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## The Uganda 'Success Story'

As the capital of one of Africa's 'fastest growing economies', Kampala appears booming and vibrant. Many of the roads are in good repair, old buildings have been painted and windows replaced, and new construction is evident. New stores, restaurants, boutiques, and nightclubs have been opened, and hotels, many renovated, are doing a steady business. A growing population of expatriates is visible, reflecting the stability that has allowed for the growth of international business and foreign development assistance. The stock exchange is located in a busy downtown office building. Other signs of progress are the European bakery, the home-made pasta shop, the mini-market that sells imported food from Europe – a big change compared to a decade and a half before, when Kampala was quiet, the buildings derelict, the streets pot-holed, and there was little evidence of commerce or an international presence. But on closer observation, Kampala still shows some signs of 'underdevelopment'. Sprawling neighbourhoods of small houses built of clay and corrugated iron continue to house many of Kampala's 'middle class'. The 2003 UN Development Report places 82.2 per cent of the Ugandan population below the income poverty line of \$1 a day, and 48 per cent have no access to an improved water source.<sup>1</sup> Access to adequate health facilities is still out of reach for 50 per cent of the population. Life is certainly better for many people than it was in the days of Amin and Obote, but the wealth stemming from Uganda's 'successful' economic liberalization has not quite yet 'trickled down'. And zones of conflict remain in the north and southwest of the country, where much of the population continue to live in terror. In this light, AIDS

is just one of a number of problems shaping the politics of daily life in Uganda, deepening for many of its citizens' already existing poverty and human insecurity.

The Uganda response to HIV/AIDS is widely touted as the African AIDS success story and the model to emulate. Surveillance data since 1993 has indicated a decline in HIV prevalence throughout the country, from an estimated peak of 29.4 per cent in 1992 (based on data from antenatal clinic attendees) to a level of 11.25 per cent in 2000.<sup>2</sup> This drop is attributed to the prevention efforts of the Ugandan government and the donor community. The reasons for Uganda's success in lowering prevalence rates, however, are not altogether clear, as evidence seemed to suggest only marginal changes in sexual behaviour by 1993. Data collected by the ACP and various donor projects did not point to sweeping and sustained changes in sexual behaviour. Also difficult to deem a success is Uganda's response in addressing the effects of HIV/AIDS-related morbidity and mortality on agricultural production, labour scarcity, and more generally on household survival and reproduction of the rural poor, despite a decade of calls for interventions to mitigate the deep impacts of HIV/AIDS. Despite a focus on the 'empowerment of women', mounting evidence points to marriage as the largest risk women today in Uganda of contracting HIV. According to an August 2003 Human Rights Watch Report, married women are most vulnerable to HIV infection because of domestic violence and unwanted sexual relations, and the pervasive acceptance throughout state institutions and society, in general, that married women are their husband's property. The report states that 'despite a rhetorical commitment to women's rights, the Ugandan government has ignored the role of violence, and, in particular, unwanted sexual relations in marriage, in exposing them to HIV infection'.<sup>3</sup> In a largely agricultural economy, where women do not own land but are responsible for 70 to 80 per cent of all agricultural work, the burden of care has fallen on the 'private sector' – overwhelmingly women in the 'private' household – resulting in intensive pressure on their labour time, as they simultaneously struggle to care for the sick and produce food for their families. Where women have also produced food for the market, their marketed food production has declined, leaving them without an independent source of cash income. And finally, life-saving ARV treatment in Uganda is out of the question for all but a tiny minority – the cost of one

month's treatment roughly equal to annual per capita income. In this light, Uganda's success can be seen as, at best, partial.

The period from 1985 to 1990 saw the institutional consolidation of the ACP in Uganda and the proliferation of agencies in the AIDS sector; the emphasis of prevention and care on medical interventions and mass education campaigns to promote sexual behaviour change. The next phase in Uganda, beginning in the early 1990s, saw a growing emphasis on the 'multifaceted' nature of the epidemic which continues to this day, reflected in the emergence of the UAC in 1992 and Uganda's multisectoral strategy, its most recent articulation, The National Strategic Framework for AIDS Activities 2000/01–2005/06.

Circumscribing the response to HIV/AIDS is the broader macro-economic policy framework within which the response has evolved, and this is where my analysis begins. I then discuss the formation of the Uganda Ministry of Health (MOH) ACP, the structural problems confronted by its implementation, and the reasons behind the evolution of the 'multisectoral strategy'. Since the beginning of the ACP, we see a gradual shift to a more 'community-based' and 'multi-sectoral' programme, reflecting a growing concern over the social and economic consequences of the epidemic, as well as the decentralization programme of the government introduced in 1992 which in theory was to create increased decision-making and control of resources at the district level. At the same time, the multisectoral strategy has conformed to the broader social policy agenda of the GOU, shaped significantly by the IMF and the WB. My basic argument is that the boundaries of the policy response have been tightly circumscribed by the neo-liberal economic and social agenda; an agenda which valorises privatization and production for the market, while devaluing the activities and relations that fall outside the market. AIDS is not only a health crisis; it is also a crisis in the reproduction of the conditions of daily life.

### **The context: the national economy and health policy**

The macroeconomic policy framework within which Uganda's multisectoral strategy has evolved was first articulated in 'The Way Forward Macroeconomic Strategy 1990–1995' formulated by the Ministry of Finance, Planning and Economic Development (Uganda) (MFPED). 'The Way Forward' was a macroeconomic framework designed

to create 'an independent, integrated self-sustaining economy'.<sup>4</sup> It centred on export promotion to increase foreign exchange earnings, prudent budgeting, and disciplined expenditure. The framework attributed Uganda's economic problems to domestic policy weaknesses, in particular, a shortage of savings in the banking system because of negative real interest rates due to inflation that in turn was related to the excessive printing of money to finance budget deficits. This – along with an inefficient and complicated system of taxation – had resulted in a very low level of financial resources for public and private investment, according to the Ministry.

Macroeconomic policy was centred on the institutional and structural reform of the agricultural sector, the major source of economic growth (accounting for 70 per cent of GDP). In a nutshell, ending marketing monopolies and price controls, minimizing the trade bureaucracy, simplifying taxation, increasing and diversifying agricultural exports, and encouraging private investment were laid out as the main strategies for achieving continued strong growth, and the increase in import capacity through foreign exchange earnings to provide the basis for industrialization. Within this macroeconomic framework, sectoral spending on health and education was to be brought in line with the priorities of fiscal adjustment, including debt repayment. At the time, Uganda's debt burden was 56.9 per cent of exports and 3.4 per cent of GDP.<sup>5</sup> Basic health and education were acknowledged to be both human rights and important investments for the future productive capacity of the economy.<sup>6</sup> But in the context of 'severe resource constraints', the role of government, rather than 'heroically shouldering the entire burden of the health sector',<sup>7</sup> was to supervise the provision of health services – to establish a 'formal network in which NGO activities can be integrated to form a unified attack on the health problems in Uganda... the Government's role... to *guide* such a programme'.<sup>8</sup> In addition, the macroeconomic strategy specified that the limited public resources for the health sector should be concentrated on the provision of essential public goods (such as immunization, family planning, and AIDS education) as opposed to curative services. The strategy called for the establishment of private wings in government hospitals for those who 'wish to pay' related to their ability to pay. Health clinics, under the jurisdiction of District Councils were to introduce user fees to make up for revenue shortfalls. In addition to AIDS prevention, a comprehensive food and

nutrition policy, and a national population programme, 'attempting to make population growth compatible with development in all parts of the country',<sup>9</sup> were laid out as the three specified targets of public health policy.

