoid the risks of pill-sharing, address psychosocial issues related to discordant relationships, and sensitize the family members about

HIV. TASO relied on the AIDS Information Center, a nonprofit its members had helped start with the Ministry of Health in 1990, for much of its testing.

On the third visit clients came to the center with their medicine companion to create adherence plans, go through a readiness checklist, commit, and talk about sexual behavior. After a third clinical assessment, the patient would receive ARVs from the TASO pharmacy. All clients received a home follow-up visit after two weeks from a FO who checked for complications.

After one month, clients who were able to afford trips to the clinic and those who were unwilling to receive visitors from TASO in their homes could choose to receive their treatment at a TASO facility. Those who were too ill or poor to travel and who did not mind home visits by TASO staff could choose to receive their treatment at home. For those choosing home-based care (HBC), FOs visited monthly to bring a supply of ARVs, provide psychosocial support, hygiene counseling, and adherence evaluation, and perform an assessment of the client's home environment. Center-based counselors visited HBC clients enrolled in ART on a quarterly basis; doctors and nurses arranged to visit the sickest home-based clients; and TASO transported clients in extreme need to the nearest hospital.

Despite the advantages of HBC, many clients chose to receive treatment at TASO facilities; some clients had chosen not to disclose their HIV status to family members. As their health improved on treatment, some clients returned to work and therefore could not wait at their home all day for a FO visit. Some clients sought treatment for new medical conditions, including ART side-effects, and they preferred the care of a physician over a community nurse or FO. TASO's most experienced counselors also worked primarily in the centers, so those clients who preferred to maintain their relationship with these counselors opted for facility-based care. These clients could afford transportation and were mostly urban; most of TASO's rural, poor clients chose home-based care. Although HBC clients did not have consistent access to the best TASO physicians and counselors and FOs were not qualified to diagnose and treat certain opportunistic infections and other medical conditions, most clients reported that they were content with the medical and social support services they received in their homes. If an FO or community nurse encountered a problem that he could not handle, he referred the client to a nearby health unit or TASO clinic close to his or her home. There was also a free mobile hotline for clients to call for advice.

In addition to the facility- and home-based care, TASO utilized regular Outreach Clinics in areas that were far from TASO Centers in order to bring services closer to their clients' homes. Most clinics provided counseling, medical, and laboratory services, and they served as the monthly food distribution sites.

Workforce

Coutinho provided strong leadership for treatment scale-up, and the staff was highly committed. One organization leader recalled, "The goals and strategies were very clear and focused, which had a trickle-down effect so that everyone was committed to the idea, and everyone was excited about it." Tina Achila, deputy director in psychosocial program management, explained, "There's a culture of commitment. I think also because the people who come, come with a heart to serve… These people have seen the suffering in the communities, and they truly want to do something about it. People go the extra mile."

Despite the physician and nurse turnover in most institutions in Uganda, managers and other medical staff (see **Exhibit 14** for descriptions of TASO medical staff positions) stayed at TASO. As Etukoit explained, "It was very, very exciting, and people were so empowered with hope – I can do this! This is work that was once restricted to doctors, but now I'm actually saving lives!" Many felt that TASO had created opportunities for professional growth. "I know that after I go ahead to study, there is more I can achieve in TASO – this is not where I started from. I see myself moving ahead to even bigger hopes. TASO is very

good at that, and it is there to help me move along in my career," an HIV positive day center supervisor said.

TASO's management and accountability structures added to its strengths. There was a clear division of labor and specialties, and clear supervision criteria for every TASO person, each of whom was hired carefully. "We've learned at TASO that it's not about being busy and looking like you're doing something. It's about adding value. And that's where our client-centered programming comes from. Every decision we make revolves around improving the quality of life of a single client—whoever we are talking about at the time. We try to appreciate every unique situation and add value for each client," said Richard Wanyama, director of resource mobilization and donor liaison. "TASO is more interested in hiring people with management skills than people who know something about HIV," Juliana Nyombi, the director of training and capacity development said.

Adapting the Model

With time, revisions were made to the treatment model in close dialogue with the clients and those working in the program. "Initially we had thought that ART was not an emergency, and we needed to do the screening and prepare people. It became clear that people's awareness of what they were expected to do even before the screening was much higher than it was at the start of the program. So we found we didn't need as much time," Nabiryo explained. Counseling sessions were combined and shortened.

The criteria for receiving ART changed as well. "We were able to say, 'Look, first in first out is good, but there are people who are really struggling…' We revised so that people who were very sick could quickly be brought into treatment—as soon as we could catch them," Nabiryo said. Decisions remained grounded in the national criteria, but in these special circumstances, it became up to the judgment of the physician and the multi-disciplinary team who participated in the case conference.

Another change was in HBVCT, which had been for the whole family. TASO found that the positive rate for those between five and 15 years was very low, and shifted the emphasis to test those under five. This led to the development of a pediatric ART program. HBVCT also showed that there was a 60% rate of discordance among married clients, requiring the creation of a discordant couples club and couples counseling. As clients began feeling better and wanting to return to normal lives, the number of pregnancies increased and the PMTCT program was strengthened. Counselors were trained in each new issue that arose with the changing face of the disease, and training in income generating activity was offered for clients to return to work or open new businesses.

Evaluating the Hybrid Model

Feedback came from clients through their organized forums as well as required satisfaction surveys and from frontline staff. In 1998 an information management system had been put in place to collect data. The most important indicator to TASO was access to its services. The organization also wanted to make sure OIs were treated, to improve health care seeking behavior, and "to see empowered clients" who could make choices for themselves, think about the future, support their family, and share their serostatus with others, reducing stigma. Coutinho explained:

> Many of TASO's benefits cannot be measured directly necessarily: first, it's a family-based approach, so the index HIV positive person may lead to the early detection of many other HIV positive people and prevent their deaths. Second, there is a lot of HIV prevention put into the model, so there's a potential for reducing many other infections. And third, it looks at the individual holistically, and even if you don't need treatment, it provides interventions like malaria prevention and safe water that will keep you alive.

The leaders were confident that the organization was successful. Ochai explained:

> TASO has always been a vocal organization. There's always freedom of voice for everyone. It's not hard to hear when good things are happening and bad things are happening…..TASO has been equated to HIV/AIDS programs in Uganda. If you go to the community and you ask anyone riding his bicycle and you ask him what he would do if he got HIV/AIDS, he'll tell you he'd go to TASO.… Even if the MOH official is driving a car and there's something that says HIV/AIDS unit on the car, people will say "that is TASO!" TASO has really established itself as the leader in HIV/AIDS care in Uganda.

