Missing the Target #4:

Time is Running Out to End AIDS – Treatment and Prevention for All!

International Treatment Preparedness Coalition (ITPC)

18 July 2007

The International Treatment Preparedness Coalition (ITPC) was born out of the International Treatment Preparedness Summit that took place in Cape Town, South Africa in March 2003. That meeting brought together for the first time community-based HIV treatment activists and educators from over 60 countries.

Since the Summit, ITPC has grown to include more than 1,000 activists from over 125 countries and has emerged as a leading civil society coalition on treatment preparedness and access issues.

All ITPC treatment reports are available online at
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Acronyms and Abbreviations

The following acronyms and abbreviations may be found in this report:

ARV = antiretroviral
ART = antiretroviral treatment
CDC = US Centers for Disease Control and Prevention
Global Fund = Global Fund to Fight AIDS, Tuberculosis, and Malaria
IDU = injecting drug user
ITPC = International Treatment Preparedness Coalition
MSF = Médecins Sans Frontières
MSM = men who have sex with men
NGO = non-governmental organization
OI = opportunistic infection
PEPFAR = US President's Emergency Program for AIDS Relief
PLWHA = people living with HIV and AIDS
PMTCT = prevention of mother-to-child transmission
TB = tuberculosis
UNAIDS = Joint United Nations Programme on HIV/AIDS
UN = United Nations
VCT = voluntary counselling and testing
WHO = World Health Organization

Executive Summary

The world is still one million people short of the original "3 by 5" goal to put three million people on AIDS treatment by the end of 2005. The slow progress has already cost thousands of lives, and is destined to cost millions more. This is particularly tragic because evidence shows that AIDS treatment delivery is working.

This report demonstrates what a catastrophic mistake and monumental betrayal it will be if the G8 and the governments of countries heavily affected by AIDS renege on their commitment to universal access to treatment, just when it is demonstrating its potential to save millions and to pave the way for broader health systems reform.

This fourth edition of *Missing the Target* provides original, in-depth assessments of the dynamics of AIDS treatment delivery in six countries – Cambodia, China, Malawi, Uganda, Zambia, and Zimbabwe. In addition to these new detailed reports, it also includes updates from the six previous report countries – Dominican Republic, India, Kenya, Nigeria, Russia, and South Africa; and short summaries from five other countries – Argentina, Belize, Cameroon, Malaysia, and Morocco. Though there are substantial challenges in every country, significant progress in the numbers of people receiving treatment and wider delivery of support services is clearly documented.

All engaged in the global AIDS response must now think and act boldly to re-envision delivery of a range of essential health care services for the poor. The effort to provide universal access to AIDS treatment represents the best hope of establishing the systems, structures, and commitment needed to achieve the 1978 Alma-Ata Declaration goal of "health for all" since that commitment was signed. If we lose this opportunity and the momentum it represents, we will have squandered the energy that is propelling us into a new era of promise for delivering health care in the developing world.

Overall findings

- The pace of treatment delivery must continue to accelerate. The current rate of growth—700,000 additional people received treatment last year—means the world will fall short of even the most modest interpretation of the purposefully ambiguous new G8 treatment target[1]– and a full *five million people short* of achieving global universal access by 2010.

- The world has entered a new phase in scale up. While timely and expanded distribution of ARVs remains the core objective, much greater attention is now needed on emerging challenges such as reaching marginalised groups, children, and people in rural areas, and providing vital support services such as transportation and nutritional assistance.

- Supplementary services, in addition to treatment, must be free if poor people are to initiate and sustain care. Our research teams found that what is called "free treatment" is not truly free to the vast majority of people. Transportation costs and charges for diagnostic tests and medical care still put lifesaving treatment out of reach for many.

- Integration of prevention and treatment services is fundamental to building healthier communities. Only a comprehensive and coordinated effort will overcome the most difficult challenges in ending the epidemic. False separation of prevention and treatment, divisive either-or debates, and competition over resources must end.

- The worsening shortage of doctors, nurses, and community health workers who can provide HIV care and prevention requires increased financial investments, coordinated policy reforms, and removal of fiscal limitations on national health-related expenditures.

Country findings

An in-country civil society team using a globally standardized survey instrument prepared each of the reports in *Missing the Target*.

- In **Cambodia** treatment access has increased steadily but there remains an acute shortage of health care personnel, inadequate support for treatment adherence, problems with the drug supply system, inattention to needed social supports, fees for diagnostics and other necessary services, and limited access to second-line treatment and TB services.

- In **China** rapid expansion of treatment delivery is still falling behind increasing need. Widespread stigma and extra charges for diagnostic tests impede treatment access. Drugs for TB/HIV co-infection and second-line AIDS therapy are scarce. UN agencies must be more outspoken about barriers to treatment delivery.

- Significant progress in **Malawi** is being hampered by a critical health care worker shortage, particularly in rural areas. Few have access to PMTCT+ or HIV testing, OI treatments are not readily available, TB services are not well integrated in HIV care, and domestic spending is inadequate.

- In **Uganda** a free ARV program has shown impressive results, yet demand for treatment outstrips supply, uptake of PMTCT+ is low, fees for some medical services impede access, second line and OI drugs are often not available, and stock outs, corruption and under-financing plague the response.

- In **Zambia** treatment has markedly reduced mortality rates, but serious inequities in access remain; availability of diagnostic tools, second-line and OI drugs, and paediatric formulations is severely limited, stock outs are frequent, PMTCT+ is largely unavailable in rural areas, and poverty undermines access.

- In **Zimbabwe** treatment access has improved, but political turmoil and a deteriorating economy jeopardize gains; in some areas the health care system is collapsing, hospitals and clinics are threatened with closure, there are long lines for the public ARV program, frequent drug stock outs, and widespread stigma against PLWHA. Greater assistance is needed from multilateral agencies.

Specific challenges in treatment delivery cited by the other eleven countries include:

In the original six report countries…

- **Dominican Republic** – insufficient access to viral load testing; exclusion of PLWHA and Haitian migrants from new government health insurance program.

- **India** – National Plan not aggressive enough to provide universal access by 2010; no plans from government on second-line ARVs or to ensure ARV access for marginalized populations.

- **Kenya** – not enough CD4 testing equipment; poor coverage in rural areas.

- **Nigeria** – very low proportion of children in need are getting ARVs; not enough viral load monitoring equipment.

- **Russia** – low uptake of ARVs due to limited awareness of availability and inadequate social support; inadequate targeted programs for marginalized groups, specifically IDUs; drug supply interruptions continue.

- **South Africa** – new National Strategic Plan process must move quickly to address great gaps between need and access and between policy making and implementation

In the five new "short summary" countries…

- **Argentina** – coverage varies greatly by region with rural areas under-served. Because of stigma, many in marginalized groups do not come forward to seek treatment and so are not counted in treatment need numbers.

- **Belize** – insufficient attention to needs of marginalized and high risk groups; serious shortfall in human resources capacity.

- **Cameroon** – registration and testing fees as well as transportation costs make access to ARVs effectively impossible for many.

- **Malaysia** – disparities in treatment access by ethnic group; many hospitals are not meeting their access targets.

- **Morocco** – limited access to OI drugs; only one viral load testing facility in the country; insufficient access to CD4 equipment.

Global agency and donor findings

Global agencies and donors, partnering with governments, are helping to make the many successes in treatment delivery possible. But donors have failed to establish a formula to secure the predictable and sustainable funding on which universal access depends. Our research also identifies many areas in which global programs must improve their work:

- **PEPFAR's** programs are saving many thousands of lives, but must do better at reaching populations outside of urban centres, integrating treatment services into existing health care structures, building public sector capacity, and increasing support for health care worker education and retention. Community health workers need living wages and other supports through PEPFAR. The program's misguided policies on abstinence-only programming, sex work and harm reduction present considerable, self-imposed obstacles to effectiveness and must end.

- Donors must support the **Global Fund's** plan to triple in size. In many countries, greater transparency is needed in financial and program management of Global Fund grants, and civil society must be more fully included on Country Coordinating Mechanisms (CCMs) so they can lend expertise and serve as watchdogs over program implementation. The Fund—and its partner organizations—must be prepared to intervene earlier and more effectively when country implementers encounter challenges or are in danger of losing grants.

- **UNAIDS and WHO** provide important assistance on global treatment scale up through policy development and, in some cases, through efforts that facilitate the inclusion of civil society. But these agencies must be more outspoken when national programs are mismanaged, targets are not met, or vulnerable populations are neglected; *it is part of the UN's moral responsibility to speak out when countries fail their people*. UNAIDS must move forward swiftly with ambitious resource needs estimates that include a package of health services for PLWHA; need estimates should demand significant increases from both donors and national governments in heavily affected countries.

- **All global agencies** must help governments reach marginalised groups, establish systems that will eliminate drug stock outs, provide CD4 and other needed testing technologies, and integrate TB and other services into treatment.

People who need access to AIDS treatment cannot rely on global institutions alone. Developing country governments must take on greater leadership on HIV/AIDS. PLWHA and civil society must engage with their governments and insist they do more. In advocating for change, PLWHA and civil society members often face serious challenges and risks. But *Missing the Target* shows that, even in countries like China, advocates can speak up, tell the truth, and urge their governments to act. These courageous voices need to be supported, encouraged, and honoured.

There can be no more excuses for losing this momentum or needlessly letting millions die of AIDS. The last three years have proven that concerted global efforts can save lives and build strong systems of care.

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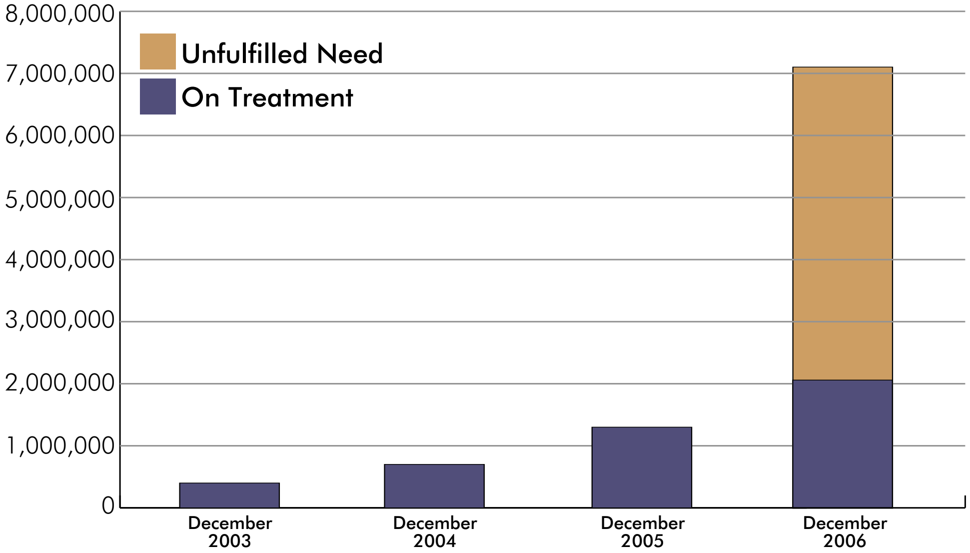
[1] G8 Summit, Growth and Responsibility in Africa, Summit Declaration, 8 June 2007, and Chair's Summary, 8 June 2007

The Global Response

It is clear that AIDS treatment can be successful, even in the poorest settings. And emerging evidence demonstrates that AIDS treatment can be scaled in a way that builds broader health system capacity, helping extend the reach of vaccination, sanitation, family planning, and other essential health services.[1, 2] Though the G8 countries parsed their words carefully at their Summit in June 2007, systems are in place to make their cautiously reaffirmed promise of universal access a reality. As the evidence of progress in this report demonstrates, governments and donors have no acceptable reason not to keep their word.

AIDS Treatment Access in Low & Middle Income Countries



Note: all numbers based on WHO AIDS treatment update reports, 2005, 2006,and 2007

Tripling the annual growth rate of treatment access, from today's 700,000 to two million new people on treatment each year, is both possible and necessary to meet the G8 commitment of coming close to universal access by 2010.

To do this, national governments and global, bilateral, and multilateral organizations must deal with the critical challenges that face every country working on treatment access scale-up. By the end of 2007:

- If WHO and UNAIDS fail to, the Clinton Foundation should establish a global **plan of action on second-line drugs** to be implemented by WHO, UNAIDS, PEPFAR, the Clinton Foundation and others. As the *Lancet* recently observed,[3] WHO has yet to set up such a plan. Fortunately, with the help of

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[1] Global Fund to Fight AIDS, Tuberculosis and Malaria, Partners in Impact: Results report, 2007, page 36

[2] Farmer, P, From "Marvellous Momentum" to Health Care for All, January 23, 2007, www.foreignaffairs.org/special/global_health/farmer

[3] The Lancet 2007; 369:1320

the Clinton Foundation, countries will soon have new options for affordable second-line treatment. If a ritonavir-boosted atazanavir can be produced at a price below Abbott Laboratories' US$500 per patient per year price for ritonavir/lopinavir, this combination should be widely promoted around the world as the preferred regimen. In addition, countries must take advantage of the flexibility within trade laws to secure generic medicines for their people. We applaud Thailand's courage in standing up to pharmaceutical giants that have attempted to prevent that country from providing lifesaving care to its people.

- UN agencies, the Global Fund, and major bilateral programs should **rationalize the technical support system** that helps implementers address technical, management, and other challenges. This system should be driven by country needs rather than provider availability. There are now multiple, sometimes overlapping technical support initiatives, which lack coordination or any systematic approach for assessing and meeting country needs. Too often, technical support is not designed to take advantage of or build country capacity, and funds are often not sufficient for the long-term support that is needed.

- WHO should provide countries with greatly expanded assistance for the integration of TB services, HIV prevention, malaria, sexually transmitted infection services, sexual and reproductive health, child and maternal health, and other health services into AIDS treatment. Every focus country chapter in this report documents the need to more fully integrate TB and HIV programming.

- WHO and others should demonstrate and document tangible results from global campaigns to address the **human resources crisis in health**, such as WHO's "Treat, Train and Retain" program. There needs to be a coherent global architecture, and significant funding increases, to support a robust response to the human resources crisis in health, especially in Africa.

- WHO and other agencies need the resources to achieve these goals. The budgets for the WHO HIV/AIDS Department and its STOP TB programme must be enhanced with a new strategic focus on a comprehensive approach to the epidemics of HIV and TB, not simply a narrow focus on circumcision, HIV testing, and other stand-alone interventions.

- All global agencies and bilateral programs should establish an AIDS **scale-up implementation service** to help providers and policy makers understand what is working and what isn't in AIDS service implementation, and to rapidly share this information in readily applicable ways. Today, no one is in charge of the wide-scale "implementation R&D" effort that is needed.