The Ugandan government's health policy framework mirrored the WB's framework of health expenditures and financing spelled out in the *Uganda Social Sector Strategy*, published in 1993. The Uganda policy framework was consistent with the WB's basic philosophy that the role of government should focus on three responsibilities: providing policy guidance, coordinating and monitoring the private sector and NGOs, and ensuring that government bureaucracy did not get in the way.<sup>10</sup> According to the strategy, certain services should remain the government's responsibility, defined as 'those which must be carried out by the government if they are to be provided in adequate quantities', such as health sector planning, education, basic sanitation, water, and environmental activities (although water privatization is on the current agenda). The second category of government involvement consisted of community health interventions of a preventive nature, such as vector control and vaccination. Curative services were to be primarily a private sector responsibility, and if the government was to provide curative care, it should do so by emulating the private sector, and should charge for them.<sup>11</sup>

Indeed, it was the case in Uganda in the early 1990s that the majority of public health expenditure was targeted at curative services – according to the WB, 90 per cent of health expenditure in 1992<sup>12</sup> – however, this was in a context of extremely inadequate spending in general. The public sector contributed approximately \$2 per capita per annum to health, the lowest in the region. The 2000 figure has increased to \$4, with private expenditure on health accounting for 62 per cent of all spending, 35 per cent of which is out of pocket, according to the WHO.<sup>13</sup> Shifting financing to PHC and prevention from curative services were to take place in a context where health care expenditure in general was woefully inadequate, the bulk of curative services already provided by the private sector. The logic of the shift according to the WB was that there would be little need for curative care if primary and preventative programmes were put in place. The spending devoted to curative care could be avoided through 'public action' such as AIDS education and nutritional counselling, the Social Sector Strategy maintained.<sup>14</sup> The WB's

specific financing of AIDS prevention constituted such public action. AIDS prevention in the form of education, however, has had only partial relevance in parts of Uganda where HIV infection had peaked, where the sick have needed treatment and care, and where the survival of family members left behind was at stake.

The general path laid out in the early to mid-1990s has been followed, although the Ugandan government is considered to be driving the reform process. Christopher Adam argues that the Ugandan government has been in the driver's seat in determining macroeconomic policy reforms such as trade liberalization and exchange rate reform, and that it has been instrumental in designing the country's Poverty Eradication Action Plans (PEAP). He states that 'the Aid Liaison office [within the MFPED] circumscribes the role of donors: increasingly they are expected not to initiate and develop their own projects but to support activities identified, designed and implemented by the GOU'.<sup>15</sup> Uganda has been considered the IMF and the WB's 'Star Pupil' and has been held up as an example of success in sustaining high rates of economic growth through fiscal restraint and trade liberalization. Under the Heavily Indebted Poor Countries (HIPC) initiative, Uganda has obtained substantial debt relief and has been able to divert significantly more resources to health and education, poverty-related expenditures, increasing from approximately 18 per cent of the budget in the early 1990s to 35 per cent in 2002. But whether in the driver's seat or not, the 60 per cent fall in coffee prices that Uganda's liberalized economy has seen over the past few years has meant that the government had to borrow more to make up the shortfall. Uganda's debt to export ratio was 210 per cent in 2000–2001 and is projected to remain close to that level for the next few years.<sup>16</sup> It is also worth noting that donor assistance to Uganda equals 50 per cent of total government expenditure, roughly 10 per cent of GDP.<sup>17</sup> The room for the state to manoeuvre is to some degree circumscribed by the parameters established by donors and the WB, by debt repayment, as well as by the vagaries in global market prices for Uganda's export commodities.

The government's broad macropolicy agenda has remained relatively unchanged, despite the deep impact of HIV/AIDS-related mortality on productivity and household survival. AIDS policy and macroeconomic policy remain separate and distinct, despite the recognition, at least on paper, that the two are intertwined, as evidenced by a

number of AIDS-impact assessments.<sup>18</sup> In the GOU *Strategies to Promote Economic Growth Progress Report*, the plan for the modernization of agriculture makes calls for a sustained increase in the productivity of agriculture, through increased privatization and commercialization, and makes no mention of HIV/AIDS, despite its negative impact on productivity and household food security. Calling on the one hand for 'pro-poor and gender-sensitive' policies, the report states that 'agricultural activity is a commercial activity, and such should be carried out by the private sector.'<sup>19</sup> A critical gap exists in understanding how particular policies and programmes have undermined rural livelihoods and food security in AIDS-afflicted communities. Growth in agricultural productivity can go hand in hand with increased household food insecurity and malnutrition in contexts where rural communities are heavily dependent on subsistence production alongside activity for the market. In SSA, women tend to produce food for household consumption and for local markets, while men tend to produce non-food commercial and export crops. What happens when their agricultural labour is diverted to caring for the sick, or when cash contributions to household income disappear on the death of their husband? In reality, macroeconomic policy development in general and agricultural policy in particular pay little heed to HIV/AIDS. It has been proven difficult to break out of the biomedical and public health boundaries of AIDS control and prevention.

### **The Uganda AIDS Control Programme**

The formal institutional response to AIDS in Uganda began in October 1986 with the formation of the National Committee for the Prevention and Control of AIDS (NCPA) and the ACP; the advisory body and the executing body respectively, within the MOH. (The NCPA was collapsed into the ACP shortly after its formation.) The programme was conceived as one in which the MOH/ACP would provide technical leadership and coordination for all AIDS-related activities in the country. It was situated directly under the offices of the Minister of Health as a means of ensuring that resources would not be diverted to other programmes and that other important programmes in the Ministry would not be swallowed up by the ACP, however, the activities of the ACP were to be integrated into the PHC

infrastructure and activities.<sup>20</sup> The response to AIDS in Uganda was part and parcel of the WHO's Global Programme, Uganda in fact the first recipient of a WHO-inspired and coordinated national programme. The programme followed WHO's 'Guidelines for the development of a national AIDS prevention and control programme'.<sup>21</sup> A director and a chief epidemiologist were appointed to oversee the four programme areas: epidemiology and research; IEC; laboratory/blood transfusion; and clinical management, and a coordinator was assigned to each programme area. At the district level, District Medical Officers (DMOs) were in charge of ACP as part of their regular duties, and at the very local level the resistance committee chairman was given the responsibility of ensuring the success of the programme. All but two of the original eighteen appointees to the NCPA were medical professionals, the exceptions being a professor of sociology and a professor of social administration, both from Makerere University. Donor funds for the programme were to be coordinated by the WHO, and evaluations were to be carried out by the WHO Regional Office (WHO/AFRO) on a biannual basis. The initial short-term or emergency plan had as its stated objective 'the reduction of the spread of HIV virus and the reduction of the impact of the epidemic on communities, families and individuals'. The plan focused on basic medical interventions – making the case definition of AIDS available to public and private practitioners, conducting a national sample serosurvey, developing a surveillance system and an intensive system to screen blood transfusion products – interventions that were to be integrated into the existing health care system.