Growth and Outcome of TASO's ART Program

By the end of 2006, there were 10,000 clients enrolled on treatment, including over 400 children. In 2006 TASO conducted about 200,000 medical sessions at its centers and almost an additional 100,000 at its outreach clinics (see **Exhibit 15** for services delivered).[53] It had a presence in 56 of Uganda's 80 districts, employed over 1,000 staff, provided care and support to over 186,000 PLWHAs (65% female, 35% male), enrolled over 18,000 clients on ART including more than 700 children, and supported over 85 communities throughout Uganda.[54]

In the first year of ART, the organization's total annual expenditures for all seven primary service areas (see **Exhibit 16** for service areas) nearly doubled from about USD 6.63 million in 2003 to about USD 11.76 million in 2004, and this number reached USD 21.02 million in 2006.[1, 52] By December 2006 international donor support (especially from PEPFAR and the Global Fund) had enabled Uganda to enroll 87,000 PLWHA on ART, nearly 11,000 of whom were TASO clients, including 407 children under age 18. In 2006 alone TASO enrolled 4,093 new clients (1,146 males and 2,947 females) on ART.[53] Levels of adherence were quite high among TASO clients, with most (83.9%) in the above-95% adherence bracket (see **Exhibit 17** for adherence by month), and overall retention was 88% (see **Exhibit 18** for retention rates by center).[53] The number of family members receiving HBVCT skyrocketed due to increasing demand from 944 in 2004 to 26,929 in 2006.[53]

Human Resource Challenges

With the number of clients on treatment increasing steadily, the organization faced human and financial resource challenges. Center-based counselors were finding it impossible to visit all clients utilizing HBC on a quarterly basis. Given the changing psychosocial issues of clients on ART—especially an increased desire to have sexual relations, to have children, and to return to work—TASO counselors required additional, time-consuming training. FOs were having more and more difficulty visiting all of their HBC clients on a given day due to the great distances they were required to travel. One TASO-Mbale FO reported only being able to see 5 or 6 of the 10 scheduled clients on a given day. Rough terrain and frequent motorbike accidents and breakdowns made the journeys treacherous and exhausting. FOs were feeling increasingly unappreciated by clients whose health had improved, and they lost motivation for the work that had become so routine. Even TASO managers at centers and headquarters (see **Exhibit 19** for TASO organizational chart) were finding the increased demands on their time and resources from more complex protocols and operational procedures overwhelming.

Between 2003 and 2006 TASO grew from 400 to 1,000 employees, and volunteers increased by 50%, which put a strain on the recruiting team. The "brain drain" from other organizations—including other NGOs, research institutions, and the UN—recruiting their trained staff members with higher pay rates was an additional stress. Although TASO physicians earned two times that of government doctors, those in the same position in another national or international NGO or donor organizations often earned two to five times as much.[55] TASO's ability to recruit new employees was limited by its donors in terms of the size of its

overall human resource envelope, which restricted TASO's ability to scale up staff numbers—especially counselors and FOs—to match the increase in client numbers.

Financial Resource Constraints

Financial resources were becoming increasingly vulnerable as other organizations became competitive, and the commitment of major global health initiatives stabilized. Between 2004 and 2005 the CDC's commitment nearly doubled from USD 4.57 million to USD 9.74 million. Yet the commitment in 2006 was only slightly larger than the previous year at USD 10.38 million.[1, 52, 56] The commitment from USAID had increased marginally from USD 5.26 million in 2004 to USD 5.54 million in 2005, but its contribution dropped to USD 3.73 million in 2006.[1, 52, 56]

Part of the decline in funding may have been due to the Ugandan Ministry of Finance, Planning, and Economic Development placing a ceiling on all sectoral budgets. The policy demanded that all donor funding be included within sector ceilings. It was not just PEPFAR resources constraining TASO's scale up, however. The Global Fund temporarily eliminated all of its grants to Uganda in 2005 after a review revealed evidence of "serious mismanagement" on behalf of the Project Management Unit in the Ministry of Health. And many of TASO's bilateral donors—including the UK Department for International Development (DFID), Danida, the European Union, and Ireland Aid's Development Cooperation Ireland—gave the same amount, if not less, over time. TASO's total income—from donations and local contributions—fell from about USD 23.25 million in 2005 to USD 21.88 million in 2006.[1] In 2006 generic ARVs became available, and cost reductions had allowed the organization to continue increasing enrollment, but the price declines would not continue.

Changing Client Demands

As clients went back to work, it became increasingly difficult for them to wait around their homes all day for a FO visit. Clients who had returned to work were missing appointments. Also, many HBC clients were complaining that they had lost their social contact with other PLWHA and the peer support that TASO had always been committed to providing. Those who received treatment at home no longer visited other HIV-positive people, heard testimony from other clients, or benefited from the community environment that TASO had worked for two decades to foster. Clients were feeling isolated, and many reverted to negative psychological states because of stigma and discrimination in their communities that was not mitigated by peer social support.

Clients from other organizations also began to migrate to TASO. "People from other organizations were coming to us saying, 'we like your model. We want to leave them and come to you.' We said, 'no, you started there, so stick there because we don't want to undermine their program and we are also overloaded,' but the migration continued.

TASO had set a target of registering 7,000 clients and 35,000 total beneficiaries in its nutritional assistance program with the World Food Program (WFP) by the end of 2005. Although the organization exceeded this registration goal, only 6,732 primary and 33,660 total beneficiaries were actually being served by the end of the year due to a planned exit strategy to wean clients off of services in place of a Sustainable Livelihoods Strategy project. Food insecurity threatened the health of patients on ART, especially those in urban areas who were unable to farm.