- UNAIDS, WHO, PEPFAR, the Global Fund, and governments worldwide should ensure that the voices of civil society are heard at every step along the way. Global, regional, and national AIDS program planning bodies all have a responsibility to stand up for proper representation of health care consumers, including PLWHA. The point isn't token representation or after-the-fact "rubber-stamp" consultations with civil society; rather it is support for full participation by civil society in every phase of development, planning, policy formation, and implementation by including civil society on Country Coordinating Mechanism boards and other planning bodies.

PEPFAR

As the single largest provider of AIDS treatment in the world, PEPFAR has an enormous role. We applaud PEPFAR's accomplishment of helping place nearly a million people on treatment as of December 2006. But as others have observed, President Bush's request for US$30 billion for the reauthorized program is wholly inadequate to meet universal access goals and represents a devastating retreat in PEPFAR's treatment targets. A recent analysis by Health GAP and other groups shows that the Bush request would actually "flatline" or even reduce AIDS funding over the next five years.[4] The US Congress must increase this funding to at least US$50 billion over five years.

Missing the Target's country-level researchers also identified several ways in which PEPFAR must improve its work: by expanding services in areas where health systems are weak, doing more to support health care worker education and training, providing community health workers with living wages and appropriate support, investing in building local public sector capacity, and integrating HIV/AIDS services into existing health care structures. The program should be willing to support recurrent costs such as health care worker salaries in order to retain provider expertise. PEPFAR's requirements on abstinence-only prevention funding are a waste of precious resources, have no basis in scientific research, and must be eliminated. Anti-sex worker provisions and limitations on providing clean needles also must go.

The Global Fund

The Global Fund Board should be applauded for setting the goal of tripling its size to US$6 to 8 billion per year by 2010, though donors stopped efforts to expand the Fund to a higher annual funding level that would have helped achieve universal access. Now donors and rich governments must step up with funding.

The G8 communiqué's commitment to achieve the new funding level must be followed by specific national pledges. We call on wealthy nations to meet their

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[4] Health GAP, Bush & G8 Announcements SLOW Commitment on HIV/AIDS

responsibilities in the international response and greatly increase their funding for the Global Fund.

New Global Fund funding mechanisms such as rolling continuation funding and support for ambitious costed national plans are important steps forward. So is the Fund's increased commitment to civil society's role in planning and advocacy.

Missing the Target's country-level researchers reported important accomplishments through Global Fund-financed programming. They also noted concerns about in-country management of Global Fund monies, delays in money flows, and the need for increased transparency in fiscal and program management.

While the Fund's board recently signalled willingness to make greater resources available to support Country Coordinating Mechanisms, still more effort is needed to make these bodies truly representative entities that can monitor implementation and program results over the life of grants.

WHO and UNAIDS

Missing the Target country reports continue to identify numerous ways in which WHO and UNAIDS are helping governments scale up delivery, including through technical and policy assistance, and convening stakeholders to address challenges. Many research teams reported, however, that both of these UN agencies need to improve their connections to civil society within countries instead of focusing exclusively on serving governments. WHO and UNAIDS also need to be on the lookout for GONGOs—government-organized NGOs—that may serve the interests of governments or country elites, but not speak forcefully for the needs of PLWHA and vulnerable populations.

Several country teams writing in this report call on UN agencies to be much more forceful and visible when national governments mismanage programs, fail to take advantage of flexibility in international trade laws to buy affordable medicines, or ignore the needs of marginalised populations. Speaking out about shortfalls in countries is uncomfortable for UN agencies, of course, since the UN is designed by and for member states. But there are many examples in the past of the UN challenging governments. Dr. Jim Kim did so when he ran the AIDS program at WHO. That kind of courageous leadership is needed today.

UNAIDS is now working on revised resource needs for the global response to AIDS. These estimates have been delayed three times and must be released soon. In developing these estimates, UNAIDS must include the essential elements that we know go into providing adequate AIDS care, like HPV vaccination. It is imperative that UNAIDS resource estimates reflect the need for an expanded investment by both donors and national governments.

Focus Country Chapters

CAMBODIA

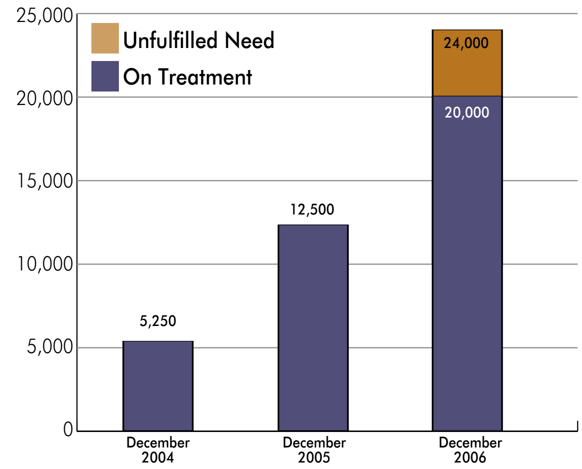
by Frédéric Bourdier and Pen Mony

The response to the HIV/AIDS epidemic in Cambodia has been recently depicted as one of the few "success stories" in reversing the trend of the epidemic.[1] Although significant progress has undeniably been made, some health officials and activists believe that future gains are uncertain in Cambodia because of lingering HIV-related stigma and discrimination, misinformation, potentially problematic trends in sexual behaviour, lack of transparency in funding and financial outlays, and continued concentration of leadership among individuals who often fail to include PLWHA in policymaking processes. Moreover, it is far from clear that HIV treatment is reaching the patients in need as seamlessly and appropriately as claimed.

Universal access response to HIV/AIDS as a political issue

In the wake of the ambitious yet ultimately unsuccessful global "3 by 5" initiative led by WHO, Cambodia began focusing on a plan to achieve universal access to treatment by 2010.[2] Its efforts so far have been influenced by a medical paradigm that gives priority to health-related activities such as epidemiological surveillance, biomedical training, treatment supply, and health care delivery. This paradigm and

AIDS Treatment Access in Cambodia



Note: The 24,000 need number represents a mid point between high and low estimates in the latest WHO report.
Note2: all numbers based on WHO AIDS treatment update reports, 2005, 2006,and 2007

- **Steady increase in number of people receiving ART**
- **Growing emphasis on medical paradigm at expense of attention to social aspects of treatment access**
- **Acute shortage of trained health care personnel**
- **Inventory and supply problems**
- **A policy of free treatment, but PLWHA often must spend their own funds on medical consultations, diagnostics, and transportation**
- **Frequent reports of problems with the drug supply system since it was moved under the Ministry of Health**
- **Increasing numbers of people needing second-line therapy, yet these drugs remain unaffordable for many**
- **Only an estimated 40% of PLWHA have been tested for TB co-infection**
- **Voices of civil society often not heard by government leaders**
- **Marginalized groups face special challenges in accessing care**

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[1] Markus Bülher, David Wilkinson, Jenne Roberts, and Tap Cattala, Turning the Tide, Phnom Penh, August 2006, UNAIDS document.

[2] As defined by UNAIDS, universal access means that 80% of people who need the treatment are receiving it.

relevant aspects that affect implementation — such as technical and health care capacity — have been developed with the guidance and support of international agencies and donors (such as the UN, the World Bank, the US Agency for International Development, and the UK Department of International Development).

Two trends have emerged. On the one hand, HIV health policymaking has been centralized through the National Centre for AIDS and STDs (NCHADS). At the same time, an increasing number of local health centres have begun providing antiretroviral treatment (ART) to needy people in their areas. As a result, there is an inherent conflict between the top-down medical approach encouraged by the government and donors, and a grassroots approach that takes into account specific local conditions and issues influencing treatment uptake.

Treatment as a medical solution rather than a component of global care

Even if one agrees that the HIV/AIDS epidemic should be approached primarily from a medical dimension, it is vital to recognize certain socioeconomic issues that have a major impact on the epidemic and those living with the virus. For example, effective responses to HIV/AIDS can only be initiated when the human rights of PLWHA and other vulnerable populations are guaranteed. That element of the response has not been made a priority in Cambodia by either the government or international supporters. The main reason is that the comprehensive approach adopted to date — strengthening, expanding, and integrating the "continuum of care" into the health care delivery system — is not nearly comprehensive enough. The most obvious gap is that input from PLWHA has not been sought to determine how to ensure better quality and more equitable access to treatment.

BACKGROUND

ARVs were first made available in Cambodia in 2001, offered free of charge at a small number of clinics run by a few international NGOs, including Médecins du Monde, Médecins Sans Frontières (MSF), and Center of Hope. These projects demonstrated the feasibility of providing ART in a difficult socioeconomic context at a time when external agencies and even many other international NGOs with local operations were convinced that providing treatment in resource-limited environments was unrealistic. With support from the Global Fund, ART was first made available (free of charge) through the public sector in 2004. As of early 2007, there were more than 40 ART centres throughout the country, which has a total population of 13 million.

NCHADS' latest official estimates in 2003 showed 123,100 adults age 15 to 49 and 12,000 children younger than 15 living with HIV. Of these, some 20,000 were thought to have AIDS (i.e., CD4 counts less than 200 and/or clinical symptoms), and were thus in need of treatment.

Since 2004, the number of individuals on ART has increased steadily. At the end of December 2005, 12,355 people were receiving ART, of whom 11,284 were adults and 1,071 were children. More than 50% of adults at an advanced stage of AIDS were on ART. Gender equity had been achieved by then as well, with female patients accounting for 48% of those on treatment.[3]

A total of 2,319 new patients started ART during the first trimester of 2006. By the end of that year, according to an NCHADS report from all sites, the number of individuals on ART had reached 18,256. Of those, 16,685 were adults. The most recent figures, from March 2007, indicated that 21,939 people were receiving ART. Nearly 49% of them were women; 1,938 were children.

RESEARCH METHODOLOGY

With these official data in mind, the authors of this report conducted field research in April and May 2007. They spoke with people living with or otherwise affected by HIV/AIDS at homes and hospitals; interviewed key individuals and staff engaged in health care delivery and advocacy;[4] and organized focus group discussions with members of vulnerable populations, including injecting drug users (IDUs), men who have sex with men (MSM), and sex workers.

Representatives of some NGOs providing treatment were also consulted, including the Cambodian Health Committee clinical coordinator dealing with HIV/TB co-infection, the Médecins du Monde medical coordinator, and a public relations officer from Friends without a Border. Also contacted were other NGOs, affiliated groups, and networks involved in advocacy and empowerment processes, especially those working at the grassroots level. They included ActionAid International, World Concern, the Cambodian Women's Development Association, the Cambodian Community of Women Living with HIV/AIDS, the Women's Network for Unity, the Cambodian Prostitution Union, and the Cambodian Alliance for Combating HIV/AIDS.

PLWHA interviewed were women and men between the ages of 20 and 45. Most were poor or lower-middle class. They included female sex workers, MSM, IDUs, Khmer migrants, recent migrants from Vietnam (who are Vietnamese citizens), and ethnic Vietnamese living for a long time in Cambodia and receiving treatment or waiting for ART access in Cambodia.

The research took place in Phnom Penh, the capital, and in the provinces of Siem Reap in the northwest and Kampot in the southeast. Three facilities provide ART in Siem Reap, including one run by MSF-Belgium, and two facilities do so in Kampot,

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[3] Ministry of Health, Annual Report 2005, National Center for HIV/AIDS, Dermatology and STD, Phnom Penh, March 2006.

[4] Among those interviewed were the NCHADS director, the WHO programme advisor, the UNAIDS country director along with his staff, the National AIDS Authority (NAA) advisor, the former surveillance and evaluation officer at Family Health International, the project officer at the United Nations Children's Fund (UNICEF), the clinical advisor from the CDC, and two Global Fund sub-recipients.

including one run by the Cambodian Health Committee in the city of Kampong Track. The decision to conduct research directly in the facilities helped ensure that a whole chain of health actors dealing with care and treatment could be reached: caregivers, treatment advisors, pharmacists, laboratory technicians, counsellors, nurses, social workers, data managers, and medical doctors, among others.

REVIEW OF THE MAJOR FINDINGS

One of the main challenges of the rapid expansion of ART has been an acute and persistent shortage of properly trained **health service delivery staff**. Basic inventory and supply systems do not function adequately to ensure the constant availability of materials, supplies, basic lab support, and medications necessary to maintain expanded program activities. In some provincial hospitals, there have been periodic stock-outs and shortages (mostly for OI drugs) that limited access to treatment and caused people to miss doses if they could not afford to buy drugs in the private pharmacies. In addition, weaknesses in procurement, accounting, and management are exacerbated by the influx of relatively large sums of money from donors such as the Global Fund.

Until early 2006, an emphasis was put on quantitative results: The more patients under ART, the better. The objective then was to meet the "3 by 5" goals and to show with selected indicators that the national HIV/AIDS program was running well despite various difficulties at the local level. However, concern with the quality of treatment access had been left behind. A mechanistic approach was encouraged in the implementing process and subsequently PLWHA began believing (and many still do believe) that receiving treatment and quality of care was a privilege, not a basic human right as codified by national law.

From the beginning Cambodia had a strong commitment to implement a policy of **free access to treatment**, and ARVs have remained free of charge everywhere they are available. However, it is common that people need to pay extra money for both medical expenses (e.g., drugs, consultation, exams) and non-medical expenses (e.g., bribes, transportation, and referral services). Treatments for OIs are normally free as well but there are reports that patients have been required to buy specific drugs when shortages exist (as has been the case with fluconazole).

The situation regarding **diagnostics** is mixed. In some health centres CD4 tests are subsidized either by the government or by NGOs, and people do not have to pay. In other facilities, patients are expected to pay for such tests. Whatever the price, it is often beyond the financial capacity of the poorest persons. Research indicates that patients seeking care through the public sector often must pay to receive other tests, such as X-rays.

There are only four places in the country to obtain CD4 tests. According to the government, 40,000 patients received CD4 tests during 2006, but no exact information is available on how many times those individuals actually were tested (national guidelines recommend two times per year). Viral load tests have been available in only one facility, in Phnom Penh, since December 2006.

Another concern is the newly implemented **drug supply system**. Traditionally, ART and treatment for OIs were supplied directly by NCHADS and the delivery system ran quite well. In January 2006, however, the system was centralized and now falls under the responsibility of the Central Medical Supply division of the Ministry of Health. Provincial hospitals regularly report major problems with drug procurement (such as late delivery of supplies and receipt of expired drugs); most of these problems are blamed on the Ministry of Health's poor logistical and human resource capacities.