A more comprehensive and longer-term plan was developed with the WHO the following month, the 'ACP Proposals for a Five-Year Action Plan (1987–1991)', the result of a second WHO consultancy mission. The seven major components of the ACP were: mass public education and information; blood screening and rehabilitation of blood transfusion systems; protection of the public, health workers, and children through supply of syringes, needles, gloves, aprons, boots, disinfectants, equipment, condoms; establishment of an effective national surveillance system; drugs for treatment of AIDS cases; operational research consisting of KAP studies for health education, and sero-epidemiology and risk factors; and finally, training and orientation of health workers.<sup>22</sup> Technical and financial support



provided by WHO and financial support from several donor agencies was coordinated by the ACP through the mechanism of a WHO trust fund. Funds were provided or committed to the trust by the UK, Sweden, USA, Denmark, Norway, and Italy, and from unspecified WHO global resources. In addition, bilateral support came from UNICEF, UNDP, the EEC, the Federal Republic of Germany, and USAID. The Ugandan government was to pay the recurrent costs of the programme – to provide office and physical facilities, pay salaries to staff at the district and local levels and pay maintenance expenses. The initial Five-year plan had a budget of just under US\$7 million.

For purposes of discussion, the programme can be divided into two major components: first, clinical management and patient care; and second, behavioural interventions and education, although the two are not discrete categories and there is considerable overlap. The first component has consisted of rather standardized technical biomedical interventions such as cleaning up the blood supply, increasing resources for and developing protocols on patient care, and providing protective equipment to health care professionals. The second component has focused on 'education for behaviour change'. It would be a few years before the impact of the epidemic – already felt profoundly in the districts of highest concentration of infection – would be a concern of AIDS policy.

### **AIDS policy delivery: medical interventions**

The deep crisis facing Uganda at the time of the appearance of HIV infection severely weakened precisely those government structures that were necessary for an effective response. A beleaguered MOH damaged by 20 years of civil war was given the task of containing the new epidemic. Health units, rural ones in particular, were derelict (lacking basics such as water and electricity) and poorly staffed. Health workers avoided postings to places where there was a lack of housing, schools, and other opportunities for income generation to supplement paltry government salaries. Staffing rural health units and dispensaries were nursing aides and dressers lacking in proper training. Basic drugs were supplied from 1985 onwards to all public clinics, hospitals, and NGO health units through Danish International Development Agency's (DANIDA) Basic Drugs Programme, but most

drugs were either pilfered before arriving at the clinics or sold by underpaid health care staff through the private sector, a problem so acute that the DANIDA seriously considered the withdrawal of its support for the programme in 1992. Both lower-level and higher-level 'eating' was common. Budget allocations would disappear before meeting their final destination and health personnel would use the resources of the public system to bolster their private practices. The structural problems of health care delivery were reflected in the poor performance during the first few years of the ACP.

The original objective of the ACP Medium Term Plan with regard to patient care was 'to improve patient management' through a strategy of 'maintain[ing] optimal quality of life'.<sup>23</sup> The plan specified that patients being treated in government hospitals were to be referred to outpatient and/or traditional health care, rather than remain hospitalized during their illness. It was recommended that counselling of patients be provided, as part of both the initial inpatient treatment and the subsequent care for the patient in the home environment,<sup>24</sup> yet counsellors were few and far between. 'Outpatient care' was understood to be care in the extended family setting, and to this end the ACP recommended that small grants be made available to relatives of AIDS patients to cover extra expenses such as soap, other hygienic material, and herbal drugs,<sup>25</sup> although grants were never made available through the ACP. The vast majority of AIDS patients received no assistance whatsoever.

At the time the MTP was being formulated, there was an unpredicted steady rise in the number of AIDS patients in hospitals. In the major towns, 50 to 70 per cent of the adult inpatient hospital beds were occupied by patients with HIV-related illness by 1992.<sup>26</sup> In Jinja that same year, the only ward filled to capacity at the municipal hospital was the ward admitting AIDS patients.<sup>27</sup> The quality of patient care was hindered by extremely severe resource constraints, both financial and human. The ACP could not ensure the supply of the most basic of equipment to the public system to protect health workers and patients from HIV, such as protective gloves, gowns and masks, sterile needles, and soap. Also in short supply were basic antibiotics, antifungal, and antidiarrhoeal drugs to treat HIV-related opportunistic infections. Another documented problem was poor vehicle service and maintenance resulting in delays of quarterly drug-kit deliveries. And although sterilization equipment for reusable

syringes was supplied to all hospitals and most health clinics, the electricity, required to run the equipment was sporadic. In units not serviced with electricity, there was often no kerosene to fuel the stoves for the steam sterilizers. The problems confronted were basic yet, in the context of such extreme resource shortages, seemed insurmountable to health care staff.

Given that hospital care was an area of health care provision where the private sector was expected to take on more responsibility, public spending on hospitals did not rise in response to the crisis in care created by rising numbers of HIV infected. Development assistance in the public sector increased, but most of the money at the time was earmarked for the rehabilitation of physical infrastructure. In any case, the majority of AIDS patients were being cared for outside the formal health system. Stated the 1991 ACP Plan and Budget: 'The reporting of AIDS cases who managed to get to a health facility leaves a lot to be desired; to this end the cumulative total of 17,422 AIDS cases as of 30 June 1990 is just a tip of the iceberg.'<sup>28</sup>

Blood transfusion services also fared poorly. Cleaning up the blood supply in Uganda was an obvious focus of the short-term and medium-term plan, as an estimated 8 per cent of infections were received through contaminated blood. A goal of the MTP was that 'at the end of twelve months new and existing blood transfusion centres should be fully equipped and running and all blood donations should be screened'.<sup>29</sup> In only one of the five regions constituting the Uganda Blood transfusion Service – the central region covering hospitals within a 100-km distance – was all blood tested for HIV and hepatitis in 1992. In 1991, WHO reported that blood transfusion continued to be a source of HIV infection, despite 4 years of sustained effort on the part of the WHO, the European Development Fund, the WB, and the Red Cross. It was still the case in 1992 that a guaranteed HIV-free unit of blood was not available in half the country's districts. Documented problems ranged from a shortage of trained staff and working vehicles to collect blood in the field and a shortage of cold storage facilities to handle supplies of blood, to banditry and break-ins at the centres. The recurrent costs of the MOH in meeting blood transfusion service requirements were difficult for the cash-strapped and resource-poor ministry to meet; at the same time, the donor community was

not meeting its stated commitments. In 1991, the WHO/GPA in Uganda reported that:

Inadequate, irregular and unpredictable mode of disbursement of funds from some donors meant that a lot of important blood transfusion objectives in peripheral areas could not be undertaken. Supervision of peripheral units was limited, supplies to these irregular, training was minimal and responsibility allowances were not paid in most cases resulting in poor performances.<sup>30</sup>

Donors withheld funds because they claimed that the spending of previous disbursements was unaccounted for. And indeed 'corruption' in the public health care system was a systemic problem. At a higher level, a number of WHO officials stated that budgetary allocations earmarked for specific purposes would often only partially be disbursed, the other part mysteriously disappearing. At the lower levels, the pilfering of funds might have had something to do with the fact that, at the time, stagnating civil service salaries barely covered the purchase of enough calories for three days for a family of four.<sup>31</sup> Requesting or extorting 'under-the-table' fees at government health units was a common practice, compounded by the bitterness of health staff at their inability to support their families on official salaries.<sup>32</sup> In this regard, the line between corruption and 'eating' was blurred; an extension of the logic of survival shaping everyday life for the majority of Ugandans.