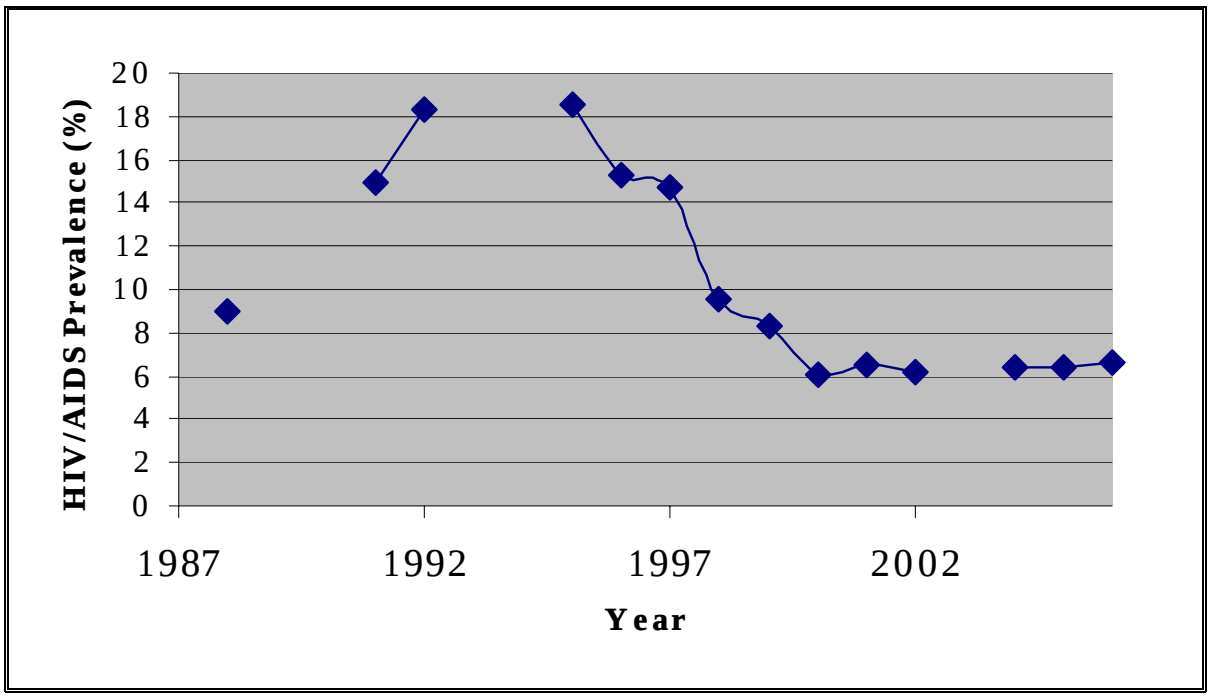
Next Steps

Coutinho was proud of all that TASO had accomplished during its first two years of providing ART to thousands of clients. However, he realized that the model needed to be revised in the face of human and financial resource constraints, staff burnouts, high administrative costs of individual home visits, and changing client needs. Were there changes that could be made to improve the efficiency of the model without losing the spirit of service-delivery catered to the individual client? How could TASO ensure that it could continue to treat an increasing number of clients every year when funds were stabilizing and other players becoming increasingly competitive in a market stretched for resources?

Exhibit 1 *Map of Africa Highlighting Uganda*

Source: Adapted from Public Domain

Exhibit 2 *National HIV/AIDS Prevalence over Time*



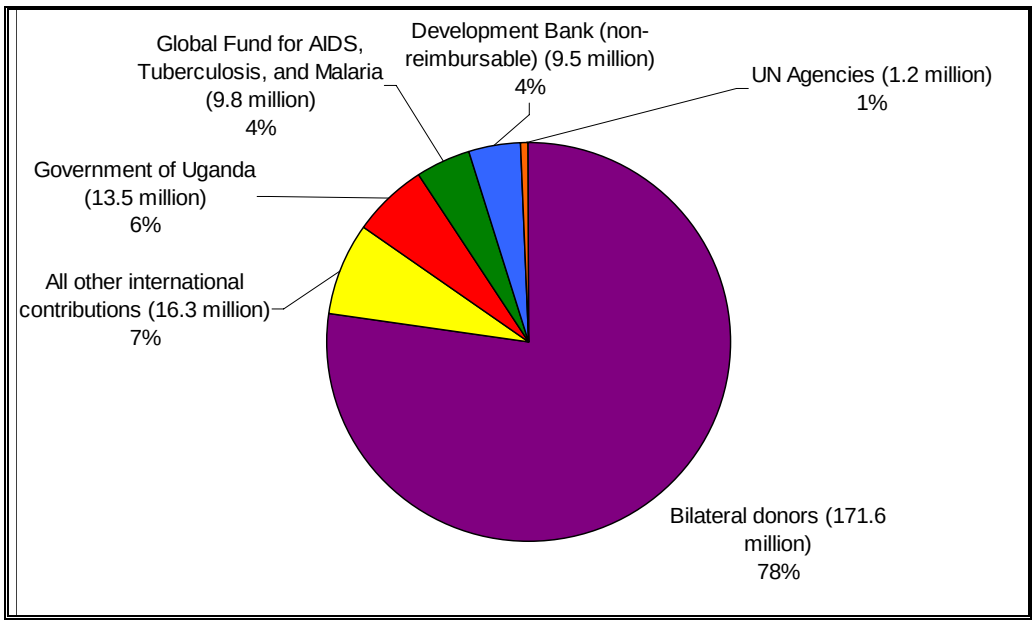
Sources: Uganda AIDS Commission, Ministry of Health of Uganda, WHO, UNAIDS.

Exhibit 3 *Sexual Behavior Survey Findings 1995, 2000, 2004-2005, and 2006*

Survey Parameters	Population-based Surveys & Findings			
	1995	2000	2004/05	2006
Adult women engaged in higher risk sex	12%	14%	15%	16%
Adult men engaged in higher risk sex	29%	28%	37%	36%
Condom use by women	20%	39%	47%	35%
Condom use by men	35%	59%	53%	57%