Efforts aimed at **prevention of mother-to-child transmission** (PMTCT) have not worked well over the years. PMTCT is supposed to be implemented at 69 sites where women should receive antenatal care and either nevirapine during delivery or a more elaborate treatment protocol (approved by national guidelines in 2006). However many sites fall short of meeting this goal. Health providers are insufficiently trained and thus often fail to inform pregnant women about their options. It has been observed by some UN representatives that less than 10% of pregnant women ask for an HIV test when visiting antenatal clinics. In the northern province of Bantey Meachey, according to observers from the CDC, most HIV-positive pregnant women who know their status never return to clinics for delivery and therefore do not receive the drug protocol that can greatly reduce the risk of transmission to their child.

ART delivery centres were originally few in number and distant from one another. However, Global Fund money has supported the opening of new sites that make access to health service much more convenient to larger numbers of people. Relatively experienced staff from the older sites have provided technical support through regular interactions with staff at the new ones.

The new national guidelines include protocols for **second-line regimens** as well. In early 2007 it was reported that more than 3% of ART recipients were taking non-first-line regimens, notably combinations including tenofovir. Additional HIV drugs are likely to be part of the second-line package in the future because of a strong commitment to increase treatment options by government authorities, international agencies, and NGOs (notably the Clinton Foundation). This is an important development, but it also raises new challenges as the number of people who need second-line regimens increases. Most of these drugs remain relatively expensive and thus not easily affordable for a poor country such as Cambodia.

The **tracking system for "lost patients"** is still very weak. Most of the referral hospitals have a monthly list of people who are in their active file but who have missed appointments or who apparently no longer come to receive care. It is difficult to find them in the absence of easily verifiable address information, but better efforts should be made to locate these HIV-positive persons in order to determine why they have stopped seeking care and treatment.

Another justifiable preoccupation is the **high prevalence of TB** in the country. HIV-positive individuals are more likely than others to have active forms of the disease and to require treatment. NCHADS has signed a memorandum of understanding with the National Center for Tuberculosis to insure that 100% of TB patients will be screened for HIV. To date, however, only about 30% of TB patients have been asked to be tested for HIV. Reciprocally, HIV patients should be systematically tested for TB, but only 40% reportedly have been screened to determine if they are co-infected. The government's main excuse for not meeting its 100% testing goal is not so much based on logistics as on the cost of extensive TB screening throughout the country. Regardless of the reason, the consequence has been that doctors screen for TB only if they identify suspected symptoms.

More generally, **all health services are supposed to be integrated** (as mentioned in the national plan). Yet compartmentalization within and poor coordination among different sectors persist at the district level in rural areas and even in some provincial referral hospitals. Global Fund money is being used to address this shortcoming, at least in part by supporting health service planners and national policymakers in their efforts to improve integration. To be effective, however, health services themselves must be better coordinated with social services. This is because non-medical considerations are of tremendous importance in providing quality HIV/AIDS care. For example, due to extreme poverty, some patients have resorted to selling their ARVs and OI medications in order to obtain money for food.

Numerous international agencies and donors are working in Cambodia, with many of them providing important technical assistance (such as in monitoring and evaluation) as ART roll-out expands. Some stakeholders, notably UNAIDS, are encouraging **greater participation by civil society**. In particular, it is recognized that PLWHA should be key participants in advocacy toward universal access. That effort can only succeed when PLWHA advocacy progresses beyond a few isolated voices raising disparate concerns and forges a strong, unified leadership. The number of civil society groups focused on health in general (and HIV/AIDS specifically) has indeed been increasing. For the most part, though, they have yet to make a significant impact on policy – including issues related to treatment access.

There are several reasons for civil society's lack of influence to date. Most members of civil society (defined herewith as patients, community-based organizations, and other associations operating at the grassroots level) have been supported by the government with the implicit condition that they agree to follow the national agendas and not raise their voices too high. The government frowns on (or even takes measures to actively block) civil society groups that seek to turn into lobbying groups, watchdog organizations, or critics of national and international policies. In other words, they are welcome to be good soldiers to fulfil certain duties only, such as collecting data, reporting local cases, developing networks, and identifying instances of social stigma and discrimination. As many involved PLWHA attest with frustration, they can participate by obeying orders coming from the top but they are not supposed to turn right or left and their representatives are not welcomed as part of the decision-making process when national policies are examined or altered. As one person remarked, "With very few exceptions, nobody in the hierarchy is ready to listen to our voices even if we point out some neglected points or insist on some issues that are not yet taken into consideration." Civil servants and public-sector authorities generally dismiss criticism from civil society as being ill-informed, unrealistic, inappropriate, or unreasonable.

The issue of **marginalised groups** deserves attention. A large but silent minority of people still lack awareness about or access to prevention, treatment, and care. They mostly include members of marginalised groups, including sex workers, MSM, IDUs, migrants, Vietnamese citizens living in Cambodia, and poor families living in remote areas or in the slums of the cities. Many of these individuals, especially recent Vietnamese migrants, MSM, and IDUs, are reluctant to seek out health services in general because of fear of stigma and discrimination, if not harassment. UNAIDS staff are taking the lead in reducing the isolation and improving the ability of these marginalised groups to receive care and support. The government, however, has yet to make this a priority.

Recommendations

- **The government should recognize the vital role of independent organizations in monitoring AIDS service delivery**
- **The government must ensure more equitable distribution of health services across all provinces**
- **Better integration of VCT, PMTCT, and ART services is urgently needed**
- **The public should have access to financial audits of Global Fund projects**
- **Expanded efforts are needed to reduce stigma, and the health provider code of conduct should be reinforced**
- **Private clinics should collaborate more closely with the national AIDS program**
- **The government and others should provide social supports, such as poverty-alleviation measures, to help PLWHA benefit from treatment**

RECOMMENDATIONS

1. Though the HIV transmission rate remains high among pregnant women, the PMTCT program is not well managed in most of the provinces. Women traditionally lack access to information and have little confidence in service delivery. To meet the needs of women, the Ministry of Health should improve integration of antenatal care, voluntary counselling and testing (VCT), PMTCT, and ART services and facilitate a coordinated referral system.

2. There is unequal distribution of heath resources and quality among the treatment centres within the 24 Cambodian provinces. A shortage of human resources, vital equipment and supplies, and technical capacity exists in most provincial health centres. Many recently established centres in remote areas have limited or non-existent services. The Ministry of Health should ensure that health providers at new clinics receive proper training and technical support from experienced personnel at established clinics.

3. Health care providers should offer adherence support for PLWHA on ART.

4. The Ministry of Health needs to ensure that at least 70% of PLWHA are screened for TB and have access to treatment (OIs and ART).

5. Paediatric AIDS cases are currently referred to only a few medical institutions due to lack of personnel and supplies (including drugs) at the paediatric treatment centres. All 19 paediatric centres need to be staffed and supplied so that they can function properly.

6. Policymakers should focus on making generic medications more widely available. This would help reduce drug costs and increase the number of people able to receive ART. Help in these efforts is already forthcoming; for example, the Indian pharmaceutical company Cipla is willing to sell AIDS drugs to Cambodia at low prices, and the Clinton Foundation has been negotiating with major companies for lower drug prices on behalf of Cambodia.

7. The Ministry of Health and WHO should advocate with the Ministry of Commerce for Cambodia to not introduce a patent protection law, as is being considered for 2016. Implementation of a new patent law could undermine access to generic drugs in the country.

8. In 2002, the Royal Government of Cambodia passed the Law on the Prevention and Control of HIV/AIDS. The law contains human rights guarantees for PLWHA and vulnerable populations in Cambodia, including rights of confidentiality, non-discrimination, and freedom of movement, residence, and association. However, compliance with these laws is poor, particularly within the health care sector. The few civil society groups working

on these issues lack the capacity to work at the national level. The National AIDS Authority and the Ministry of Justice should establish monitoring and enforcement mechanisms with respect to these rights.

9 For the past 10 years, private clinics have been involved in ART procurement and supply.[5] They rarely collaborate with the national program, however. Coordination between the private and public drug supply channels should be strengthened to guarantee the safety of medicines used across all sectors, and to improve efficiency in drug delivery.

10. Community health workers should be given increased visibility and social recognition. Caregivers, for example, are in constant contact with PLWHA in hospitals and other care facilities. Their input and observations deserve to be heard by policymakers at all levels.

11. WHO should cooperate with government to strengthen the national health care program, and develop and transfer appropriate technology, information, and standards. WHO can also help the government develop national monitoring and evaluation tools for the health system.

12. Civil society and PLWHA have a role to play in mobilizing their members and communities to create demand for services, and in reminding the government and other partners to deliver on their prevention and treatment commitments. Yet greater activism is needed. Government officials and UN agencies should officially recognize and accept the involvement of autonomous bodies (both civil society and affected communities) to act as watchdogs and lobbying groups. One of the main focus areas of these advocacy organizations should be on basic health care delivery, where such independent efforts are currently rare in Cambodia.

13. Financial audits required by the Global Fund are helping to determine if money is spent properly. All citizens should have the right to consult not only these specific audits but all financial statements of public-sector HIV/AIDS programs. This is an ambitious undertaking, but some powerful citizen groups have managed to do it in countries such as India. Financial tracking (with transparency) can help the public become aware of how money that is supposed to reach them is spent. This can be a constructive way to mobilize civil society in the fight against the epidemic.

14. The ability of Cambodia's health sector to sustain the ongoing expansion of the continuum of care for PLWHA and to maintain the availability of services over time will largely depend on a continued influx of external resources to complement government funds made available for HIV activities, and on the capacity of provincial and district health departments to provide

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[5] Taing Youk Lin, Antiretroviral circulation in the private sector (2004–2006), Phnom Penh/Paris, IRD research document, January 2007.

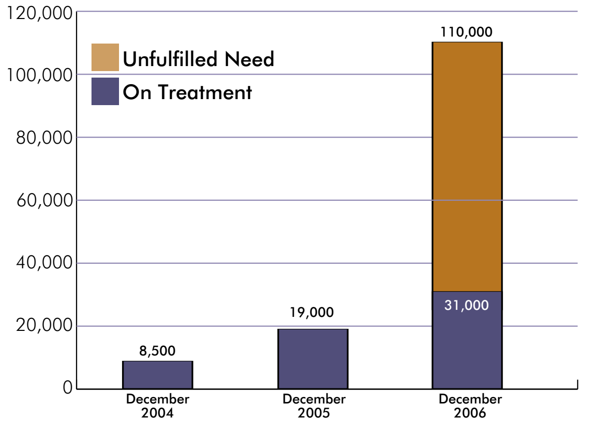
quality prevention and care services. The **Global Fund** and other international aid agencies should support least developed countries like Cambodia in implementing free ART programs, which help to consolidate national purchasing efforts and improve the logistics of supplying health care products.

15. In a poor country like Cambodia, access to free treatment alone cannot solve the plight of PLWHA living in extreme poverty. People require not only medical assistance but social aid, especially food, to help them improve their own prospects as well as those of their families. So far, there are no official data on the economic status of HIV-positive individuals, but it is clear that HIV prevalence among the very poor is growing. The **World Food Programme** must make a commitment that PLWHA and their families have a right to food.

CHINA

Anonymous research and writing team

AIDS Treatment Access in China



Note: all numbers based on WHO AIDS treatment update reports, 2005, 2006,and 2007

- **Rapid expansion in treatment program, but services falling behind increasing need**
- **New AIDS plan promises to bring a more strategic approach**
- **Stigma inhibits many people from seeking treatment, and IDUs, migrant workers, sex workers, and others face significant stigma and discrimination**
- **Need for expanded adherence support and treatment follow-up**
- **ARVs provided free to many, but related costs (such as Western blot, CD4, liver function, and other tests) make treatment prohibitively expensive**
- **Few have access to second-line drugs, though the need is growing rapidly**
- **PMTCT services are limited, and paediatric ARV formulations are not registered in the country**
- **Drugs for treatment of HIV/TB co-infection not readily available to many**
- **UNAIDS and WHO provide helpful policy assistance, but are not out-spoken enough on failure to meet treatment targets, inadequate use of flexibility within TRIPS, and the need to involve civil society**

China's National Free ARV Treatment Program started as a hastily put-together "emergency" response to the blood-selling scandal four years ago. The program has since expanded rapidly: by August 2006, approximately 26,000 people had started taking ARVs; by June 2007, this figure has grown to more than 30,000 people. However, with an official government estimate of 650,000 HIV-positive people in China, this is only around 10% of those who need ARVs. After the initial rapid scale-up (primarily in Henan Province in central China), the number of people coming onto ART continues to fall further behind the need. An initially chaotic response is being standardized through a more systematic approach and through a government HIV/AIDS control and treatment plan ("Four Frees and One Care") announced in December 2003. However, numerous institutional, bureaucratic, social, and budgetary barriers limit the number of people receiving treatment.

The actual number of HIV-positive people in China remains a topic of debate. The Chinese government reduced its estimate of PLWHA from 840,000 to 650,000 in December 2005, on track to meet its long-term target of containing the number of HIV infections at 1.5 million by 2010. However, many people privately express doubt about this estimate, and there are reasons to think the real number is much higher.

Nearly all ARV therapy in China comes via government clinics or hospitals, with the exception of two MSF clinics and a tiny number of privately paying patients. There is a limited choice of ARVs, with no second-line regimens available, and the extremely small private-sector market has not encouraged foreign pharmaceutical companies to market their newer ARVs in China.

The training of doctors in HIV awareness, prevention, and treatment is widespread in China, but much of it is superficial and does not reach the front-line medical staff who actually need it. There continues to be a serious shortage of skilled medical personnel working—and willing to work—to treat PLWHA. This is due to widespread stigma against PLWHA among medical staff, and also to the strongly commercial nature of medical care in China. In China's medical system, doctors' monthly salaries and bonuses are directly linked to the amount of medicine and tests that their patients pay for. Since ARVs are free, it is much harder for doctors to profit from HIV/AIDS care, particularly if they are specializing in HIV/AIDS.

Although ARVs are provided for free, patients are usually charged user fees for diagnostic tests such as CD4 and viral load tests, and for treatments for OIs.

Because of China's enormous size, the autonomy granted to local provinces in managing the ART program, and huge geographic variations in economic development, there is an equally wide variation in the number of services available under the ART program. Some wealthy provinces—or certain cities within wealthier provinces—provide free OI treatment or CD4 tests to local residents, while hospitals in other poorer provinces continue to charge market rates or even higher for these services. Despite a strong central government, the lack of effective checks and balances has prevented even well-intentioned government officials from compelling local authorities to respect the rights of PLWHA and offer discounted treatment.