The first few years of AIDS control in Uganda made clear that unless the infrastructure for basic health service provision throughout the country was sound, AIDS-specific programmes would perform poorly. Still, the trend is towards the establishment of vertical programmes, and increased emphasis on the privatization of services and cost recovery where it is deemed feasible. As the number of donor agencies mushroomed in the AIDS sector, the balance of activities shifted from activities under the direct control of the ACP towards semi-autonomous programmes and projects of the major donor institutions. The alternative to strengthening government health services was donor-funded projects filling in the gaps. All donors were required to meet the priorities as established by the ACP but in reality the MOH did not have the resources to monitor the growing number of AIDS projects.<sup>33</sup> A common complaint was the lack of remuneration to

staff of the ACP. Staff would often not be at their desks, instead would be elsewhere engaged in other activities to supplement their salaries.

Given the poor state of the public health care system, the message of the WB/WHO/UNDP GOU mission of 1990 (which led to the Multisectoral AIDS Control Strategy) was that the provision of bilateral, private, NGO, and voluntary services and projects for AIDS patients must be strengthened. The WB emphasized the need for improving the administrative capacity of the state – stressing internal administrative efficiency and effectiveness – but at the same time called for the privatization of service delivery. The role of the state was to strengthen and support communities and families in providing care/counselling to AIDS patients. NGOs were providing alternatives to hospital-based care, although the demand for care greatly exceeded the supply. Most HIV-infected people were (and are still) cared for within their homes without public or private sector assistance, particularly in the rural areas. The 'core poor' simply do not have the resources to pay fees, whether formal or informal, or to pay for transport to the health centre. Privately run and church-based hospitals with external sources of funding were implementing mobile home-care programmes. One of the first was the RAIN which provided absolute basics such as aspirins, protective gloves, soap and bedding, as well as moral support to families who were caring for the diseased, and then burying their dead.

### **AIDS prevention: education for behaviour change**

The 'ultimate goal' of the research component of the ACP in Uganda was to aid in the discovery of a vaccine or cure, but until that time the only way to halt progression of HIV infection was through behaviour change, in essence, through promoting monogamy, 'stable polygamy', or safer sex. Condom use was at the beginning a contentious issue, but by the 1990s was quietly promoted, although the Pope's visit in 1993 represented a major setback when he openly condemned condom use and preached that chastity and monogamy were the only solutions to the AIDS scourge. Considered by policy-makers to be at the root of the presumably high levels of promiscuity was modernization and urbanization, resulting in the breakdown of traditional cultural and moral codes that governed sexual relations.

Underlying the main accounts of risk behaviour was a reified notion of 'culture' removed from space and time, which constituted an explanation not only for rapid HIV and STD spread, but for the masking of the political and economic realities that shaped the specific Ugandan context of HIV spread: labour migration, continued instability, and particularly for women, insecurity of land tenure, and men's control of their sexuality and production.

The first educational interventions were mass-media activities – billboards, posters, pamphlets, and radio and newspaper advertisement – warning people to 'love carefully' and 'zero graze', and imparting information about the main transmission routes. AIDS awareness throughout the country was almost universal by 1990. In this regard, the first decade of AIDS control had a positive impact. But the ACP admitted in 1992 that its mass education campaigns had not sustained changes in 'high-risk' behaviour throughout the general population, stating that '... IEC activities have resulted in a very high level of HIV/AIDS awareness nationally. This level of awareness has apparently not, however, been matched by an equally significant change in high-risk sexual behaviour.'<sup>34</sup> Evidence pointed to resistance to abstinence and monogamy as practical or realistic behavioural options. 'The major finding from this study is the importance of sexuality in everyday Ugandan life... shown in varied ways including frequency of multiple sexual partners and contacts that people have now, or have had in the past.'<sup>35</sup> 'Education for behaviour change' became the main locus of intervention. Just less than 27 per cent of the 1991 budget for the ACP was targeted at AIDS education. There were a variety of approaches to achieving the common goal; some such as USAID-favoured vertical, individual behaviour-oriented programmes involving condom promotion and distribution, and treatment of sexually transmitted infections (STIs), while others emphasized 'community-based' approaches which integrated other aspects of AIDS prevention and care (such as income generation and mobile home care). NGOs were to be instrumental in getting the message across and providing services.

Supplementing the activities of the ACP were the programmes of the most important international donor institutions: UNICEF, USAID, CARE, MSF, GTZ, Save the Children, and AMREF. USAID was the largest single player in AIDS education through its AIDSCOM projects, as well as a whole range of projects executed through the US-based

NGO 'Experiment in International Living', and supported the activities of the ACP. Donors have had considerable freedom to design their interventions at arms length from the MOH and the ACP. USAID channelled most of its funding through AIDSCOM – a public health communication programme administered by the US-based Academy for Educational Development aligned with US-based consulting groups which carried out the planning, monitoring, and evaluation of AIDSCOM projects. A central component of AIDSCOM's 'Public Health Communication Support Program' consisted of training peer educators and trainers in the workplace, who would in turn communicate messages to co-workers and act as role models for behaviour change. It was predominantly urban men of high educational level who were exposed to the programme in a workplace setting. A similar programme had reached 53 NGOs through AIDSCOM's technical assistance to the US-based NGO, Experiment in International Living (now called World Learning).

According to their programme evaluations, there was no significant visible change in number of sexual partners, although there was a marginal increase in condom use. The programme, however, was considered a success because 'indicators of programme activity show that the programme has been implemented successfully, with significant increases in the number who report talking to a peer educator, attending a talk about AIDS in the workplace, and seeing the dramatic film "Its Not Easy"'.<sup>36</sup> The quantitative indicators of programme evaluation were such that as long as the programme was smoothly implemented, it was deemed successful. By focusing on well-educated urban males and condom use as the main strategy of HIV prevention, USAID was able to sidestep the more thorny issues relating to the socio-economic and cultural barriers to safe sex which were encountered by a large section of the female population and the rural poor. The same can be said of its vertical, STD control projects. USAID also funded the \$15 million 'STD Prevention and Control Project', its purpose was to limit the impact of HIV/AIDS infection in 'target populations' through interventions that promote changes in sexual behaviours and reduce risk factors, in this case, sexually transmitted infections.

An important component of the STDCP was the pilot research project CHIPS – 'Community Health Intervention Project against STDs' – implemented in Kisenyi, a densely populated, low-income

neighbourhood in Kampala. It was a comprehensive set of activities including testing, treatment, and counselling for STIs, and community health initiatives including condom promotion and peer education. The main objective of the project was to reduce the spread of HIV in the community through the treatment of STIs and to determine the best way to go about STI control. According to the head of STD control in the MOH, CHIPS was the only comprehensive project of its kind in the country. Some of the insights from CHIPS were raised by the chief investigator on the project, a physician from the University of California, at the Post-Amsterdam Public Seminar of Uganda-based AIDS Researchers organized by the UAC in October 1992. Cheryl Walker found that counselling of individuals was of limited success and that condom use was not consistently effective because it was not female-controlled. Given the stigma and shame attached to STIs, women in particular were not attending clinics. Walker's comments spoke about the limitations of vertical interventions that focused on individual behaviour and STI treatment without regard for the specific social conditions that influenced access to and use of services, and the ability to adopt less risky behaviours, such factors as the lack of privacy and visibility within the community in a context where women were largely blamed for the spread of infection. Significant stigma was attached to attending the STD clinic, more so for women than for men. And it was not the case that all women could negotiate condom use.