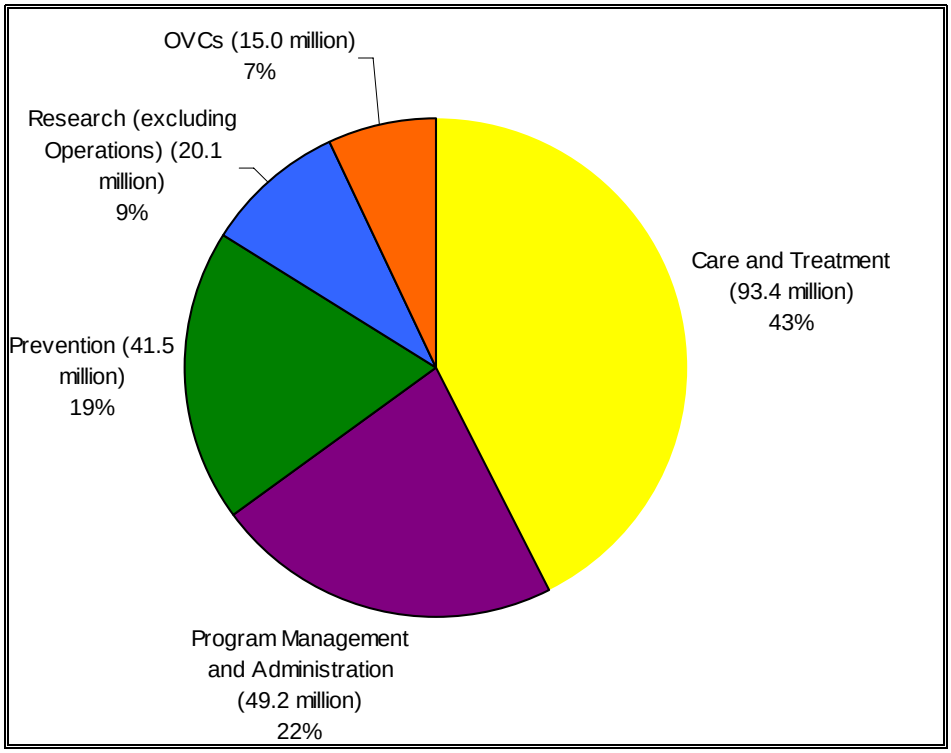
Source: UNAIDS Epidemic Update, 2007.

Exhibit 4 *HIV/AIDS Funding Sources for Uganda, 2005-2006*



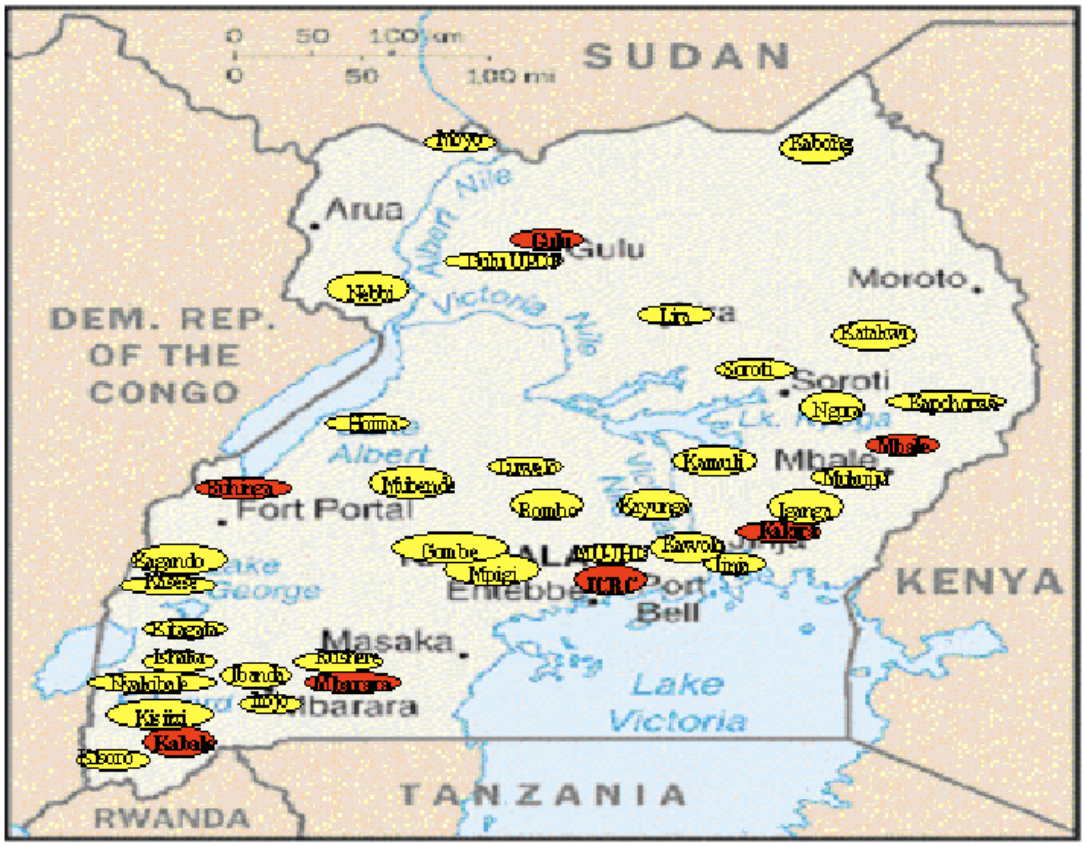
Source: UNAIDS. *Country Progress Report: Uganda*: Government of Uganda, Uganda AIDS Commission; 2008

Exhibit 5 *HIV/AIDS Spending in Uganda, 2005-2006*



Source: UNAIDS. *Country Progress Report: Uganda*: Government of Uganda, Uganda AIDS Commission; 2008

Exhibit 6 *Joint Clinical Research Center (JCRC) Coverage Map, September 2006*



Source: JCRC Website, http://www.jcrc.co.ug/

Exhibit 7 *TASO Service and Training Centers*

Source: TASO.