> *"We've made a lot of mistakes, not because of lack of trying. We've made mistakes because we didn't know what else to do…"*
> —China CDC staff member

> *"If it weren't for the activists who protested back in 2002, there wouldn't be a free treatment program today."*
> —China CDC staff member

RESEARCH METHODOLOGY

This report was prepared by a team of four independent researchers, all of whom are working with NGOs and three of whom are living with HIV. Information was collected through interviews, e-mail, and phone calls with doctors, PLWHA, national and international non-governmental organization (NGO) workers, and UN and government staff, as well as through a review of existing literature and reports on the HIV/AIDS epidemic in China. Due to the sensitive nature of open criticism of the treatment program in China, none of the interviewees or researchers are identified by name in this report.

REVIEW OF THE MAJOR FINDINGS

The two major questions posed to the sources were:

1) What are the two most important barriers to expanded ARV treatment delivery in your country?
2) What needs to be done –- and by whom –- to address these challenges?

Answers include:

- ***Finding the patients and making sure that they enter and remain within the care system.*** Stigma and discrimination against PLWHA means that many people are not willing to seek treatment. The CDC and hospital staff, rather than peers, provide what limited information and counselling is available to ensure that PLWHA understand treatment before they start.
- ***Making the services truly free and accessible to all.*** The lack of a rapid HIV testing protocol and the requirement that all people seeking care must pay for the prohibitively expensive Western blot test to confirm their diagnosis is a major barrier to obtaining treatment. In addition, exorbitant fees charged by some hospitals while implementing the "free" national ART program and residency requirements that effectively exclude migrant populations from provincial programs strongly limit treatment scale-up efforts.
- ***Lack of essential drug formulations****, including second-line ARVs and fixed-dose combinations for first-line therapy*. This continues to be a major impediment to effective treatment and treatment scale-up. Forty percent of people on the national free ART program are still on regimens including ddI/d4T, a combination that is *not recommended* by WHO.
- ***Adherence support and treatment follow-up*** are both seriously lacking in many places, which results in drug resistance and a large number of patients falling out of care. The overall lack of support, information, and counselling could be remedied by supporting community groups to do counselling and education**.**
- ***Not enough qualified medical staff.*** Doctor trainings are often superficial and not engaged with actual HIV patients. Many doctors who are trained in HIV/AIDS treatment do not actually work in HIV/AIDS. There are two reasons for this: 1) stigma and discrimination; and 2) AIDS treatment negatively affects their income because there is less profit to be made.

What is working well

The central government in China, with the help of the international community, has made a huge shift in policy and has increased awareness about HIV and AIDS in the country. Until 2003, Chinese leaders were largely in a state of denial about the epidemic; on December 1 (World AIDS Day) in 2006, the Chinese premier was seen on national television visiting AIDS patients. The promise of free ART at government expense was a bold move for the leadership, and efforts are continuing to build upon this high-level leadership to break down additional policy barriers. Despite its many failings, China has scaled up ART, created an effective system of national drug distribution, and reduced the mortality rate among PLWHA from 9.8% to 4.1%.

Marginalised populations

According to the national AIDS policy, all Chinese citizens are eligible to receive ARV therapy within their registered residence. But in reality there are many factors affecting certain populations' abilities to access treatment. There is still a high degree of stigma against IDUs, sex workers, and migrant workers, and policy and institutional barriers prevent them from accessing ARV treatment and care.

- ***IDUs:*** IDUs are viewed with particular suspicion by treatment providers because they are seen as unreliable and at high risk of being nonadherent to ARV therapy. They are at times refused entry to treatment programs. IDUs also face the constant risk of arrest and detention, and it is extremely difficult to provide a continuum of care once they have been sent to a mandatory drug detox centre or detention facility. In addition, many IDUs are extremely reluctant to register using their real names because they fear their identities will be passed on to police and other authorities, and thus are not willing to participate in the national treatment system.

- ***Migrant workers:*** PLWHA are only allowed to access ARV therapy in their area of residency (China has a national residency system), and this is a major barrier for PLWHA who are not residing where they are registered. In some cases, doctors or patient groups will negotiate to send ARVs across the country, but in most cases, people living outside of their area of residency simply do not have access to treatment.

- ***Sex workers:*** As the majority of sex workers are also migrants, they confront the same restrictions on access to free ARVs that migrant workers do. Facing the choice between an income and medical treatment, most choose the former.

Women and MSM, as minority populations, face few barriers to accessing treatment, other than those encountered by any individual (i.e., residence requirements, financial burdens).

Prevention of mother-to-child transmission of HIV

Despite a national plan to ensure that all pregnant HIV-positive women have access to PMTCT, there is still very limited provision of PMTCT services. Some provinces (such as Guangdong) have relatively broad coverage, but PMTCT training has only been done in 121 "pilot" sites. Resources are extremely limited and some sites do not even have appropriately formulated ARVs. There are a number of identified barriers facing the PMTCT program:

- Women often present to medical care very late in their pregnancy, and there is little or no access to information or counselling.
- PMTCT programs are done at county level, while many HIV-positive women seek services and deliver their babies at township level.
- It appears that the majority of HIV-positive women are counselled to abort rather than go through with the pregnancy, reducing the need for PMTCT interventions.
- After testing positive with an ELISA or rapid test, women are sent for expensive confirmatory tests, and drop out of the program if they cannot afford them.

A new government effort (the Chinese CDC's "Family Care" program) to include HIV information in routine prenatal care may reduce these barriers and increase the number of women receiving PMTCT services.

Paediatric treatment

There are approximately 600 HIV-positive children receiving ART in China, virtually all via a drug donation program sponsored by the Clinton Foundation. The national target for 2007 is to treat 800 children, though there are an estimated 2,000 children who need treatment. Even in Beijing's premiere AIDS treatment facility, there are only three children on ART. There are a number of identified barriers facing the paediatric treatment program:

- Paediatric formulations of ARVs are not registered in China, and are being imported under a special "waiver." This is a risky and unstable arrangement. These drugs should be registered and imported legally, to avoid treatment interruptions and allow for scale-up of paediatric treatment.
- There is very limited capacity to do early infant diagnosis and few doctors are trained in paediatric treatment.
- There is competition between China's CDC and the Chinese hospital system (maternal and child hospitals) over who is taking the lead in paediatric treatment.

- There needs to be improved guidance and information for parents and family members to ensure adherence of children to ART. In Henan, where hundreds of children were on ARVs, there is strong evidence that drugs were not being taken properly due to lack of information and support for parents or guardians. Some NGOs were providing adherence support in Henan, but were requested by the local authorities to leave the province. Some studies indicate that 50% of the children have already developed resistance to the first-line ARVs available in China.

> *"It's ridiculous that the government can say in one year we're only going to treat 800 children—that's our target—when you have in one province alone 1,400 kids known to be HIV-positive. How can they say that? The drugs are all donated; are they so pathetic that they can only treat 800 children?"*
>
> —NGO staff member

> *"They're trying to treat 800 children by the end of this year …but a lot of children are dying unidentified (undiagnosed). There are supposed (thought) to be about 2,000 children living with HIV."*
>
> *"The women who cannot afford the test, when they are delivering, they are given a test.… Although it's being done in the name of preventing mother-to-child transmission, that test is basically to protect the health worker. It's being done at delivery when you would have much less chance of preventing transmission from taking place, you should have done it at the first antenatal visit, and she didn't do it because she didn't have money. At delivery, she will accept doing it because she has to…but she's doing it at the wrong time."*
>
> —UN staff members

Access to second-line treatment

There is at present no second-line ARV therapy available in China under the National Free ART Program, though there are plans to introduce it soon. One of the major barriers is the lack of registered, marketed second-line ARVs in the country. At present, fewer than 25 people are thought to be on second-line therapy; all receiving ARVs that are either privately purchased abroad in Thailand or Africa, or else donated from developing countries). Yet there is a rapidly growing need for second-line ARV therapy, as cases of treatment failure are increasing and there are many indications that drug resistance is widespread.

Ongoing negotiations with international pharmaceutical companies have yielded prices that are apparently (according to both company and government sources) acceptable to both sides, but there remains no indication when these medicines will become available. The prices offered by Abbott and Gilead for the second-line ARVs most likely to be specified in the new National Free ART guidelines (currently being drafted) are US$1,000/year for lopinavir/ritonavir (LPV/r, marketed as Kaletra by Abbott) and US$365/year for tenofovir (TDF, marketed as Viread by Gilead). After years of pressure from PLWHA groups and MSF, Abbott finally started marketing the old formulation of LPV/r in China early in 2007, but the retail price is US$271/ month (or US$3,252/year). At the time this report is going to press, Abbott says it will lower the retail price for LPV/r in China to US$132/month (or US$1,584/year), but it is not known when that price will be available. TDF is still not registered in China, but a Gilead representative says it will be submitting the registration dossier soon. Given the slow pace of drug registration in China, it is unlikely that second-line ARVs will be available in the Chinese government treatment program before the last quarter of 2007.

Access to OI drugs

While drugs to treat or prevent OIs are widely available in China, they are not included for free under the government-mandated “Four Frees and One Care” program and must be purchased by patients. There are numerous reports of local doctors prescribing OI medications and other tests as a way of supplementing income “lost” while providing free ARV therapy.

For many PLWHA, the cost of OI therapy represents a formidable barrier, and many choose to forgo some OI treatment due to lack of funds. The central government actually has a budget to help poor patients access OI treatment, but in most of the provinces (except Guangdong), the use of this budget lacks transparency. Although many local officials admit to having a budget of RMB500-2000 per patient per year for OI treatment, these funds seem to be used as part of their general operating budget rather than to purchase OI treatment. Almost all local PLWHA would agree with one person’s statement that “besides ARVs, we need to pay for everything; I’ve never heard of any subsidies from the government.”

The true cost of treatment

Under the National Free ART Program, all ARVs are supplied free of charge by the central government. All other treatments and medicine, however, are supplied by local government agencies or treatment centres (usually hospitals) on a *fee-for-service* basis. While these costs to the patient are theoretically meant to be discounted, each local government or service provider determines the price. Provincial governments are allocated funds from the central government to cover some of these costs, but they are normally incorporated into local budgets and rarely cover the actual fees. Even such affordable and important prophylaxis drugs as cotrimoxazole must be purchased by patients.

There are two instances in which some OI treatments and CD4 and other routine tests (though notably not viral load tests) are available for free. In Henan Province, where many tens of thousands of poor villagers were infected when selling blood plasma during the 1990s, and in wealthier cities such as Beijing, Shanghai, and Guangzhou, these additional costs are covered by the national and local governments respectively. Except in the case of drug resistance investigations (normally funded by external, usually international donors), viral load tests must be paid for by the patient, a cost that few PLWHA can afford.

The costs associated with the "free" National ART Program (including CD4, liver function, and many other tests that are required by the National ART Treatment Protocol) are often cited by community members and front-line medical staff as important barriers that prevent many PLWHA from receiving ARV therapy. In some areas, groups such as the Clinton Foundation have helped local governments to purchase test reagents, but it is unclear whether tests are really being provided for free to patients.

> *"For China there should be no financial barrier. In this country the money is there. Why should a person living with HIV –- why should any poor person for that matter -– be paying user fees in this country? Why? Why? Abolish user fees; abolish user fees so people can use the services."*
>
> —UN staff member

> *"Lack of access for many people boils down to cost. From the first step, if you don't have money you have no way of getting on treatment. OI treatment is a major financial burden for patients."*
>
> *"We joke that a patient asks a doctor, 'Doc, when can I get out?' and the doctor answers, 'How much money do you have left?' It's not a joke. This is a problem with the system, it's really happening....It's terrible, it's really terrible."*
>
> —International NGO staff members

TB and HIV

China has a big problem with HIV/TB co-infection, and has policies in place to provide free treatment for both illnesses. Efforts are being made to link the two treatment systems, but coverage varies depending on the motivation of local authorities, the relationship between the AIDS and TB treatment facilities, and the existence (or lack) of a clear system for referral, in some instances due to the vested interest of some providers to keep patients within their own systems in order to receive fees or government bonuses. In some wealthier provinces, preventive therapy such as cotrimoxazole, counselling, and support services are available and free, but this is not the case in most places. The China National Center for AIDS Prevention and Control is trying to improve referrals and link the two systems, and joint surveillance and planning is taking place under the Global Fund Round 5 TB program (though only at a small number of pilot sites). A number of systemic barriers are limiting the effectiveness of these efforts:

- Diagnosis is inadequate both in the case of TB patients being screened for HIV and HIV-positive people being screened for TB. Since the TB program requires sputum-positive tests, and AIDS patients tend to be sputum-negative, an estimated 50% of TB cases among AIDS patients may be missed.
- Counselling is extremely limited, and in most places is provided by health care workers who have not had formal training in counselling or psychological support.
- Efavirenz, which is recommended for use in HIV/TB co-infection, is available and on the list of "free ARVs" in China, but the high fee paid by the government means that doctors are under pressure not to prescribe it. In some areas, such as in one city in Yunnan where 60% of AIDS patients are TB co-infected, efavirenz is not available at all.

Integration of HIV into other health services

All AIDS-related treatment services in China are provided exclusively by the infectious disease system, and it is difficult or impossible to integrate them into other health services. There is little awareness of HIV and AIDS among general practitioners, and there is strong stigma against not only AIDS patients but also against medical staff who work with AIDS patients. There are numerous documented cases in which general hospitals refused to perform basic surgery on HIV-positive people, instead referring them to the infectious disease hospital, even though that hospital lacked the ability to perform the necessary surgery.

In one general hospital in Guangxi Province, some doctors in the infectious disease department were not willing to see AIDS patients, preferring to see Hepatitis-B patients instead. In another case, communication and referral between TB and AIDS departments in the same infectious disease hospital was difficult. These scenarios are common across China.

HIV testing is generally provided in its own special facility within a larger health care setting, making it cumbersome for women accessing reproductive health services to also access HIV testing as part of routine health visits.

> *"The problem is the parallels in the systems -- all the systems are separate, and in the case of an AIDS patient they actually need all the systems to be working together."*
>
> —Medical staff member

> *"People are not used to integration here; it's a big problem. Even at the national level, integration is not easy; people are learning how to work together… but everything is vertical, and when you go down to the local level it's even worse."*
>
> —UN staff member

The work of multilateral agencies

Bilateral and UN agencies in particular are in a difficult position in China, because they are unable to challenge the Chinese government on civil society issues or human rights issues, and are also dependent on the government for data regarding the HIV/AIDS epidemic. (In China, epidemiologic data is so confidential that even those writing Global Fund grants do not have access to it.) For example, even though it is well recognized that China's TB control efforts have major problems and find a high rate of multidrug-resistant TB, WHO echoes the official government assessment that TB control efforts have been successful.