Walker was aware of the limitations of the project and sought to introduce different approaches. She viewed enhancing women's negotiating skills through community-based organizing and couples counselling as more promising options to the current approach of individual counselling. But women's power in negotiating sex was and is not simply a matter of 'skill' and empowerment. Women's unequal power in intimate relationships was related to the pervasive view of sex within marriage for women as a marital obligation, and the view that married women and their labour are the physical property of their husbands. Some women acquiesced in unwanted sex for fear of being abandoned or stripped of their means of support.

The largest project under the control of the ACP, the District AIDS Mobilization Project (DAMP), went beyond individual counselling and condom promotion. The DAMP was a project designed by the Health Education Division of the MOH in collaboration with the ACP and



began after a programme review of the ACP's AIDS education and prevention activities in 1988. Prior to 1988, prevention activities were limited to Kampala, but by 1992 20 of Uganda's 38 districts had DAMP. Plans were developed by the ACP in collaboration with the DMO in each district, and were geared towards the use of existing structures at the district level: health staff, local-level RCs, NGOs, and religious groups. The programme's implementation was constrained by the same structural factors, that limited the success of other components of the ACP related to the lack of funds and weak institutional capacity: 'at a technical level Damp was never provided with the financial nor the central infrastructural resources to fulfil its mandate'.<sup>37</sup> Further,

it seems that in planning DAMP activities there was over-expectation of time and resources available to the RC system in this case, for AIDS education. In particular, there was strong evidence that the district department heads had not the time, and perhaps not the inclination, to be actively involved in AIDS education.<sup>38</sup>

Programme activities included the reproduction of AIDS educational materials in the form of booklets, pamphlets, and posters on AIDS, training seminars for health workers, government administrators, and NGO representatives, and a mass campaign on prevention and control. The general public was expected to receive materials through the LCs and key people such as mass mobilizers and development workers in the community. The main strategies to control the spread of AIDS included abstinence, monogamy, and the promotion of alternate recreational activities. An evaluation of the DAMP was conducted between July and December 1991. Three districts were chosen for the evaluation: one with no DAMP, one where DAMP had been ongoing, and one with recent DAMP. A key finding of the evaluation: 'There appears to be little difference in awareness to AIDS and knowledge about the basic facts about AIDS between the two districts that have DAMP compared to Mbale which does not.'<sup>39</sup> Among the sample, knowledge of the sexual transmission of AIDS was high, at 99 per cent in all three districts. But there was no related evidence of sustained sexual behaviour change across the sample population. Nor was there evidence of alternative income generating

and recreational activities despite their encouragement, this latter point reminding me of the laughter met by the slogan 'don't play sex, rebuild your country' by some young people in Jinja in the context of a casual discussion about AIDS at a community meeting. These are the words of a 20-year-old man:

What else are we to do here, when after 7 o'clock there is no light and unlike you, we have no TV's or places to go? Instead of enjoying ourselves, they want us to fill up the pot holes in the roads.<sup>40</sup>

In 1992, UNICEF introduced SYFA, 'Safeguarding Youth from AIDS'. SYFA attributed the failure of message-based campaigns providing AIDS strategies on the messages themselves – they called for monogamy among populations whose sexual behaviour was already established as non-monogamous, they were negative and relied on fear, and they failed to target pre-sexually active youth. The basic assumption was that the AIDS epidemic could begin to be brought under control in a measurable way within 5 years as the 9–14-year-olds who were free of the virus moved into the more sexually active 15–19-year cohort and beyond. SYFA would meet its measurable targets by empowering youth – especially girls – to make informed decisions based on a set of plausible alternative behaviours: the delay of sexual debut; celibacy and abstinence; faithful monogamous relationships; and the practice of safer sex including the correct and regular use of condoms. If learned at an early age, these behaviours might be maintained in adulthood. SYFA was implemented through established channels: NGOs, churches, and the RCs, as well as through UNICEF's School Health Education Project. A key component of the project was to assist national and local capacity to make the programme sustainable. An evaluation of the programme conducted in 1995 pointed to the difficulties, both in achieving targets and in fostering local sustainability. Most of the problems were related to the poor institutional abilities of the executing organizations and the very low levels of funding, often far below what was needed to implement their programmes; other problems reflected local struggles for power and resources. HIV rates have dropped among this cohort, although remain higher for girls.

Despite the fact that AIDS education was reportedly not resulting in widespread behaviour change, levels of HIV seroprevalence

began to drop. How do we explain the drop, given the reports on marginal changes in sexual behaviour, and the widespread and systemic problems of the implementation of the ACP on the ground? Helen Epstein questions whether the epidemic is truly waning; pointing out that the incidence of infection – the rate at which people become infected – may be stable or even rising in some areas, while the prevalence – the number of infected people in a population – is falling. She points to smaller studies conducted by epidemiologists that show little change in incidence throughout the 1990s. Epstein hypothesizes that the first phase of HIV infection likely resulted from 'one-off' sexual encounters during the war, a time in which high numbers of soldiers carried HIV, rape was very common, and women in areas of the highest concentration of infection were drawn into sexual servicing out of economic necessity.<sup>41</sup>

The hypothesis that the HIV epidemic in Uganda occurred in two phases implies that HIV prevalence may have fallen in the 1990s because many people infected during the war in the 1980s died of AIDS. Nevertheless, HIV incidence rates during peace-time may still be quite high, although they are probably much lower than they were during the war.<sup>42</sup>

Likely the ACP also contributed to declining rates of infection, but the extent to which AIDS education has contributed to declines in infection remains an open question. But what the policy response was not addressing was the effects and impacts of AIDS outside the health care sector – hence the emergence of the multisectoral strategy. As the first articulation of the Multisectoral Approach stated, 'the HIV/AIDS epidemic has produced socio-cultural, psychological, economic, moral, ethical, and legal ramifications, each with current or potentially catastrophic implications, and issues that the health sector has never been equipped to handle'.<sup>43</sup>

### **The multisectoral strategy**

The formulation of Uganda's multisectoral strategy for AIDS reflected the evolution of thinking within the international AIDS community more generally, which by the early 1990s was increasingly viewing

the epidemics in Africa as a concern beyond the health sector. It also corresponded to the emergence of UNAIDS. The document *AIDS Control in Uganda: The Multisectoral Approach* provides the following rationale for broadening the scope and mandate for AIDS control and prevention:

Coordination efforts of the Ministry of Health ACP helped to create the high national level of awareness about the disease that now exists. The programme also played an important role in bringing the international community to the assistance of Uganda. However, coordination of activities being in the health sector, the epidemic continued to be addressed as primarily a health problem. Consequently, there has been limited response by the public sectors of information, labour, local administration, and youth and culture. The social and economic implications of the epidemic have not, therefore, received as much vigorous attention as they should.<sup>44</sup>

The UAC was formed to play an 'enabling role' in all national efforts. Under the umbrella of the Commission, all AIDS control interventions in the public and private sectors would be planned, implemented, budgeted for, and evaluated.<sup>45</sup> The multisectoral strategy corresponded to the WB's more authoritative voice in health policy, both within UNAIDS and in Uganda specifically. The WB was the largest single donor to the multisectoral strategy.<sup>46</sup> The total budget of the UAC was estimated at US\$4,427,000, of which slightly less than half had been pledged by 1993. The GOU was the main funder of the UAC, but in 1993, USAID, through World Learning, was paying the salaries of the secretariat, which were high compared to other government employees. It was unclear what the relationship would be between the highly paid UAC and the struggling MOH ACP, the politics between the two described as extremely difficult by more than one senior policy official with USAID. But the structural contradiction of a well-funded bureaucracy financed with outside monies overseeing the activities of the poorly financed health sector, NGOs, and CBOs was bound to create tensions.