Exhibit 8 *Dates of TASO Center Openings*

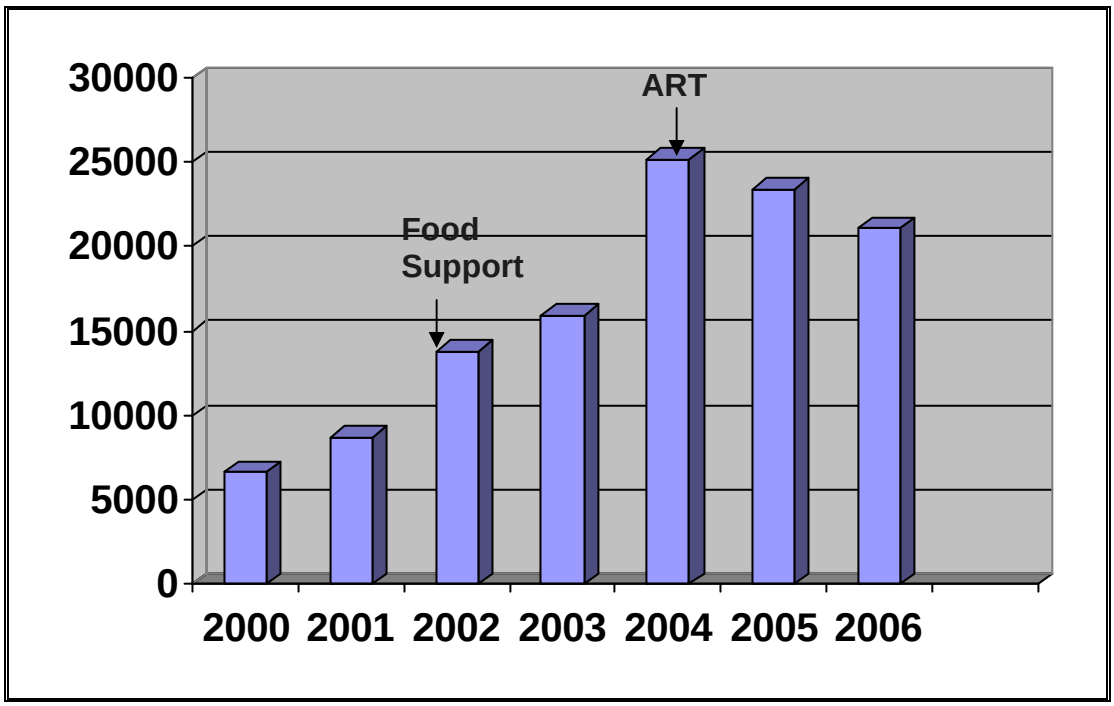
CENTER	DATE ESTABLISHED
Mulago (Kampala)	November 1987
Masaka	May 1988
Training Centre, Kanyanya (Kampala)	October 1988
Tororo	November 1988
Mbarara	January 1989
Mbale	March 1990
Jinja	March 1991
Entebbe	November 1991
Gulu	January 2004
Rukingiri	August 2004
Soroti	August 2004
Masindi	August 2005

Source: TASO.

Exhibit 9 *TASO-Mulago Center*

Source: Sarah Kleinman, Kampala, Uganda. 2008.

Exhibit 10 *New Clients Registered for Services by TASO, 2000-2006*



Source**:** TASO Management Information System.

Exhibit 11 *TASO Income Statements in Ushs, 2003-2006*

	2003	2004	2005	2006
Donations				
Pfizer	694,400		9,182	
DFID	1,092,433	1,546,568	2,559,930	2,428,470
Danida	1,796,079	2,727,273	1,969,697	1,714,286
SIDA- Embassy of Uganda	1,380,186	1,927,267	1,494,391	1,637,849
SIDA- Embassy of Zambia			499,759	1,360,197
EU	76,062	455,996	644,111	
Ireland Aid (DCI)	2,150,316	2,406,699	2,478,050	2,725,800
USAID/DISH Project	33,227			
CDC Life Funds	264,892	7,384,858	15,729,185	16,771,098
Title II PL 480 (ACDI/VOCA)	719,972	667,413	551,146	1,131,383
Local Government of Uganda	9,108	0	33,854	
USAID/John Snow International	3,982,018	8,487,493	8,942,329	6,032,879
Celtel Uganda	20,000	20,000		20,000
Rockefeller Funds	280,369	259,911	320,355	
WFP Funds		58,207	102,736	173,734
UNICEF Funds			261,387	187,366
Johnson and Johnson			171,000	
Medical Research Council			297,161	166,075
King Baudouin Foundation US				183,000
Global Fund		313,322		
Other Donations	237,925	995,495	225,356	150,697
Taxes Paid by GOU	282,937	180,913		
Total Donations	13,019,924	27,431,415	36,289,629	34682834
Local Income				
Uganda Community	73,255	37,318	17,685	784
Bank Interest	8,672	931	6,047	4,861
User Charge	65,826	97,820	117,325	114,656
Training Fees	368,941	579,648	851,593	399,784
Miscellaneous	169,276	196,959	229,466	93,440
Membership Fees	9,385	34,260	38,552	38,294
Sale of Old Assets	6,028	2,079	4,312	9,766
Total Local Income	701,383	949,015	1,264,980	661,585
Total Donations and Income	**13,721,307**	**28,380,430**	**37,554,609**	**35,344,419**