The work of multilateral agencies on HIV/AIDS has primarily occurred at a high-level policy or leadership level and has had a significant impact on treatment policy, on the development of treatment guidelines, and on the treatment system in general. However, very few funds have been used to change the attitudes or improve the ability of caregivers who treat PLWHA. The result is that at times the attitudes of front-line caregivers are lagging behind those of the top leadership, creating a big gap between policy and policy implementation. There has been limited support or meaningful interaction with civil society, despite numerous structures being in place for consultation and meetings. In particular, there is disappointment among PLWHA and treatment advocates that the UN agencies (UNAIDS and WHO primarily) have not spoken out about China's low ARV treatment targets, its inadequate use of flexibility within the TRIPS trade agreement regarding generic drugs, or other important issues related to treatment scale-up.

> *"By their nature, these organizations are addressing the needs of the government; they are following the lead of the government. They have a mandate [to help the people], but it is in second place behind their mandate to help the government. Ask the United Nations agencies -– if they want to go to visit the provinces, they have to ask permission, and 80% of the time they will fail to get it. The more mobile is UNICEF, but WHO is not effective at all."*
>
> *"They [UN agencies] push; they try to push but the system doesn't listen. They make their recommendation, but the government doesn't listen, then nothing happens."*
>
> —NGO staff members

> *"Are we having sufficient impact? Not sufficient impact, but some impact. Definitely it's having some impact. The money is coming in to fund pilots to provide evidence, which is good, to fund areas where there are gaps....Our money is for catalytic action, that's what it should be for. It's happening, but with lots of challenges, because the coordination is missing."*
>
> —UN staff member

> *"UN agencies don't really do much in China; they're mostly just worried about their own jobs and positions, and are doing very little to promote treatment scale-up in China."*
>
> —PLWHA/NGO staff member

The Global Fund

China's Global Fund grants all appear — on the surface at least — to be implemented relatively smoothly, and none of them are considered "at risk" by the Fund. Global Fund funding is a major part of China's AIDS control budget, with more than US$200 million approved in rounds 3, 4, 5, and 6 (all of which are being implemented through the Chinese CDC). Though the grants are not "at risk," serious questions remain about the capacity of staff on the ground (in particular at the province level and below) to effectively use the funds and achieve real impact. The vast majority of money goes to government agencies with serious human resource and capacity limitations. Because there is little or no independent monitoring of actual implementation, and because local government officials are extremely skilled at presenting the desired results (regardless of whether those results were really achieved) to central government officials, there are many doubts about the real impact of these programs.

China's Global Fund grants are primarily concentrating on prevention rather than treatment, in part because all ART is already paid for by the government. There is also very little treatment expertise among CCM members, and an apparent unwillingness to address treatment-related issues. The functioning of the CCM is very high-level and is seen by those in the provinces as distant and unclear.

> *"So much money is spent by the Global Fund in China…. What is it all spent on? How much is actually spent on PLWHA? Many of the staff in the project offices are young and inexperienced, but they're hired because they speak English. They don't even understand AIDS treatment."*
>
> —NGO staff member

ADDITIONAL CONSIDERATIONS

Hukou (residency registration) system

All Chinese have their residency registered in a "hukou" (family registration) system, and perhaps 20% of people actually live outside their "home" areas. Under the free ART program, PLWHA can only access ARV therapy in their "home" area, creating a major barrier for many people. (Sex workers, IDUs, and MSM are all relatively mobile.) In some cases, doctors or patient groups will negotiate to send ARVs across the country, but this is difficult to arrange and in most cases people simply do not have access to treatment.

Drug resistance

The success or failure of an ART program can be seen in the rate of drug resistance that develops. In China, despite ARV therapy only being available during the past four years, there are already many reports of treatment failure and ARV resistance. Because there is no second-line therapy available at present, it is critical to preserve the efficacy of the first-line regimen (currently 3TC+d4T+NVP or 3TC+AZT+NVP). While the government has been conducting its own studies on drug resistance, the results of those studies have not been made public. Instead, an indication of the problem can be gleaned from a number of smaller local prevalence studies:

- Guangdong: 20% drug resistance rate (one treatment site with less than 4 years of treatment history) [Source: local treatment activist].
- Guangxi: One treatment site lost over 30% of patients on ART in less than 3 years [Source: local treatment activist].
- Hubei government treatment site: Only 70 patients remained on treatment (of the initial 150) after one year. *The other 80 had failed treatment or died*. [Source: international NGO]
- Drug resistance rate in a group of Henan villages: 13% to 20% [Source: local treatment activist].
- Rates of resistance: over 50% in some areas [Source: international NGO and China CDC researcher].

Research

As a developing country with a relatively low degree of protection for patient rights, China is host to a fair amount of medical research. Because China's AIDS treatment program does not include funding for CD4, viral load, and other tests, local caregivers often find a way to use these research programs to provide services (especially expensive ones like viral load tests) to their patients. Unfortunately, such research programs can also complicate and distort the care provided, and health facilities participating in such research also receive funds –- and thus have a vested interest in keeping the patients within their own facility even if it is not in the best interest of the patient. In many instances, PLWHA from around the country report that they are not started on ARVs even if their condition might warrant it because they are still participating in a drug trial or other research project. At the national level, the Chinese CDC staff are under pressure to publish their own research articles, and data from national AIDS treatment and control efforts are protected carefully, and often indefinitely, until it is used for such purposes. In addition, operational research funding is available from many foreign governments — e.g., the CDC and National Institutes of Health in the United States — but the research agenda in China is definitely not framed in the interests of patients. Rather, it is driven very much in terms of what grants are available from different countries or organizations.

> *"It disgusts me that people come over and say, 'We have a grant for this' and the China CDC has to run around and prepare a plan. They should be helping with the Chinese agenda. We should say, 'No, go away –- what can you do for China?" The Americans, the Japanese, the French -– none of them are coming in and addressing the country's needs. And where is WHO in all this? WHO has a policy on innovation and public health, but what are they doing on this; where are they in China?"*
>
> —NGO staff member

Counselling

> *"In China, only health worker staff are trained as counsellors, and it tends to be doctors. Do they have time to counsel? There needs to be a policy decision that counsellors for HIV testing or ARV adherence do not have to be health workers. It can be a 'lay' person; it can be anyone who has training and the interest."*
>
> —UN staff member

Doctor training

Many thousands of Chinese medical staff have been trained to work on AIDS treatment, but there are only a handful of skilled clinicians actually working in this field. This is a major problem for the scale-up of ARV therapy, but also for the survival of PLWHA once they are on ART. The lack of skilled caregivers is due to a number of factors:

- Much of the training is superficial, only consists of a one or two-day seminar, and does not include any hands-on training (though there are some smaller, local trainings that are more effective and systematic, such as in Guangzhou's No.8 hospital and Beijing's You'an Hospital.)
- As CDC or hospital "leaders" make training trips into a "junket," training often does not reach the front-line medical staff who are seeing patients and have the greatest need for advanced treatment skills.
- Most of the training is of big city doctors, while much of the need is for rural and small town doctors.
- Widespread stigma against PLWHA means that many doctors are not actually willing to treat HIV/AIDS patients.
- The limited income to be made through HIV/AIDS treatment is a serious disincentive for medical staff, most of whom are under pressure from their hospitals to sell more medicine and tests in order to increase their department's "profitability".
- China's highly commercialized and profit-driven medical system leads to the abuse of HIV/AIDS funding and depresses the motivation of doctors working on HIV/AIDS.

> *"The problem is that the doctors actually leave their jobs to participate in this; they actually lose money by coming. Their salaries are not enough in these hospitals, so they do a lot of private practice on the side…but the government can't really compensate them because nobody wants to talk about their 'private' salaries."*
>
> —Medical staff member

Information control

It is important to note that the government keeps very tight control over information about HIV and AIDS, and maintains a firm "party line" about statistics, epidemiologic data, and any other information that might be cause for criticism. This is possible because the government controls the collection, analysis, and release of such information. An example is the December 2005 re-assessment of the total number of people living with HIV in China, which yielded a reduction of nearly 200,000 people. This included a likely significant underestimation of both the size of the MSM population in China (estimated at 5 to10 million) and the infection rate among MSM (estimated at 1.35%). In reality, numerous surveys have shown the HIV prevalence among gay men in Chinese cities to be between 3% and 5%, with a recent survey in Chongqing reporting a 12% infection rate.

This type of "control" culture also creates barriers for NGOs working to support the free ART program by providing treatment education, counselling, and adherence follow-up and support. The medical sectors do not allow these groups to access a patient's basic treatment information such as CD4, liver function, viral load, etc., even if the patient gives his or her consent to share this information.

Recommendations

- **Government needs to speed up drug registration, including second-line drugs, fixed-dose combinations, TB medicines, and paediatric formulations**
- **Government should employ flexibilities in TRIPS to import affordable drugs**
- **Free treatment package should include treatment for OIs and CD4, liver function, and other necessary tests. Initiation of ARV therapy should not depend on confirmatory Western blot testing**
- **Government and international donors should expand funding for civil society organizations that provide support to PLWHA**
- **Treatment facilities should increase hands-on training for doctors providing HIV care and the government should create incentives for doctors to treat PLWHA**
- **National and local governments should create a system to provide treatment to people living outside their "registered" area**

RECOMMENDATIONS

1. Drug registration must be sped up, and new medicines (including fixed-dose combinations of both ARVs and TB medicines, paediatric formulations of ARVs and second-line ARVs) must be made available as soon as possible. WHO and other international agencies should push the Chinese government to act on this, and should consider making their own HIV/AIDS program assistance contingent on progress in this regard.
2. China should utilize flexibility within the TRIPS trade agreement to import affordable versions of efavirenz and other medicines, or to produce generic versions locally. WHO and other international agencies must openly support these activities.
3. Government should adopt "alternative testing criteria" that do not require the Western blot confirmation test to start ARV therapy, or else should make the test free for all patients. Other diagnostic protocols (such as a combination rapid test + ELISA + clinical assessment) exist, but they are not used. WHO and other international agencies should lobby harder for expanded diagnostic criteria, and should provide evidence that alternative algorithms are equally reliable.
4. Treatment for common and inexpensive OIs should be included in the free treatment package, and information about free or reduced-cost treatment must be distributed to local communities.
5. All required tests (CD4, liver function, etc.) should be included in the free treatment package. The cost of this would be nominal in comparison with the cost of ARVs already purchased with government funds, and providing these tests would improve the chance that those already on ARVs remain stable and stay on treatment.
6. Government and/or international agencies must increase funding and support for independent civil society organizations (especially PLWHA groups) to provide support, counselling, and other care services to those on ARV therapy. Local CDCs and hospitals should be required to allow these groups to function independently and provide them with facilities and/or funding.
7. National and local treatment facilities should increase practical, hands-on doctor training, and decrease the amount of didactic, theoretical classroom training on HIV/AIDS treatment.
8. National authorities should create an incentive system for front-line doctors to treat HIV/AIDS patients in order to reduce the pressure on doctors to be "financially viable" within medical institutions (i.e., to sell their quota of medicines) even though they are providing free ARV therapy.
9. National and local governments must create a system to provide ARV therapy to people not living within their "registered" area, and to people migrating from one area to another. International agencies should help the government to create a "smart card" or similar system that allows delivery of medical care and free ARVs while also ensuring the protection of patient identities.

MALAWI

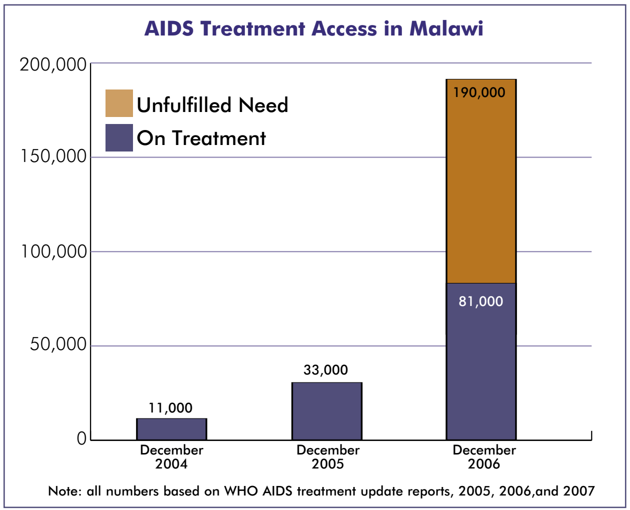
By Lot Nyirenda, Ireen Namakhoma, Victor Kamanga, Beatrice Chirwa, Isaac Msukwa, Eddie Banda, Dickeins Kolondo, Deidre Madise, Davie Nyirongo, Martha Kwataine, and Grace Bongololo

This paper is a result of research conducted for the International Treatment Preparedness Coalition (ITPC) on the status of access to ART in Malawi. The research was conducted through collaboration amongst four institutions: Research for Equity and Community Health (REACH) Trust, Malawi Network of People Living with HIV/AIDS (MANET+), National Association for People Living with HIV/AIDS (NAPHAM), and Malawi Health Equity Network (MHEN).

The study team would like to thank all respondents who offered their time to answer questions. The team is also grateful to individuals who provided documents for review. Your commitment is a great contribution to efforts aimed at ensuring universal access to AIDS treatment in Malawi and across the globe.

RESEARCH METHODOLOGY

Data for the study was collected using a template formulated by ITPC. Each researcher was assigned a list of respondents to interview and documents to review. A total of four focus group discussions were conducted with PLWHA in rural Lilongwe. The discussions involved a group of women on ART and a group of women not on ART, as well as a group of men on ART and a group of men not on ART. Using the template,


AIDS Treatment Access in Malawi

Note: all numbers based on WHO AIDS treatment update reports, 2005, 2006,and 2007

- **Significant progress made in scaling up ART delivery**
- **Acute shortage of health care workers to provide HIV care, particularly in rural areas**
- **Many PLWHA forced to travel long distances and wait in long queues to receive treatment**
- **Relatively small percentage of population has access to HIV testing**
- **No specialized services to meet the unique needs of marginalised groups**
- **Mother-to-child transmission is the second most common mode of HIV transmission, but PMTCT services not widely accessible**
- **PLWHA are commonly charged for CD4 tests; and second-line drugs, although provided for free, are not widely available, making them inaccessible**
- **Drugs to treat HIV-related OIs are not available in many health facilities**
- **TB and HIV services are not well integrated and fewer than half of TB patients are tested for HIV on an annual basis**
- **Inadequate funding from national government creates a worrisome over-reliance on donor support**

researchers interviewed key informants living with HIV/AIDS, as well as officials from the Ministry of Health HIV/AIDS Unit, the Tuberculosis Control Programme, a pharmaceutical company, the Christian Health Association of Malawi, and several PLWHA organizations. Interviews were also conducted with health workers in eight districts of Malawi (two districts from the north, three in the centre, and three in the south).[1] Four meetings were held at which the research team discussed the study. Following the interviews and review of documents, Lot Nyirenda synthesized the findings with the assistance of Grace Bongololo. The draft was circulated to all members for comments. Finally, Lot Nyirenda fine-tuned the paper before submitting it to ITPC.