The role of the UAC was to guide and monitor the activities of the other ministries, the charitable and the private sectors, in line with

broader policy reforms taking place at both national and local levels. 'One of the key assumptions was that on-going policy reforms would continue in favour of strengthening the role of women in development (WID), decentralization of planning and service provision, promotion of self-reliance and community empowerment, and developing close partnership between government, NGOs and CBOs.'<sup>47</sup> Thus began the development of a Kampala-based bureaucracy to guide community-based district level interventions and to 'empower' people to cope.

The goals and strategies of the Multisectoral AIDS Approach were stated as follows: to stop the spread of HIV infection; to mitigate the adverse health and socio-economic impact of the HIV/AIDS epidemic; to strengthen national capacity to respond to the HIV/AIDS epidemic; to establish a national information base on HIV/AIDS; and to strengthen the national capacity to undertake research relevant to HIV/AIDS.<sup>48</sup> *The Uganda National Operational Plan for HIV/AIDS/STD Prevention, Care and Support 1994-1998*, the outcome of the National AIDS Consensus Conference, and the National AIDS Planning Workshop held in Kampala in June 1993 were the first steps in operationalizing the strategy. The Ministry of Local Government was given the responsibility of coordination at the district level, in line with the government's decentralization policies. The implementation of the various components of the strategy was earmarked as the responsibility of local and foreign-based NGOs, local level committees, and the private sector, including traditional healers, and individuals and families. The wisdom of how to prevent transmission of HIV (as well as other STIs) had evolved from a strict focus on individual behaviour change, given the wide 'knowledge vs. moral behaviour change gap'<sup>49</sup> throughout the country.

To address the behaviours, practices and other factors determining the sexual transmission of HIV infection it is not sufficient to address the individual's behaviours only, as these are to a very great extent determined by factors over which the individual has limited control. The priorities of the programme over the next five years therefore, will focus on empowering the individual and at the same time addressing norms, values and collective behaviours and practices.<sup>50</sup>

To this end, three main areas were selected as priorities: first, children and youth; second, 'gender issues and the special situation and needs of women, particularly rural women and occupationally pre-disposed and exposed women – barmaids, prostitutes, clerical workers and house girls'; and third, 'situations and sites – the places and events where increased risk of sexual transmission occurs, such as visits to bars, discos and social functions, last funeral rites, weddings, twin ceremonies, offices, truck stops, migrant work situation, offices, factories'.<sup>51</sup> Within all government ministries, AIDS-related sectoral policies were to be developed, and all ministries were expected to establish ACP in their specific sectors – Defence, Education, Information, Labour and Social Affairs, and Local Government. So, for example, the MOH was to oversee AIDS surveillance, safe blood, and IEC; the Ministry of Labour was charged with developing policy guidelines for NGOs, private charities, and local communities for orphans and other children, and assessing the impact of changing demographics; the Ministry of Defence was to improve condom use, HIV testing, counselling, family planning, and care of HIV-infected soldiers, in addition to assessing the impact of the epidemic on the military.<sup>52</sup>

The second goal of the multisectoral strategy was to mitigate the socio-economic impact, although UAC acknowledged difficulty in this regard from the beginning. The impediments to mitigation activities were not only the thin knowledge base – very few specific studies on the impact of HIV/AIDS have yet been carried out – but also the lack of financial resources, in particular the deficit that in the words of the UAC 'hinders rational planning'.<sup>53</sup> At the time (between 1995 and 1996), the government was transferring approximately US\$200 million to the IMF as part of the debt service of Uganda's US\$3.1 billion debt it owed to the institution and other bilateral donors.<sup>54</sup> What was clear was that the National Operational Plan would target 'the individual and family in the community at the grassroots level'.<sup>55</sup> One half of the overall proposed budget was earmarked for mitigating the impact – US\$246 million over the four-year period, over half of this sum was allotted specifically for orphans.<sup>56</sup> With regard to orphan support, the public sector's role was to develop standards of community-based care and education, solicit funds, strengthen welfare offices, promote awareness of possible neglect of fostered children, and to monitor the adherence to the rules and policy guidelines for

the care of orphans.<sup>57</sup> The anticipated impact of AIDS on various sectors was delineated in brief (agriculture, industry, transport and communication, health, education, public administration, and national security) and viewed principally in terms of impact on the labour supply and productivity, as well as on public expenditures, and private investment and savings. Suggestions as to what 'could be done' were briefly summarized. For example in agriculture, the recommended interventions included the introduction of more appropriate and affordable means of production (for example, labour-saving technologies and high yielding, early maturing and resistant crop varieties), the improvement in research and training methods, and enhanced credit provision and marketing.<sup>58</sup>

How these policy goals were to be implemented was not spelled out in the operational plan, and with the exception of orphan support, were not translated into concrete policy. In 2000, a new National Strategic Framework for HIV/AIDS Activities was designed by a core group of 11 stakeholders from the UAC, MOH, Local Government, MFPED, and other organizations working in the AIDS sector and PLWAs, organized around the themes of prevention, care, mitigation and research.<sup>59</sup> The framework placed more emphasis on mitigation, and specified what was involved, but left untouched a consideration of the relationship between macroeconomics and HIV/AIDS. The current discourse on 'community', 'partnership', 'ownership', and 'empowerment' is used to articulate an approach to mitigation that is unquestioning of the neoliberal framework within which communities are to cope with the impacts of AIDS morbidity and mortality.

## **The community response**

What community means in the multisectoral strategy is broad. LCs are the geographic and political units responsible for overseeing the implementation of the multisectoral strategy, as are local and northern-based NGOs, private health practitioners, traditional healers and birth attendants, church-based organizations, and individuals and families. Women are singled out for specific consideration – previously the invisible farmers, they are now the visible nurses of HIV sufferers who need to be encouraged and 'empowered' in their new role. The multisectoral strategy states that '...communities which have been sensitized about their own role in the management of HIV/AIDS will

need to identify local sources of support (financial, material, spiritual) that will enable them to take full responsibility for their sick'.<sup>60</sup> What is implied is that within the broad managerial frame of AIDS control and prevention, targeted interventions can empower individuals and local groups to deal with the AIDS crisis, while at the same time tapping into local knowledges and capacities, and fostering self-reliance.