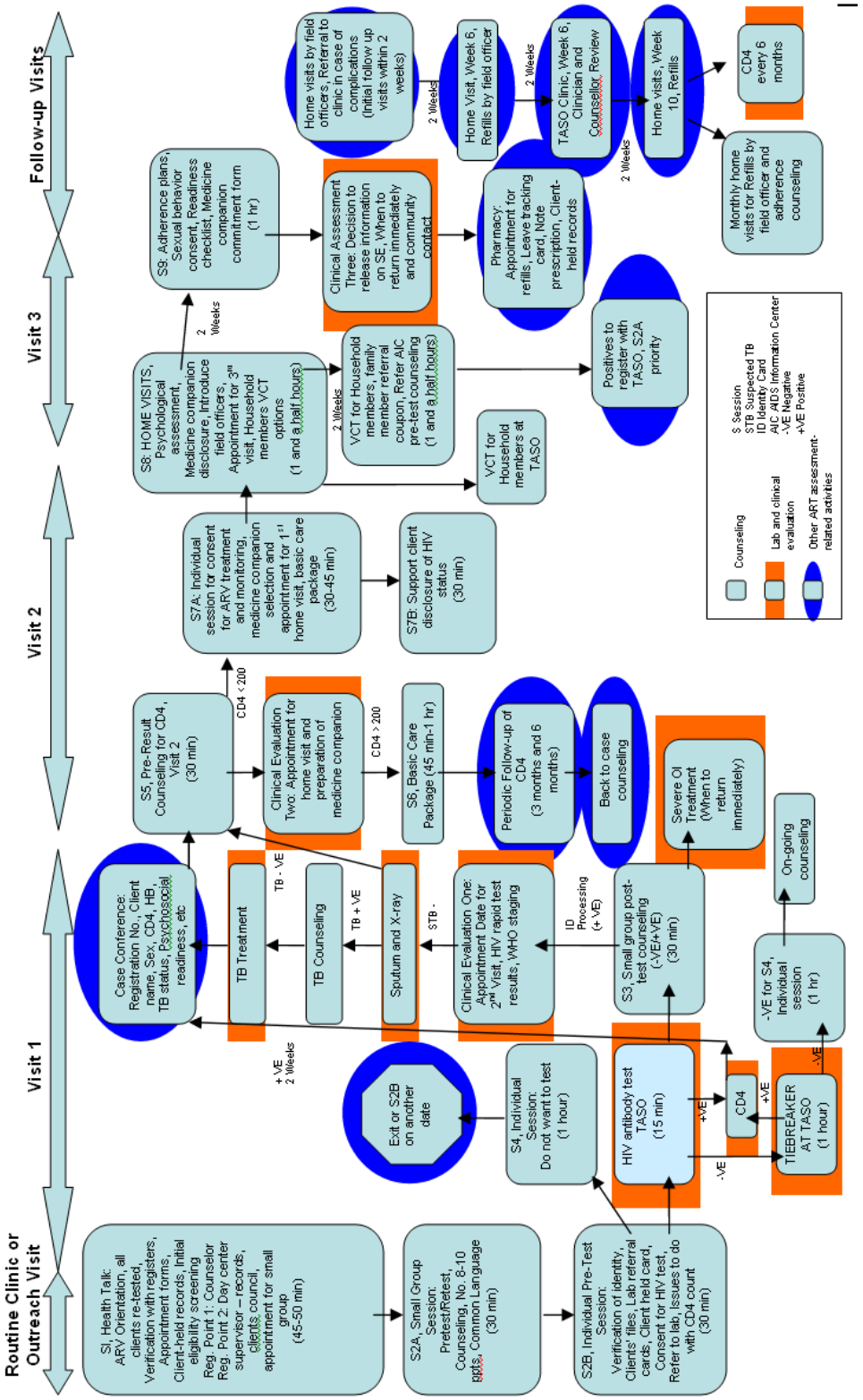
Source: TASO.

Exhibit 12 *TASO Expenditure Statements in Ushs, 2003-2006*

	2003	2004	2005	2006
Expenditures				
Client Counseling	1,038,338	1,553,712	1,912,578	2,144,189
Personnel	1,417,653	1,961,030	2,573,588	2,592,737
Medical Services	1,861,252	6,551,138	3,167,734	3,245,292
Training Centre	607,384	785,517	827,947	736,342
Advocacy and Collaboration	794,127	1,157,785	1,431,840	1,384,759
Office Expenditure	819,335	1,436,838	1,695,291	1,363,089
Social Support	1,195,327	1,308,234	987,202	872,264
Institutional and Community Capacity Building	842,753	1,023,500	1,612,595	1,501,062
Travel and Transport	340,039	601,953	773,911	726,334
Client Day Center	232,761	374,149	496,130	443,814
Monitoring and Evaluation	389,287	693,896	918,110	1,180,736
Staff Capacity Building		346,381	110,872	
AIDS Education and Sensitization	392,348	453,901	526,066	493,779
Title II-Nutrition Project	611,635	635,393	754,931	1,055,729
Antiretroviral Therapy			11,299,860	13,701,745
Strengthening Counselor Training in Uganda (SCOT)			825,884	1,273,199
TASO Experiential Attachment to Combat HIV/AIDS			304,797	942,126
Technical Assistance	70,554	52,559	72,666	51,933
Board of Trustees and Client Council Expenses	92,319	135,699	230,465	244,971
Total Expenditure Before Capital Expenditure	**10,705,112**	**19,071,686**	**30,522,466**	**33,954,100**

Source: TASO.

Exhibit 13 TASO ART Care Pathway, 2007



Source: TASO.

Exhibit 14 *TASO Medical Department Staff, 2006*

Physicians: When fully staffed, each TASO centre had at least two full-time physicians. Generally, one of the physicians was the Medical Coordinator, supervising all clinical programs and staff, and the other physician was charged with coordinating all aspects of the ART program. Since most of the physicians were trained as generalists, they faced a steep learning curve in developing the more nuanced clinical knowledge and skills necessary to manage and coordinate the provision of HIV/AIDS services when coming to TASO. After being trained, physicians are siphoned off regularly by other organizations. Because they were generally the most well-educated people in their families, they faced the challenge of educating and supporting their own families and they were expected to contribute to the education of their less fortunate relatives as well as other expensive family undertakings such as weddings and funerals.

Clinical officers: Like many countries in East Africa, Uganda trained a cadre of health workers known as clinical officers. The clinical officers' training was intermediate between that of a doctor and a nurse and was comparable to that of physician's assistant in the U.S. system. In the national public health system, clinical officers were among the most senior clinical staff and supervised a team of nurses at the level of the community health centre. They also practiced relatively independently at district and regional hospitals under the supervision of a physician. TASO relied heavily upon the clinical officers in the management of HIV patients, including those on ARVs. Seasoned clinical officers and nurses often had much more experience managing opportunistic infections and the side-effects of ARVs than physicians who were new to the organization. Unlike doctors and nurses, clinical officers were less frequently recruited away by international organizations and were also less likely to pursue advance degrees, so they helped to provide continuity of care when physicians left for further studies or other organizations.

Nurses: TASO also broadened the scope of practice for nurses who were initially the bedrock of the clinical program within the organization. The responsibilities of nurses within TASO varied depending upon their level of training and their comfort with quasi-independent patient care. The comprehensive nurses and other nurses with adequate knowledge and skills were trained in ART management. Like the clinical officers, these nurses managed straightforward patients on ART relatively independently.

Field officers: In order to continue its community-based orientation in the setting of ART, TASO trained and employed field officers (FOs) who visited patients in their homes on at least a monthly basis, assess their clinical condition and their adherence to their medications, and provided ongoing education in areas such as hygiene and nutrition. Most of the TASO FOs had at least two years of university education, and some of them had four-year degrees. FOs were trained by TASO in ART, HBC, nutrition, hygiene, family planning, PMTCT, and other related issues. The field officers played a crucial role in the management of home-based services. They had basic training in counselling and recognition of the signs and symptoms of opportunistic infections, and they served as a bridge between the clinicians and counseling staff and the patients in the field. There were generally between 12-15 FO per center.