Study Focus

The study's focus was on the challenges to universal access to AIDS treatment, lessons learnt in the delivery of AIDS treatment[2], and recommendations to the local, national, and international community on what needs to be done in order for universal access to become a reality in Malawi.

BACKGROUND

Malawi is a small landlocked country in the eastern part of sub-Saharan Africa with a population of about 12 million people and a GNP of US$200 per capita. The country has been severely hit by the HIV/AIDS pandemic, with 14% of the population living with HIV/AIDS.[3] AIDS is the leading cause of death amongst people age 15 to 49 in Malawi.[4] The Ministry of Health has estimated that 170,000 people may need ART at any given time.[5] With support from the Global Fund, ART has been provided for free at the point of delivery since June 2004. Malawi's goal of universal access is that adopted by the G8 countries in July 2005 – the same goal that has been adopted by WHO and UNAIDS. The goal for Malawi is to have up to 250,000 people ever started on ART by 2010, representing a 50% "universal access" rate.[6]

Significant strides have been made in scaling up ART in Malawi. The number of people on ART was around 3,000 in 2003; 13,000 in 2004; 40,000 in 2005; and 100,000 in March 2007. The number of sites offering ART was 9 in 2003; 24 in

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[1] This was possible because during the study period, two members of the research team, Lot Nyirenda and Grace Bongololo, were also involved in collecting data for a study involving health workers in Malawi. Some of the issues investigated in the two studies were similar.

[2] AIDS treatment in this paper refers to ART, HIV Testing and Counseling, PMTCT, and elements of the health system needed to provide such services.

[3] MoH and NAC (2005)

[4] Ibid.

[5] MoH (2004) Treatment of AIDS: The two year plan to scale up Antiretroviral Therapy in Malawi 2004 – 2005 Ministry of Health, February 2004.

[6] MoH (2006) Treatment of AIDS: guidelines for the use of ARV therapy in Malawi, 2nd Edition

2004; 60 in 2005; and 103 in 2006. Of the 81,821 people ever started on ART by December 2006, 39% were male, 61% were female, and 7% were children age 14 and below. An analysis of outcomes of people ever started on ART showed that 70% of the 81,821 were alive and on ART, 11% had died, 9% were lost to follow-up, 9% had transferred out to another facility (and were presumably alive), and ~1% had stopped treatment. Of the 57,356 patients alive and on ART, there were about 97% on the first-line regimen and about 3% on the alternative first-line regimen, with 148 people using a second-line regimen. The Ministry of Health HIV/AIDS Unit data show that TB is the leading cause of death amongst PLWHA, followed by oesophageal candidiasis and Kaposi's sarcoma. The data also show that 30% of people who died while on ART did so during the first three months of treatment.[7]

CHALLENGES TO SCALING UP AIDS TREATMENT IN MALAWI

Although Malawi has made progress in rolling out access to AIDS treatment, a number of challenges remain.[8] The major challenges are human resources shortages, long distances for patients to travel to the nearest health facilities, an enormous shortfall in the PMTCT program, shortages of drugs for OIs, poor integration of HIV and TB services, and over-reliance on donors. These and other challenges are discussed below.

Shortage of health workers

HIV/AIDS has exerted pressure on the already weak health system in Malawi. Hospital-based studies have shown that 40% of all in-patient admissions are due to HIV/AIDS-related conditions.[9] The challenges posed by HIV/AIDS are magnified by the decreasing number of health workers. Vacancy rates are high, with an average vacancy rate of around 50% for all professional health worker posts sector-wide.[10] The lack of qualified health workers is further exacerbated by non-responsive recruitment and deployment processes and bottlenecks, the continued drift of health workers to NGOs and research institutions, and overseas migration of highly qualified nurses (approximately 100 per year) to the UK and other countries.[11] Of the 28,600 established posts in the health sector comprising the Ministry of Health and Christian Health Association of Malawi, as of the year 2005, 17,800 or 62% are filled, leaving 10,800 (38%) vacant, mainly in the service provider/professional health worker categories.[12]

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[7] Routine data from HIV/AIDS Unit, Malawi Ministry of Health, December, 2005

[8] Panos (2006), Keeping the promise: a study of progress in implementing the UNGASS declaration of commitment on HIV/AIDS in Malawi.

[9] DHRMD and UNDP, July 2003; cited in Africa Human Development Report, 2005.

[10] Babu Seshu V.V.R (2006) Tracking of Human resources for health in Malawi, Ministry of Health report (unpublished), Lilongwe, Malawi.

[11] Ibid.

[12] Malawi 6 year Emergency Human Resource for Health programme running from 2004 to 2010.

The distribution of available health personnel favours the more urban areas, with half of all of doctors working in the four tertiary hospitals of the country.

Staff shortages have a negative impact on patients who have reported poor staff attitudes[13] and long waiting times[14] as barriers faced in government health facilities. These staff shortages are compromising the quality and availability of HIV/ AIDS care in Malawi.

According to a new MSF report titled *Help Wanted* (2007), a medical assistant in Thyolo district of Malawi may need to see up to 200 patients per day, far too many to ensure quality care. Though it is known that most health workers leave the health sector due to poor working conditions including poor salaries, the wage bill ceiling imposed by the International Monetary Fund and World Bank deters government from recruiting more health workers to meet the increased demand for ART. The shortage of health workers is critical in rural areas[15] due to poor infrastructure and unwillingness of health workers to work in the rural areas, among other reasons. This has led to inequalities in the provision of health services in general and AIDS treatment in particular.[16]

Long distances to nearest health facilities and long waiting time

Most Malawians, especially those in rural areas have problems accessing health services in general due to long distances to health facilities. Considering that ART is not provided at all health facilities, most clients have to travel long distances to access the treatment. Since the demand for ART is outstripping supply, there are long queues and long waiting times leading to congestion in some health facilities. Focus group discussions with some people on ART revealed that, in some cases, patients fight on the queues as each one wants to be served first. The equity in access to ART policy by the Ministry of Health advises that people should be served on a first come, first served basis. Although there are exceptions to the policy, it implies that people who are strong and live close to the facilities will be served first.[17] [18]

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[13] MANET+ (2003), Voices for equality and dignity: qualitative research on stigma and discrimination issues as they affect PLWHA in Malawi, Lilongwe, Malawi: MANET .

[14] Nyirenda L., Bongololo G., Fitzgerald M., Bwirire D., Theobald S., Makwiza I., (2006),Barriers to accessing and adhering to antiretroviral therapy in Thyolo district, a research report.

[15] According to the Malawi Demographic Health Survey (2004) about 85% of Malawians live in rural areas.

[16] Makwiza I; Nyirenda L; Bongololo G; Loewenson R.., Theobald S., (2005) 'EQUINET Discussion Paper 24: Monitoring equity and health systems in the provision of Antiretroviral Therapy (ART): Malawi Country report', EQUINET: Harare: Zimbabwe.

[17] Panos (2006), Keeping the promise: a study of progress in implementing the UNGASS declaration of commitment on HIV/AIDS in Malawi.

[18] Nyirenda L., Bongololo G., Fitzgerald M., Bwirire D., Theobald S., Makwiza I., (2006),Barriers to accessing and adhering to antiretroviral therapy in Thyolo district, a research report.

The ART sites have been given ceilings regarding the number of people to put on ART per month.[19] While reasons given for the ceilings are plausible, these ceilings have in some cases condemned people to death as reported by some NAPHAM support groups. There are several reported cases of people who have died while on the waiting list.[20] Some people have to wait for three months or more before being put on ART. These are people who are already certified eligible for ART, which means that their immunity is already low. The delays have led to people starting treatment too late to benefit from ARVs. In order to be served first, there are cases (though isolated) of people spending nights at some health facilities in order to be first on the queue the next day. In such cases, people sleep on the floor without proper shelter and food and thus are subject to further ailments. There have been cases of husbands or wives sleeping on the queue on behalf of their spouses who are too weak to queue.[21]

The long distances and long waiting times have a strong bearing on adherence as well as on access to ART. In the absence of socio-psychological and economic support, some people have dropped out of treatment while others have not even attempted to start, as the long distances mean costs in terms of transport, food, accommodations, and continuous encouragement from close family members. Such challenges are more pronounced for women than they are for men.[22] The following quotes illustrate the point:

> *"Imagine this is just my first month but I'm already tired. I'm supposed to foot transport costs for two people whenever we come here [one being his guardian]. Now I wonder that if things will continue to be like this in future am I going to adhere to the drugs? I'm saying this based on the instructions attached to these drugs – that one has to take them for life, without skipping scheduled times. Thus one may fail to adhere to the drug due to transport costs."*
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> —Man on ART, Thyolo district

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[19] These ceilings are based on TB burden per district, capacity of the institution- especially in terms of human resources- to deliver and population of the catchment area in question

[20] Panos (2006), Keeping the promise: a study of progress in implementing the UNGASS declaration of commitment on HIV/AIDS in Malawi.

[21] Interviews with health workers at Kamuzu Central Hospital and guardians of patients accessing ART

[22] Nyirenda L., Makwiza I., Bongololo G., Theobald S., (2006) "A gender perspective on HIV treatment in Malawi: A multi-method approach" in Gender and Development, OXFAM GB; Routledge: UK, Vol 14 No 1, pp 69-79.

> *"If my brothers were helpful I could have gone to the hospital so that the doctors could see if my condition was due to an allergy with the ARV drugs or not and help me, as the health personnel had insisted that I was supposed to go with my guardian to the hospital. Now considering the way my brothers were reluctant to help me I did not know how I could make it and I failed to go. I feel transport is the major problem. In my case I stopped taking ARV in August 2004."*
>
> —Widow age 42, who had defaulted[23] from ARV treatment, Thyolo district[24]

It can be said therefore that although Malawi has made tremendous strides in rolling out ART, many people who were supposed to be put on ART are left out, while some of those who started treatment are dropping out. Thus programs aimed at ensuring adherence to ART should be enhanced to avoid early resistance to the first-line drugs. Second-line drugs are very expensive. If government and partners are failing to give out first-line ARVs to all people that need the drugs—having defined universal access as 50%—what will happen if a majority of people require second-line drugs which are even more expensive than first-line drugs?

HIV testing and counselling in need of great attention

Access to ART cannot happen in the absence of HIV testing and counselling. Apart from acting as a conduit to ART, HIV testing and counselling (HTC) is also a proven prevention method. While some progress has been made in moving the HTC program forward, an enormous shortfall remains, with only 15% to 20% of the sexually active population going for testing.[25] The 2004 Demographic Health Survey indicates that about 83% of the population does not know their serostatus either because they have never gone for testing or they did not go back for their results. Testing sites are also concentrated in the urban areas and district headquarters (*bomas*). There is also a shortage of qualified counsellors. Though a campaign has been mounted urging people to utilize HIV counselling and testing, there is an acute shortage of test kits across the country. These challenges require swift attention from the government and its partners.

Difficult to determine access to AIDS treatment by marginalised groups

The national HIV and AIDS policy commits itself to providing ART services without discrimination.[26] There are no special ART services for marginalised groups such

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[23] According to Malawi ART guidelines, one is considered to have defaulted from treatment if they have not taken their ARVs for three consecutive months.-

[24] Nyirenda L., Bongololo G., Fitzgerald M., Bwirire D., Theobald S., Makwiza I., (2006),Barriers to accessing and adhering to antiretroviral therapy in Thyolo district, a research report.

[25] Presentation made by Kerita Kamoto, Head of HIV/AIDS Unit, Ministry of Health, Malawi at the National PMTCT Conference, April, 2007, Lilongwe, Malawi.

[26] NAC (2003) National HIV and AIDS Policy: a call to renewed action.

as sex workers, transgendered persons, and drug users. In Malawi, it is illegal to live on earnings of prostitution, wholly or in part. When sex workers are arrested by the police, they are charged as rogues and vagabonds, and these are regarded as misdemeanours. It is also illegal to run a brothel in Malawi. Homosexuality is also illegal. Data monitoring tools do not disaggregate patients on ART according to these demographic descriptions, therefore it is difficult to say for sure if the ART program is adequately treating people who can be described as marginalised.

It is believed that the way services are provided (one size fits all) serves the needs of all groups of people whether regarded as marginalised or not. It can be said however that groups such as sex workers, who are mostly and almost entirely female, are more likely to face problems such as stigma at sites where they queue up with the same clients they serve in their trade. As for men having sex with men and women having sex with women as well as transgenders, their activities are done entirely undercover in Malawi. It can be said therefore that it is not known whether or not they face any challenges to accessing ART as it cannot be ascertained whether or not anyone in the health facilities knows about their sexual orientation.[27]

Enormous shortfalls in the PMTCT program

Mother-to-child transmission of HIV is the second most common mode of transmission in Malawi. Without any intervention, about 16% to 35% of the babies born to HIV-infected mothers will acquire the virus. Of these HIV-infected babies, the majority (65%) are infected during labour and delivery, which can be reduced by appropriate preventive interventions.[28] In Malawi, a program for PMTCT started in 1999-2001 by NGOs. The program is very important to Malawi because of the high rate of HIV transmission in women of reproductive age. For instance, 60% of new infections occur among girls age 15 to 24. In addition, there is high fertility rate of 6.3 children per woman in Malawi.[29]

The goal for PMTCT in Malawi is to reduce incidence of HIV among infants by 50% by 2010. Although such a goal already condemns the remaining 50%, it is very unlikely that the proposed goal will be met considering the progress so far. PMTCT services are currently provided at only 119 of 542 health facilities. Uptake of HTC amongst mothers is worrisome, with only 50,000 out of 125,000 in need of the services accessing HTC. There is also weak linkage with other programs such as family planning, integrated management of child illnesses, and referral to HIV care

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[27] To the knowledge of the research team behind this study, no one has come in the open to declare their minority sexual orientation in Malawi.

[28] MoH (2004) prevention of mother to child transmission of HIV in Malawi: training manual for health workers, users guide.