Communities were struggling with the effects of HIV/AIDS as early as the late 1980s. An enumeration and needs assessment of orphans carried out in 1989 documented the increasing pressure being experienced by extended family systems due to the demographic damage caused by high AIDS mortality. The large number of children orphaned in the wars since 1971 had mostly been absorbed through fostering systems and family networks. But in the context of the near complete breakdown in essential services coupled with increasing numbers of orphans due to AIDS, the ability of the 'extended family' to care for orphans was crumbling. In 1989, 12.8 per cent of children in the district of Rakai had been orphaned. The definition of 'orphan' for the purposes of the enumeration was a child who had lost only one parent. In the case of the father's death, this definition makes more sense, because in the majority of cases where the father dies, the mother is no longer the child's guardian, the responsibility shifting to the father's clan. Children whose parents had both died of AIDS were considered the worst off, followed by children whose father had died of AIDS. In the event of a husband's death, women would often be chased off their husband's land by their husband's clansmen and would take the smallest child or children who were still being breastfed, and would seek out remarriage, or some existence in Kampala. The older children would stay behind, cared for by women of the father's clan. It was reported that widows who did stay behind to care for their children could not expect any assistance from her husband's relatives, and had no say in clan decisions. Often they were allotted a plot too small to grow enough food, making their burden overwhelming.<sup>61</sup>

Janet Seeley and others conducted a study during the period January–June 1991 on 30 clients of the counselling component of the MRC Programme on AIDS in Uganda, who had requested home-based care. The objective of the study was to assess the family response to coping with the care of AIDS patients, given the commonly held assumption of policy-makers that the extended



family system is a national strength in the context of AIDS care and prevention. Their findings suggested that the care of AIDS patients in the community often fell on individuals with limited assistance from extended kin. There were a number of reasons given why the care given by caregivers often fell short in some way, including lack of food in the home, lack of money for medications, and other responsibilities including the care of children, cultivation, care of other sick relatives; care was also denied because of stigma and blame. The following case was offered as the typical experience of a poor, AIDS-infected household:

[The client] . . . was a 35 year old woman whose husband had died earlier in the year. She was living close to her elderly mother-in-law, who was too weak to help. She had seven children. The youngest two aged three and six months were sick. Her son aged 16 and daughter aged 15 cared for their mother. On two occasions the eldest son went to fetch his maternal grandmother, who lived some distance away, when he believed his mother to be dying. On both occasions this proved not to be the case, the grandmother returned to her own home because of her own family responsibilities. When the client died the extended family gathered for the funeral, but returned to their homes after the funeral rites leaving behind the 16 year old boy as household head in charge of his six siblings.<sup>62</sup>

In 1992, I met with a number of people living in AIDS-afflicted households in Kampala, Jinja, and the surrounding rural regions. Not untypical was a 50-year-old female craft seller in Kampala, divorced, with five children and three grandchildren. Only her youngest daughter was living with her when her eldest son came home to die. She was supporting her son and two grandchildren with no other support from 'extended kin'. To supplement her income, she grew beans, cassava, and matooke on an empty plot of land near her house. When asked about extended kin, she stated that two of her daughters are unemployed and have nothing to share. Her other son was not interested, having his own child to take care of. 'These days in Kampala, we take care of ourselves' were her words.<sup>63</sup> Another example: a young woman infected with HIV living with her infant

and toddler and her aging mother in a hut on municipal land, who survived by growing potatoes and groundnuts, and collecting wild mangoes and greens. Her mother was too old to work, but would be left with the children if they survived – both were malnourished and sickly. This woman had knowledge about HIV/AIDS transmission, but said that she would have sex with any man if he helped support her and her children. She has not been targeted by any HIV/AIDS interventions.

There is great variation in community-based AIDS-related activities in Uganda. On one end of the spectrum are groups of widows securing small grants or microloans to start a piggery- or poultry-raising project for the raising of school fees; often these groups falter as quickly as they are formed. (A women's group in Jinja that had secured a small amount of funding from UK-based charity collapsed when the piglets purchased escaped from their pen – they did not know how they would pay back the loan.) On the other end is an organization like TASO, which commands hundreds of thousands of dollars and has an international reputation. Many of the local agencies, whether small or large, receive funding and technical assistance from foreign or international NGOs operating within Uganda's borders – such as MSF, Care, Save the Children, AMREF, Canadian Physicians for Aid and Relief, Concern, World Vision, the Christian Children's Fund, and Oxfam, whose activities in most cases pre-date the AIDS epidemic. The boundaries between the community, northern NGOs and the state are blurred, even to the extent that in some cases NGOs are contributing to the operating budgets of government departments.

The first indigenous AIDS-specific NGO in the AIDS sector was TASO founded in 1987. TASO became the model for other NGOs involved in patient care in the country and in the region, and quickly developed an international reputation. TASO assists families in the care of sick relatives through the provision of information and counselling, food, some clinical support, and home-care kits containing items such as protective gloves, soap, and antiseptic creams. In 1993, it had branches in eight districts, and mobile home programmes within a 20-mile radius of its offices. TASO also provides 'encouragement' for income-generating activities among families in order to alleviate their economic problems, although its activities in this regard are limited. The main focus of TASO's activities has been emotional

support, education, and clinical care. Anthony Klouda observed in 1992 that NGO reliance upon external donor funding to provide services that the public sector was not equipped to provide was beginning to breed distortion in the provision of health services, TASO was receiving so much funding that it could provide comprehensive health and social support service for people with HIV. But the problem was that no equivalent existed for people with other very serious health problems (the public service paled in comparison) and that its reach was limited.<sup>64</sup>

TASO's very good services can be contrasted with those available in the southwestern district of Kisoro. The AIDS Programme of St Francis Hospital, called the Hope Clinic, was one of the few programmes in Kisoro District in 1995. Sub-clinics at the parish level did not exist and for some patients it was four hours walk to the clinic, which was held every Wednesday, when food and treatment were made available free of charge. The clinic had other programmes as well, providing support for orphans, client-group counselling, a home-visitor's programme, and support for income generation. A study of the services was carried out between 1995 and 1996. Thirty people associated with the Hope Clinic who were affected by AIDS were followed – clients, orphans, and their guardians. The findings were taken as the basis for five main recommendations to improve the programme, which involved increasing the cultural, economic, and social capital of clients. To summarize, five main directives were proposed: (1) education, training, and seminars to make clients aware that AIDS-related issues should be put in place; (2) clients should be supported to set up income generation; (3) clients should be stimulated to be involved in social groups; (4) communities should be made to share the responsibility for clients in the villages; and (5) more initiatives should be developed to reach unregistered AIDS patients in the district.<sup>65</sup>

In Kisoro District, self-reliance was taken to a new level. The problems and recommendations reflect the degree to which AIDS patients and their families are left to fend for themselves. Avoiding dependence and creating responsibility were emphasized. Clients of the clinic – the ones who are still physically strong enough – were the volunteers for the home-visitor's programme. The initiative was not functioning very well because 'clients raise their hands when they are asked to join the home visitor team, but they never show up'.<sup>66</sup> To help this

component of the programme succeed better, the report suggests that volunteers could be trained and given a certificate stating that they are qualified to administer basic drugs. In addition, home visitors could be stimulated more by giving them free food in the clinic or a T-shirt after finishing the training seminar. It was also recommended that to increase their economic capital, clients (be they HIV positive, suffering from AIDS, or caring for one or more sick family members at home) propose a sustainable plan for income generation, for which loans should be made available (rather than grants, which foster dependency), such as a credit and savings group or rotating funds.<sup>67</sup> This begs the question of who is to pay off the loan once the client is dead, a serious problem when it means that when assets such as land or profits are taken over, the spouse or children are saddled with repayment or the loan is written off, creating strain for the creditor. The author points to the specific difficulties of setting income-generating projects in Kisoro District: 'lack of education, overpopulation, shortage of land, lack of running water, bad roads, etcetera'.<sup>68</sup> Moreover, 'most clients do not have a long future anymore and their needs are urgent. This requires income generating activities that can make a fast profit'.<sup>69</sup> It is suggested that the clinic could organize workshops, having positive effects on coping behaviour; needlework, mat weaving, table-cloth making, repairing second-hand clothes. The report acknowledges that certain people might not be available for income generation – for instance, widows supporting children on a subsistence basis – in short, those most marginalized and in need of assistance. The programme has a structure similar to TASO's, which in turn was modelled on the ASOs that sprung up in the affluent gay communities in Europe and North America. The meaning of empowerment and self-reliance in the context of deep economic crisis and social marginalization, where everyday life is a struggle for survival, HIV notwithstanding, takes on a more sinister connotation. Weaving mats and baskets in order to pay for one's funeral is perhaps the ultimate expression of self-reliance.