Counselors: Counselors played a role in helping to evaluate patient readiness for ART initiation and helping to manage the lifestyle and cognitive adjustments associated with beginning lifelong therapy. Traditionally, counselors also made quarterly home visits to all patients. Most of the counselors were women.

Source: Compiled by case writers with support from TASO.

Exhibit 15 *Basic Health Care and Support Outputs*

BASIC HEALTH CARE SERVICES	2004	2005	2006
No. of people given HIV counseling	43,498	49,362	54,009
No. of counseling sessions conducted	104,378	131,250	146,035
No. of clients given medical care (including TB/HIV)	48,612	75,290	76,709
No. of medical sessions conducted	251,879	321,557	320,630
Proportion of clients cared for screened for TB	87%	70%	92%
Proportion of clients screened diagnosed with TB	6.4%	8.2%	4.0%
Proportion of clients diagnosed with TB treated	96%	64.3%	42%
Proportion of sexually active clients screened for STI	46%	77%	97%
Proportion of clients diagnosed with STI treated	99%	99%	96%

Source: TASO-Uganda PEPFAR Project Closeout Report. 2008.

Exhibit 16 *TASO Services, 2006*

Counseling: Counselors provided psychosocial support in pre-test, post-test, prevention, and supportive aspects of HIV/AIDS. Services were provided at TASO centers, outreach clinics/Community Drug Distribution Points (CDDPs), and homes to individuals, couples, children, and family members of index clients.

Medical Care: TASO medical services were part of the national health system. They included the following: screening, treatment, and prophylaxis of opportunistic infections; ART; sexually transmitted infections screening and management; family planning; prevention of mother to child transmission (PMTCT); and health education to clients and their care givers.

Social Support: TASO's social support programs were designed to mitigate the impact of HIV/AIDS on clients and their families. The package for orphans and vulnerable children (OVC) included formal education, vocational training and facilitation for the start-up of Income Generating Activities (IGAs) for youth out of school. Clients and families experiencing food insecurity, particularly those who were on treatment for TB, received supplementary food aid. Many TASO clients were trained with skills for sustainable livelihoods as they were phased out of nutritional support.

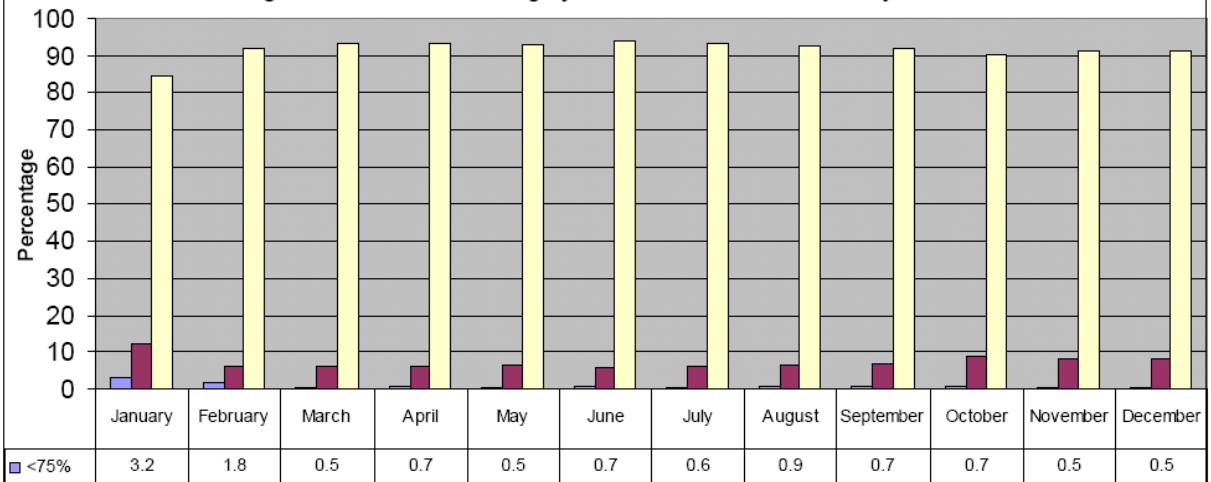
Training: TASO aimed to strengthen the competencies of HIV/AIDS service providers throughout Uganda through training and capacity building activities. Courses were offered at the TASO Training Centre in Kanyanya, Regional Training Offices (Gulu, Kampala, Mbale, and Mbarara), TASO Centres, and through partnerships like Strengthening Counselor Training in Uganda (SCOT) and TASO Experiential Attachment to Combat HIV/AIDS (TEACH). TASO's Professional Volunteers Program enabled undergraduate, Masters, and PhD level students or recent graduates of certain universities to come to TASO for hands-on training and experience in the field. People traveled to Uganda from all over the world to participate in workshops and experiential training with TASO.

Community Mobilization and HIV Education: TASO engaged in community mobilization and sensitization through its Drama Group performances and by training partners to provide AIDS education, care, and support services at the grass roots level. TASO worked to enhance the service delivery capacities of other institutions, CBOs, NGOs, and government health units through training in HIV/AIDS counseling, medical care and Project Planning and Management (PPM). TASO gave small grants to CBOs to enable them to provide TASO-like services, especially in districts that were not included in TASO's catchment areas. TASO's AIDS Challenge Youth Club (ACYC) used youth-friendly strategies to address youth sexual reproductive health issues. With a network of clubs based at TASO centers and schools across the country, ACYC reached out to Uganda's infected and affected youth.

Advocacy and Networking: TASO was involved in various networks that promoted common voice advocacy for policy formation and resource mobilization. TASO offered technical support, training and production of materials with messages advocating for the rights of PLWHA. TASO's HIV-positive clients were involved at the governance, management, and program implementation levels.

Research: TASO was involved in a number of research projects with various partners, including the Medical Research Council (MRC), Centres for Disease Control (CDC), and the University of Washington.