[29] Presentation made by Kerita Kamoto, Head of HIV/AIDS Unit, Ministry of Health, Malawi at the National PMTCT Conference, April, 2007, Lilongwe, Malawi.

and support services. For instance, the referral of women from the antenatal clinic to the ART clinic can result in some women falling out of care during the process, considering there is no follow-up of the women. Correcting this situation requires horizontal integration of the services to ensure that every woman eligible for treatment is accessing it.

There is also lack of space in maternal and child health clinics, and difficulties in supply management of drugs and supplies persist. Besides, the monitoring system is weak and there is poor mother-infant follow-up to 18 months. Obstetric care is also poor in Malawi.[30]

Most pregnant women visit the clinic at least once in their pregnancy to access antenatal services. However, research has shown that around 40% of pregnant women do not deliver at the health facilities. Children born to these women are therefore ruled out of PMTCT services. Moreover, not all pregnant women who test positive are accessing nevirapine prophylaxis. Of 6,069 HIV-positive pregnant women in 2004, only 2,719 (44.8%) received nevirapine. However, in 2005, of 7,052 HIV-positive pregnant women, 5,062 (71.7%) received nevirapine.[31]

Statistics show that by end of 2006, 8% of women ever started on ART began as a result of referral from the PMTCT program.[32]

The PMTCT program has also been faced with the challenge of obtaining informed consent from women before having them tested for HIV. There have been reports of women who were forced to test before accessing other antenatal services. This can lead to some women shunning the reproductive health services altogether, thereby putting their lives as well as the lives of their babies in danger, in a country where 984 women per 100,000 die due to pregnancy-related complications.

Some women do not go back to get their HIV test results. This defeats the purpose of HIV testing as such: women do not know and therefore cannot act on their HIV status. Women have been beaten up or chased away by their husbands after they were found HIV positive. The situation for HIV-positive pregnant women must therefore be treated as an emergency and the PMTCT program declared an emergency response.[33]

Children (age 14 and under) make up 7% of people accessing ART. HIV prevalence is 11% among adults and 2% among children. One could argue that the disparity in ART treatment access in Malawi between adults and children is representative of

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[30] Ibid.

[31] PMTCT status report (2006), Ministry of Health, Lilongwe, Malawi.

[32] Ministry of Health report (2006), Antiretroviral Therapy in Malawi up to 30th September, 2006, Lilongwe, Malawi.

[33] TB was declared an emergency in Malawi on 27th of March, 2007. This was meant to draw world attention to the situation with a possible increase in funding towards the cause.

the prevalence for the two age groups. But until recently, there has been no ART in syrup form for children in Malawi. As an imprecise alternative, drugs meant for adults were split to make smaller doses. Thus, the quality of treatment administered to children has been compromised. The syrup is now in use but is not widely available. Efforts are underway to provide specialist services (including HIV/AIDS care) to children, such as through the Baylor Clinic in Lilongwe. But this facility cannot serve children who are unable to go there. Deliberate efforts should therefore be made to ensure that high quality ART is provided to all children in need.

Cost of CD4 counts, viral load testing, and drugs for OIs

In Malawi ART has been provided free at the point of delivery in all public as well as Christian Health Association of Malawi (CHAM) health facilities since June 2004. However, some health facilities charge fees for certain tests. As of December 2006 there were only 17 health facilities (17% of the total) with CD4 count machines in the country.[34] Shortage of lab staff is another major challenge to offering and scaling up this service. Viral load testing is said to be done only in research centres.

The standardised second-line drug combinations for Malawi include zidovudine, lamivudine, tenofovir, and lopinavir/ritonavir for adults; and didanosine, abacavir, and lopinavir/ritonavir for children. These drugs cost US$80 per patient per month.[35] Interviews with PLWHA on treatment reveal that they have problems in accessing second-line drugs. The HIV Unit[36] of the Ministry of Health points out that second-line drugs are only available in central hospitals as the administration of such drugs requires more expertise. Should second-line ART remain centralised as it is now, it is clear that many people will face acute problems in accessing the treatment. As of December 2006, 148 people were ever started on second-line drugs. It cannot be said that these were the only people in need of second-line treatment.

Medications to prevent and treat HIV-related OIs are not always available in health facilities. In-depth interviews and focus group discussions with PLWHA revealed that they face enormous challenges when they need to access drugs for OIs. At present, there is an acute shortage of cotrimoxazole in public facilities, and drugs available in CHAM hospitals are not free. Unlike ARV drugs, which are procured through a strong supply chain, procurement of other HIV/AIDS related commodities such as drugs for OIs, lacks a comprehensive and coordinated approach, and this has translated into a fragmented supply chain for these services.[37] This situation requires serious attention from the government.

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[34] MoH (2007) HIV/AIDS Unit updates on ART access in Malawi.

[35] The cost for first-line drugs is US$18 per patient per month.

[36] Interview with Mr. Makombe, HIV Unit, Malawi Ministry of Health

[37] Gilks C., Blose S., Carpenter B., Coutinho A., Scott F., Reuben G.,Luo C., McCoy D., Pazvakambwa B.(2006), Report of the Malawi ART programme External Review Team , Ministry of Health Malawi.

Poor integration of HIV/AIDS services with TB and other services

Malawi is one of the countries trying to integrate TB and HIV services. Research has shown that 70% of TB patients have HIV.[38] Despite this high co-infection rate, less than 50% of TB patients are tested for HIV on an annual basis, and only 16% of all patients ever started on ART are referred from TB clinics.[39] These patients have the increased challenge of adhering to both drugs, because of the pill burden and the increased side effects.[40] Not all HIV-positive clients are tested for TB, and not all TB patients are referred for HIV testing and counselling. TB and HIV counsellors have different training, and as such most HIV counsellors do not know much about TB and vice versa. Integration of TB and HIV services should therefore begin with training the counsellors. Efforts have been made by Lighthouse in Lilongwe to provided TB and HIV services under one roof. This facility was officially opened by the Malawian President Dr. Bingu wa Mutharika early this year. Just like the Baylor Clinic, Lighthouse is located in urban Lilongwe, making the HIV/TB services inaccessible by most people in the country.

Cotrimoxazole preventive therapy (CPT) is available to over 90% of people living with HIV. However, CPT has been compromised by stock-outs in most health facilities when patients are told to buy it in pharmacies. This is a challenge especially to the poor who rely on CPT to fight off OIs but cannot afford to buy the drugs.

There are no mechanisms in place for joint surveillance and planning for HIV/TB. With funding from the CDC, plans are underway to come up with a strategic plan on how to implement HIV/TB scale-up programs in Malawi. Furthermore, there is no current plan aimed at reducing the burden of HIV among TB patients, and there is no active case finding of TB among HIV patients.[41] [42]

Over-reliance on donor funding for AIDS treatment

The bulk of funding for HIV/AIDS activities in Malawi is from donors. The Global Fund provides 51.6%, followed by a pool of funding from the World Bank, the

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[38] Kwanjana J.H., Harries A. D., Gausi F., Nyangulu D.S., Salaniponi F.M.L., (2001), TB-HIV sero-prevalence in patients with TB in Malawi, Malawi medical journal 13:7-10.

[39] According to WHO clinical staging, having TB qualifies an HIV-positive person to be put on ART.

[40] Chimzizi, R. (2006), TB patients' barriers to antiretroviral therapy (ART) adherence in Lilongwe, Malawi: a qualitative study. Masters of Community Health (MCommH) degree submitted to the university of Liverpool school of Tropical Medicine (LSTM), International Health Research Group (unpublished).

[41] Active case finding is the process by which individuals who are considered to be at risk of a disease (HIV positive persons in this case) are sought out and screened for that disease. This is in contrast to passive case finding in which those same individuals bring themselves forward to seek medical care when they become symptomatic.

[42] Interview with Rhehad Chimzizi, TB/HIV Officer, TB Control Programme, Malawi.

United Kingdom's Department for International Development, the Norwegian Agency for Development Cooperation (NORAD), and the Canadian International Development Agency (CIDA). The Malawi government contributes 2.4%.[43] The current Global Fund grant runs to September 2008. The government has submitted another proposal, which it is hoped, will be funded.[44] The Clinton Foundation, currently supporting some paediatric treatment in Malawi, is said to be another potential funder for ART in the country. Without being 'overhypothetical', it can be said that, if donors withdrew funding today, almost all activities related to HIV/AIDS would grind to a halt. Government's efforts to encourage people to go for HTC should be supported with adequate funding to ensure that all those eligible for ART would have access to the treatment. This situation calls for the need to seriously think about channelling locally generated resources towards the health sector in general and AIDS treatment in particular. Efforts must also be made by government to meet the Abuja Declaration of allocating 15% of its budget towards the health sector.

In our study, development partners were noted to be helpful. They have worked hard to support initiatives on treatment scale-up and other HIV-related services. They have worked effectively with the government, civil society, and others to improve treatment delivery. However, there is a need for them implement policies that would empower poor African countries to become self-reliant.[45] Their procurement process and proposed development procedures were seen as cumbersome, delaying implementation of activities. In addition, the bureaucracies attached to Global Fund money disbursed by NAC were seen as one of the factors leading to under-spending of funds in the context of unmet need for ART. There is a need for these multilateral organizations to work with their counterparts at all levels from the zonal to the district level to improve the capacity of the local people to take responsibility over their own lives.

LESSONS LEARNT

- Gradual enrolment of clients on ART ensures that stocks of drugs and supplies do not run out and that a sufficient number of health workers are available to cope with the current number of people on ART. But this is problematic in a country like Malawi where many people requiring ART are not yet accessing treatment. It can only work in countries where supply is exceeding demand for services. Thus, universal access cannot be achieved with gradual enrolment of clients on ART in countries where demand for ART outstrips resources.

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[43] The Malawi government also spends money on HIV/AIDS when caring for patients admitted to hospital wards suffering from HIV/AIDS-related illness. Some money is also spent on human resources and infrastructure, among other expenditures.

[44] Malawi has been put on a program of Global Fund Rolling Continuation Channel (RCC). This entails that after September 2008, there is hope that ART will still be funded in Malawi.

[45] Mavuto Bamusi, Director of Programmes, Malawi Economic Justice Network (MEJN) quoted in The Nation, June 1st, 2007.

- Uninterrupted supply of ARVs ensures that people's lives are not endangered. This is made possible by ensuring that those entrusted with procurement of ARVs –- UNICEF[46] in the case of Malawi -– have the capacity to do so. But mechanisms should be put in place to ensure the sustainability of supplies.

- ARVs can be rolled out even in a very low-income country like Malawi using a public health approach. This entails keeping the process of enrolling clients on ART simple. This means that most patients are started on ART based on WHO clinical staging without performing rigorous laboratory investigations such as CD4 count or viral load measurements and liver function tests (LFTs). This has allowed Malawi to put many patients on ART within a short period of time, a rate recognized as one of the highest in the Southern African Development Community (SADC) region. However, the high figures may mean downgrading the quality of the service being provided. The challenge is to ensure that this clinical staging is conducted professionally.

- Involving the community in ensuring adherence to ART can help to avoid the development of resistant strains caused by defaulting from treatment. Centres of excellence in ART provision in Malawi such as Lighthouse in Lilongwe and Thyolo District Hospital have been characterized by strong home-based care programs where the community is involved in the strict follow-up of patients on ART to ensure adherence to the treatment.

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[46] UNICEF has been contracted by the government of Malawi to procure ARVs on behalf of the government. Meanwhile, it was hoped, the capacity of the central medical stores (CMS) would be built to take over from UNICEF. This capacity building, however, is likely to take longer than was anticipated, as the central medical stores are still swimming in troubled waters. The government has hired a consultant to sort out problems at the stores. But recurrent problems at the CMS show lack of seriousness by the government to build the capacity of the stores, considering that the CMS have been there for a long time and are very crucial to the health sector in Malawi.

Recommendations

- **The government should step up efforts to address the health care worker crisis by expanding training and retention programs and salary increases**
- **The IMF and World Bank should remove the wage ceiling for health care workers**
- **The government and partners should decentralize ARV provision, increase use of mobile clinics, expand task shifting, and ensure each district hospital has a CD4 count machine**
- **The government should ensure adequate availability of test kits and trained testing counselors**
- **The government should declare mother-to-child transmission to be an emergency in the country: Access to PMTCT should be greatly expanded by improving coordination among providers, renovating health clinics, and strengthening linkages to other health programs**
- **The government and partners must accelerate integration of TB and HIV services by training providers in handling both diseases**
- **Persistent stock-outs of cotrimoxazole (for HIV/TB co-infection) should be urgently addressed by the government and partners**
- **The government must dedicate increased domestic resources to the health sector**

RECOMMENDATIONS

Recommendations regarding health worker shortage

1. Government and partners should train more health workers. This will ensure that the effects of brain drain (both to internal and external opportunities) are not debilitating. The donor community such as the Global Fund and the World Bank should support such initiatives. This situation requires a long-term remedy.
2. In the short term, the Ministry of Health and the donor community should enhance programs aimed at retaining the existing health workers. Thus, salary top-ups for health workers should continue and measures should be put in place to ensure sustainability of the salary top-ups program. The Ministry of Health and its partners are planning to implement a program of providing other incentives to health workers in rural areas, which would include free electricity, water, and housing, among others. This program should move forward urgently and rural areas in most need should be prioritized.

3. The IMF and World Bank should seriously consider revising the wage bill ceiling for health workers. Donors should change their policies and start financing recurrent costs such as salaries. Unless this is done, the government's response will not be adequate to meet the need for treatment. Therefore, the IMF and World Bank should revise the wage bill ceiling for health workers by June 2008. The Medical Counsel of Malawi and Nurses Council of Malawi should participate in the revision.

Recommendations regarding long distances and long queues

4. Government and partners should decentralize ART provision further. This entails building new health facilities and ensuring that available facilities are adequately staffed. Therefore, government and partners should ensure that at least 300 health facilities are providing ART by June 2008.
5. Government and partners should enhance the use of mobile clinics for the provision of ART. Such clinics run by MSF in Thyolo and Chiradzulu have alleviated problems of travelling long distances to ART sites faced by people in the district. Government should therefore pilot the use of mobile clinics modelled on what is happening in Thyolo and Chiradzulu districts in at least three rural districts where health workers are not willing to stay and work. This should happen by February 2008.
6. Government and partners should enhance task shifting amongst health workers. Health workers of lower cadres should take on more tasks formerly performed by those of higher cadres.
7. Community involvement should be encouraged by government to take some pressure off the health workers. Apart from getting involved through home-based care groups, PLWHA on ART can act as expert patients/counsellors. This work would also provide a source of income for PLWHA.