The local NGOs that do manage to secure funding through northern NGOs often can provide services beyond the scope of the Hope Clinic in Kisoro. More than 700 agencies in Uganda are involved in direct service delivery to the community in 2001, according to a survey conducted by AMREF and commissioned by the UAC. In such a context, despite the fact that through the UAC the control of AIDS

policy is in Ugandan hands, it is very difficult to imagine that programmes can be evenly distributed, can be 'unified' and 'integrated' into the overall policy response, and that the limited resources that do exist are being used in the most 'cost-effective' and 'efficient' manner. While local NGOs and CBOs compete with each other for project funding, few question why there are no resources for increased public spending in the health and social sectors. Hence the reliance on 'the community' – essentially women's unpaid labour – onto whom contradictions and wider problems can be offloaded. This is not to denigrate the very real efforts of NGOs and community groups working on the margins, nor is it to say that their interventions have no impact. Indigenous NGOs such as Ugandan Women's Effort to Save the Orphans (UWESO), made up largely of female volunteers established before the HIV/AIDS epidemic in response to the problem of children orphaned during the war, has 35 branches and assist communities to support orphans; Uganda Community-based Association for Child Welfare (UCOBAC) is a network similar to UWESO with a focus on sustainable 'community-based' initiatives, education, and income generation targeted largely at women who are caring for the current one in nine children who are orphans across the country. These organizations, and ones like them, provide much-needed care to the most vulnerable. But it is the case that wider constraints, embodied in the relationship between donors, the local and central government and financial institutions, and the fragile and impoverished nature of communities, limit the scope of AIDS-specific interventions.

The National Strategic Framework for HIV/AIDS Activities, which was drawn up to cover the period 1998–2002, placed more emphasis on the specifics of mitigation at the individual, household, and community levels, and has called for the expansion of microcredit and income generation as solutions to economic impacts at the household level. 'Support to people with AIDS to start up income generating projects is extremely essential...but should be monitored consistently to limit mismanagement and capital loss.'<sup>70</sup> The 'community' is to be supported through income-generating projects, and the private sector is to be mobilized to provide more resources to support people living with AIDS. Palliative care is to be strengthened through the provision of training for people in the home, traditional healers, and religious leaders, and subsidies are to be granted for the

treatment of opportunistic infections. Financial support is to be extended for child-headed households and AIDS orphans.

Few AIDS-related interventions have been established outside the parameters of health education, orphan care, and fostering self-sufficiency. In response to the growing problem of widows being chased off of their land, or their children being taken on the event of their husband's death, The Uganda Women Lawyer's Association (FIDA) instituted legal aid clinics in urban and rural centres for women without access to a lawyer, and has held seminars to teach, interpret, and discuss the laws of Uganda having to do with land, inheritance, and children, at local community schools. They have translated the law pertaining to women's rights into local languages and have lobbied for amendments to several existing laws, particularly the succession and inheritance laws that are unfair to women.

Those within the AIDS community in Uganda, who are involved on the ground, struggle with the constraints imposed by the funding institutions, by a weak state with few financial resources, and by the specific local conditions that shape survival strategies in the hardest-hit communities. Joyce Butera, a counsellor with the Rakai project, said that people's daily struggles to survive mean that they do not have time to think about AIDS. The Project Manager of World Learning's AIDS Prevention and Control project said that donor staff were aware that their interventions are essentially microsolutions to what are macroproblems, and that the very structure of development assistance militated against institutional capacity-building and 'ownership' of projects by the stakeholders. 'We have no desire to perpetuate ourselves, but what can we do in what is essentially an emergency situation?' He also pointed out that the NGOs themselves are beholden to their funders. 'USAID regulations are extremely constraining, and simply getting approval and authorization is a bureaucratic nightmare.'<sup>71</sup>

It is in this context that new partnerships are being developed to 'scale up' ARV access in Uganda. In August 2003, the Director of Health Services announced that all Ugandans suffering from AIDS would have access to free ARVs. The MOH was preparing to buy the drugs with resources from the Global Health Fund, and the ACP was working out the details for delivering treatment.<sup>72</sup> The number given for those in immediate need of treatment was stated to be 150,000 among the 1.2 million infected people. Uganda had reached agreements with

four of the main pharmaceutical companies in 2000 for substantial price cuts, under the four-country pilot project spearheaded by UNAIDS, the HIV/AIDS Drugs Access Initiative. Launched in partnership with the Ugandan MOH, the pilot project has involved training and capacity building at six regional hospitals to provide access to ARV treatment at cost. Prices have been in the neighbourhood of about \$250 a month for double therapy and \$420 for triple therapy, although prices have fluctuated – rapid currency devaluation resulting at one point in an increase of 20 per cent of the cost to patients.<sup>73</sup> The pilot project has proven that some Ugandans can benefit from ARV treatment. But the cost of a month's drugs is far beyond the reach of the vast majority of Ugandans, and given the current state of the health care system, there is deep scepticism about how the public provision of ARVs will ever be realized. Who will get access to treatment, and who will fall through the cracks? How can all Ugandans in need receive ARVs when half the population still lacks access to the very basics, when outpatient health care is free only in principle, when money for transport is still a major impediment to seeking health care, when there is still a chronic shortage of trained health personnel? When, according to the National Strategic Framework 1998–2002, condoms are still inaccessible and unaffordable to the majority of people, voluntary counselling and testing services exist only in 31 out of 56 districts, there are no staff and rooms to provide counselling in hospitals, and laboratories lack inputs?<sup>74</sup>

The major constraints on HIV/AIDS programme implementation were captured and summarized by AMREF in its survey of agencies working in the AIDS sector.

Most agencies have been unable to break the vicious cycle of poverty that propels the spread of HIV infection, precipitates the development of AIDS, compounds its psycho-social impact on the affected, and negatively impacts on the quality of life for PLWA, eventually reducing the productive potential of the affected in the community. Companion to this problem are the high illiteracy rate, gender inequality, sex discrimination, stereotyped attitudes and traditional practices that negatively impact on one's rights and individuality.<sup>75</sup>

Nelson Sewankambo, a medical doctor aligned with a number of AIDS projects, echoed these sentiments back in 1992. 'The biggest

impediment to the local response is the vicious circle of poverty that is unending. We don't have time to look at the bigger picture... we can't afford to look at the bigger picture.<sup>176</sup>

## Notes

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