Exhibit 17 *Percentage of Clients in Each Category of Adherence Measurement by Month, 2006*



	January	February	March	April	May	June	July	August	September	October	November	December
<75%	3.2	1.8	0.5	0.7	0.5	0.7	0.6	0.9	0.7	0.7	0.5	0.5
75-95%	12.3	6.1	6.1	6	6.7	5.6	6.2	6.6	7.1	8.8	8.5	8.4
>95%	84.5	92.2	93.5	93.3	92.8	93.7	93.2	92.4	92.2	90.5	91.1	91.2

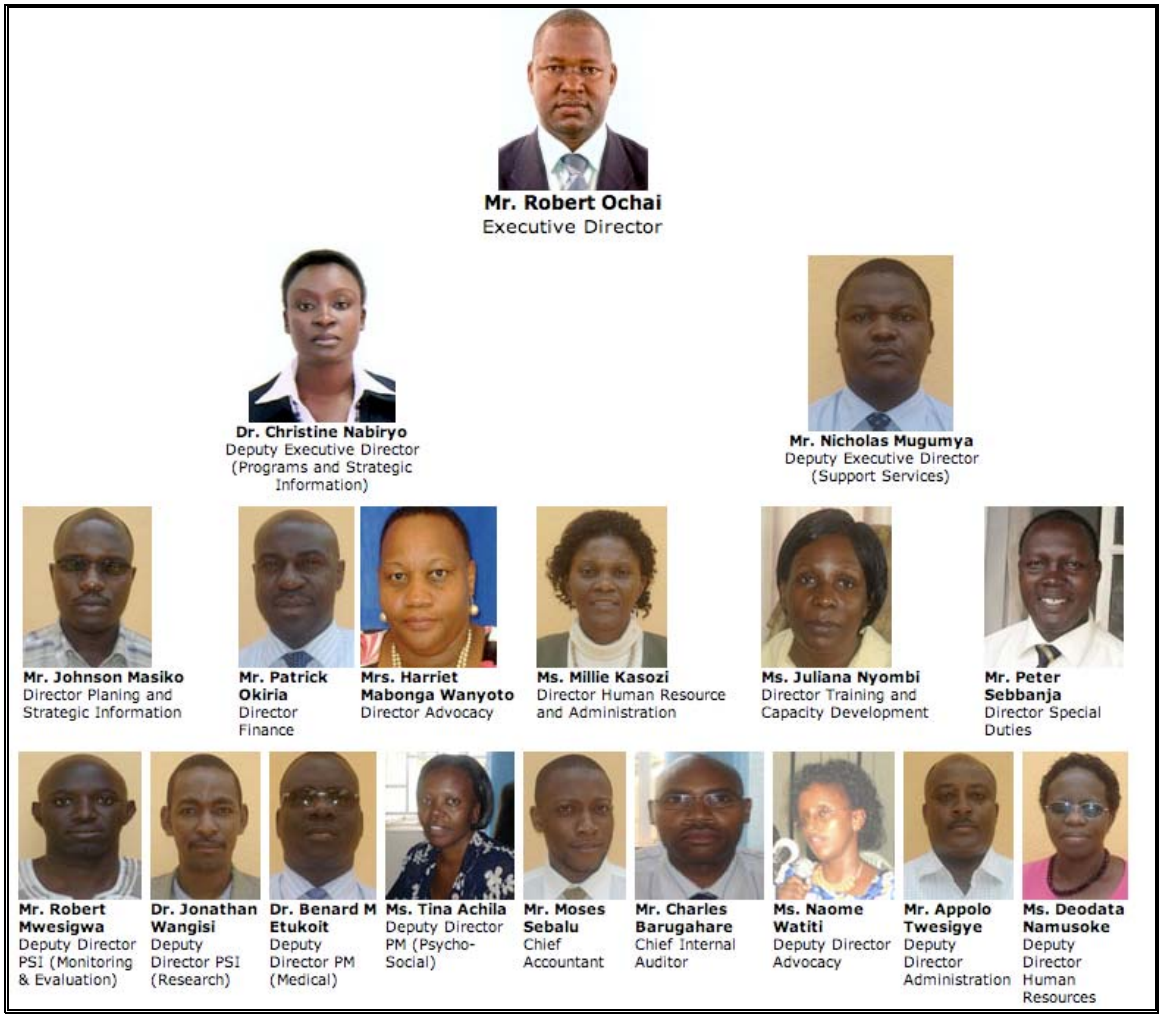
Source: TASO-Uganda 2006 Annual Report.

Exhibit 18 *Retention Rates for Clients on ART by Center, 2006*

	TASO Centers											
	Mbale	Jinja	Msk	Mbara	Mulg	Gulu	Trro	Ebbe	Rukgri	Msdi	Srti	**Total**
Ever Started	1,412	1,917	1,275	1,425	1,358	883	771	884	156	77	138	**10,296**
Number Lost	146	266	212	204	180	52	67	29	25	6	23	**1,210**
Active Clients	1,266	1,651	1,063	1,221	1,178	831	704	855	131	71	115	**9,086**
Retention Rate	90%	86%	83%	86%	87%	94%	91%	97%	84%	92%	83%	**88%**

Source: TASO-Uganda 2006 Annual Report.

Exhibit 19 *TASO Organizational Chart, 2008*



Source: TASO Website (2008). http://www.tasouganda.org.

Appendix *Useful Abbreviations*

ACP	AIDS Control Program
AIC	AIDS Information Center
AIDS	acquired immunodeficiency syndrome
ART	antiretroviral therapy
ARV	antiretroviral
CAC	Center Advisory Committee
CBO	community-based organization
CC	Client Council
CDC	Centers for Disease Control and Prevention
DFID	United Kingdom Department for International Development
DOTS	directly observed treatment short course
DTP3	third dose of diphtheria toxoid, tetanus toxoid, and pertussis vaccine
FBO	faith-based organization
FO	field officer
GDP	gross domestic product
HBAC	home-based AIDS care
HBC	home-based care
HBVCT	home-based voluntary counseling and testing
HIV	human immunodeficiency virus
IDI	Infectious Diseases Institute
IMF	International Monetary Fund
JCRC	Joint Clinical Research Center
LRA	Lord's Resistance Army
MOH	Ministry of Health
NCPA	National Control Program for AIDS
NGO	non-governmental organization
OI	opportunistic infection
PEPFAR	President's Emergency Plan for AIDS Relief
PLWHA	people living with HIV/AIDS
PPP	purchasing power parity
PMTCT	prevention of mother-to-child transmission
STD	sexually transmitted disease
TASO	The AIDS Support Organization
TB	tuberculosis
UAC	Uganda AIDS Commission
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV and AIDS
USD	United States' dollar
VCT	voluntary counseling and testing
WFP	World Food Program
WHO	World Health Organization

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