Recommendations regarding HIV testing and counselling

8. Government and implementing partners should ensure a consistent and sustainable supply of test kits across the country especially in rural areas. Government and partners should therefore ensure that the problem of test kit stock-outs is resolved by December 2007.
9. Government and partners should train more counsellors and efforts should be made to take on as many PLWHA as counsellors as possible. While acting as a source of income for PLWHA, the general population will benefit from the lived experiences of PLWHA, thus moving counselling from a theoretical school to an embrace of a paradigm that encourages practicality.
10. Implementing partners should decentralize HTC to rural areas.

Recommendations regarding PMTCT

11. Government should ensure that there is coordination amongst partners implementing PMTCT in Malawi.
12. Government and its partners should train service providers in cross-competency skills.
13. Government and partners should enhance the renovation of maternal and child health clinics.
14. Government and implementing partners should strengthen the linkage of the PMTCT program with other programs such as STI, family planning, integrated management of child illnesses, and ART.
15. Government and partners should scale up the provision of PMTCT.
16. Government and implementing partners should actively involve men in PMTCT.
17. We recommend that PMTCT be declared as an emergency in Malawi, just as was the case with TB. This should be done by October 2007.

Recommendation on the cost of CD4 counts, viral load testing, and drugs for OIs

18. Government should ensure that at least each district hospital has a CD4 Count machine by December 2007.
19. Government should maintain/repair the available CD4 Count machines.
20. Government and partners should reduce stock-outs on drugs for OIs by 80% by December 2007.

Recommendations regarding integration of HIV/AIDS with TB and other services

21. Government and its partners should integrate the training of counsellors handling TB and HIV clients. This will ensure that meaningful referrals of clients are made to each of the services.
22. Government and its partners should speed up plans to set up joint surveillance of TB and HIV.
23. Government and its partners should treat the stock-outs of cotrimoxazole as a matter of urgency. Plans should be put in place to ensure that such stock-outs do not take place in future. Government and partners should therefore decrease the stock-outs by 80% by the end of 2007.

Recommendations regarding funding for AIDS treatment

24. Government should ensure that more resources are channelled to the health sector in general and to HIV/AIDS treatment in particular.
25. Creative ways of raising funds, such as through a fuel levy, should be seriously considered. Government and partners should start discussing a fuel levy for funding ART in earnest by October 2007 and implement it by June 2008.
26. Government should make clear what actions it will take if the Global Fund or other partners withdraw support for AIDS treatment in Malawi.

UGANDA

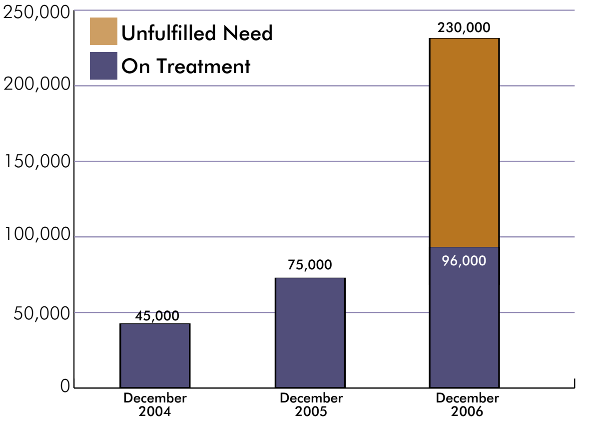
By Rosette Mutambi, Aaron Muhinda, Beatrice Were, Prima Kazoora, and Richard Hasunira

The HIV/AIDS epidemic in Uganda has gone through three broad phases. The first phase featured rapidly rising HIV prevalence (1982-1992), with antenatal HIV prevalence peaking between 25% and 30% in major urban areas. The second phase saw a significant decline in nationwide prevalence (1993-2000) from 18% to about 6% as a result of a highly successful public education campaign. The third phase (since 2000) has been characterised by stabilization in prevalence rates (6% to 7%). But fears are now growing that the country could be entering a new phase of resurging HIV rates, following official revelations of an increase in new infections in some parts of the country.

It is estimated that two million people in Uganda have been infected with HIV and that about half have died since the first HIV/AIDS case was diagnosed in 1982. The Ministry of Health's 2004/2005 National HIV Sero and Behavioural Survey estimated that almost one million people were living with HIV/AIDS: 6.4% of adults age 15 to 49 years, 0.7% of children under age 5, and 5.8% of older people (age 50 to 59). The Ministry of Health also estimates that in 2005 alone about 132,500 people were infected, while 91,000 lost their lives to HIV/AIDS-related illnesses.

Official statistics show that sex is the main channel of HIV transmission,

AIDS Treatment Access in Uganda



Note: all numbers based on WHO AIDS treatment update reports, 2005, 2006,and 2007

- **Free ARV access program has resulted in significant increases in treatment access**
- **New concerns about a resurgence in infection rates**
- **Demand for treatment continues to outstrip supply, and the gap is widening**
- **More PMTCT sites have opened, but uptake remains low and PMTCT services do not adequately address the pregnant woman's need for treatment**
- **HIV/TB co-infection is widespread, though access to TB services has increased. Travel distances, insufficient provider training, and inadequate community awareness limit program reach**
- **Severe financing shortfall and corruption undermine HIV service delivery**
- **Inadequate number of health care facilities and laboratories; medical equipment limited in supply**
- **Severe shortfall in doctors and counselors**

accounting for more than three-quarters of new infections, with infections within marriage contributing 42% (largely due to extramarital sex); commercial sex, 21%; and casual sex, 14%. Mother-to-child transmission accounts for 22% to 25% of new infections (Ministry of Health, 2005).

Objective of the study

This study was conducted to establish the status and trend of the national HIV/AIDS treatment effort and to identify specific barriers to ART treatment scale-up in Uganda.

Research methodology

Primary and secondary data from the Ministry of Health, Uganda AIDS Commission, UNAIDS, ART service providers, HIV/AIDS activists, and PLWHA were collected through personal interviews using the standard structured questionnaire for this study. The research team also reviewed existing literature and Internet resources to gather information presented and analyzed in this report.

- **Second-line treatment and drugs to treat OIs generally not available in public clinics**
- **Global Fund grants suspended in 2005 and 2006; restored last year following creation of new management structures**
- **PEPFAR is significantly contributing to ARV delivery and supporting a range of services, but better integration into existing health care structures and expanded programs to build sustainable local capacity are needed**
- **Economic deprivation undermines access to care due to fees for CD4 and viral load tests, OI treatments, and nutritional support**
- **Drug stock-outs are ongoing and drug supply chain is inefficient**
- **Stigma against PLWHA remains a significant issue**
- **Marginalised groups, including the disabled, face special challenges in accessing ART**

HIV/AIDS TREATMENT

Status of anti-retroviral treatment

There has been a significant increase in antiretroviral treatment delivery over the past few years, thanks to a free ARV program supported by the Global Fund, PEPFAR, and other donors. According to the Ministry of Health, 70,000 patients out of an estimate of 150,000 people in need of ART were accessing ARVs from 173 health facilities by June 2005. The latest estimates show that 85,000 PLWHA access ART from 220 centres. The Ministry estimates that the number of PLWHA who need ART reached 234,500 at the end of 2006.

Data from a parallel monitoring mechanism by the CDC also show an upward trend, albeit with a slightly different set of figures. The CDC reports that by the end of 2005, 67,369 out of 189,000 AIDS patients were receiving ART. That number increased to 71,077 by June 2006, to 84,170 by September 2006, and to 91,560 by December 2006.

Uganda ran one of the first pilot ARV programs in Africa. This was a partnership program between government and UNAIDS. It began in 1998 and aimed to see how an ARV program could be set up and run in a resource-poor country. The 399 patients involved were responsible for paying for their treatment, and bought their drugs at reduced prices. After the two-year pilot, the Ministry of Health drew up the National Strategic Framework for HIV/AIDS (2000/1-2005/6), with targets that were ambitious but still short of universal access to ART for AIDS patients.
The Framework prioritised access to HIV/AIDS care, including prophylaxis to prevent the infected from progressing to the AIDS stage, treatment of OIs for all those in need, and sustainable ART to about 60% of those eligible (to avert about 90,000 deaths) by 2006.

It was not until June 2004, when the Antiretroviral Expanded Access Initiative was launched, that Uganda, with funding from the World Bank, begun to offer free ARV medication to people living with HIV. In this initiative, the target was to avail free ARV drugs to 3,000 AIDS patients by June 2005. The drugs were distributed through 26 accredited centres, and National Medical Stores, which imported the drugs, reported 7,000 AIDS patients accessing free ART under the initiative by April 2005. The initiative gradually expanded as more resources became available through the Global Fund, PEPFAR, the NGO sector, and other development partners.

As a result of that initiative, going by Ministry of Health data, Uganda was able to achieve WHO's "3 by 5" campaign target for providing ART to at least 50% of those eligible by the end of 2005. However, most of the PLWHA who need ART are still not accessing it. Scaling up to provide ART treatment for every Ugandan who needs it will be a major challenge. The number receiving ART includes 8,800 children, representing only 11% of the sick children in need of ART.

Table 1: ART Provision at Selected Service Points

	Jun. 2005	Dec. 2005	Jun. 2006	Dec. 2006	2007
Pallisa Hospital	-	47	96	116	137
Kadic Hospital	-	185	92	93	91
Mayanja Mem. Hosp.	-	175	-	90	23
Mildmay Centre	919	-	1315		1534

Source: ART Centres

Table 2: ART Service Provision by Selected Organizations

	Dec. 2005	Dec. 2006	2007
TASO	6,002	9,621	12,198 (Mar 07)
Uganda Cares	5,269	9,163	9,849 (Apr 07)
Elizabeth Glaser Paediatric AIDS Foundation (PMTCT)	8,745	4,398	10,566 (Mar 07)

Sources: TASO, Uganda Cares, & Elizabeth Glaser Paediatric AIDS Foundation

Table 3: Trends in STD/HIV/AIDS Indicators FY 2000/01-2004/05

Indicator	Baseline 1999/00	Achieved 2000/01	Achieved 2001/02	Achieved 2002/03	Achieved 2003/04	Achieved 2004/05	Target 2005
HIV prevalence among Women attending ANC	6.8%	6.1%	6.5%	6.2%	6.2%	6.8%	5.1%
No. of PMTC services delivery outlets	7	7	11		140	224	286
No. of clients receiving ART	1,200	3,000	60,000	12,000	43,000	67,000	60,000
Proportion of STI patients who are appropriately managed according to guidance	21%			33%		40%	50%

Source: Ministry of Health

A National Roadmap for Prevention was launched in August 2006, declaring 2006 as the year of HIV prevention. It features an analysis of the risk factors and drivers of the epidemic, a comprehensive prevention package, and critical steps, milestones, and targets for achieving universal access to HIV prevention information and services. It targets 80% access to a prevention package, with a target of 40% reduction in the incidence rate of new HIV/AIDS infections by 2012, to avert 160,000 new infections. The Roadmap however, emphasizes prevention, and does not envisage universal access to ART.

The demand for ART continues to outstrip supply, and the gap is only expected to widen. At current trends in the epidemic, the number infected with HIV is expected to increase from 1.1 million in 2006 to about 1.3 million in 2012, and 1.7 million in 2020. The Ministry of Health also estimates that the number of PLWHA in need of ART will increase from 234,500 in 2006 to about 263,000 by 2012, and to 342,200 by 2020 -– far outstripping the capacity of the response system and the available financing.

The Uganda Government is in the process of formulating a new 5-year HIV/AIDS National Strategic Plan (2007/8-2011/2) to set new targets and strategies for prevention, treatment, and care and support, targeting universal access by rolling out ART to all Health Centre IVs by 2012.

Prevention of mother-to-child transmission of HIV

It is estimated that 1.2 million women in Uganda give birth every year. Given an average antenatal HIV prevalence rate of 6.5%, about 78,000 of the pregnant women are living with HIV. It is estimated that 25,000 children are infected by their mothers each year.
The Uganda Government launched its Prevention of Mother-to-Child Transmission of HIV Programme (2000-5), aiming to provide counselling to about 35% of all pregnant women in the country and testing services to about 20%. Elizabeth Glaser Paediatric AIDS Foundation, in partnership with The Ministry of Health and funding from PEPFAR, is running Uganda's biggest initiative on PMTCT. It provides ART for PMTCT to 6,833 pregnant women and mothers and 3,933 infants in 254 centres across the country.

Table 4: Women and Children Receiving ART for PMTCT at Elizabeth Glaser Centres

	2005	2006	2007
Women	5,241	2,751	6,833
Infants/Children	3,504	1,627	3,933

Source: Elizabeth Glaser Paediatric AIDS Foundation

Although Uganda was able to increase PMTCT service delivery sites from seven in 1999/2000 to 334 by May 2006, the country's PMTCT program targets were conservative, and its overall performance poor. By December 2005, only 15% of the pregnant women living with HIV had been identified, and only 10% had accessed PMTCT prophylactic ARVs. The program did not specifically address the needs of pregnant women living with HIV/AIDS. It was primarily concerned with the baby, despite the fact that for the baby to grow up well it needs a mother who is alive and active. Findings from the 2004/5 HIV/AIDS Sero-Behavioural Survey and other reports indicate that only 4,000 children have access to ARVs compared to an estimated 10,000 who need them.

The PMTCT program focused on formal health facilities, where only 38% of pregnant women in Uganda deliver, and lacked a comprehensive plan to reach out to community settings, where most women deliver. PMTCT services exist in accredited public health centres, yet most expectant mothers in need of the services live in rural areas. Also most organizations do not offer PMTC services.

A follow-up PMTCT program (2006-10) has been drawn, with a more ambitious target of reducing mother-to-child transmission of HIV by 50% by the year 2010, and increasing the number of HIV-positive women accessing ART from 20% to 80%, through intensified community mobilization, especially involving male partners, integration into the reproductive health service system, and establishing linkages to appropriate care and support services.

What can be done to improve PMTCT delivery?

- The PMTCT services should be scaled up and rolled out to the lower health facilities. Provision of effective and relevant information, education, and behavioural change communication interventions should target the community and the male partners' participation.
- There is need to train more midwives in the field of PMTCT and to empower birth attendants and the community with PMTCT information. Since most women deliver from home, there is a need to expand services to rural areas.
- Enable earlier diagnosis of infants by increasing access to polymerase chain reaction (PCR) testing.
- It is critical to expedite practical measures that will address alternative feeding for infants, especially for poor and marginalised populations such as internally displaced persons.

The burden of HIV/TB co-infection

The burden of HIV/TB co-infection is a widespread problem in Uganda. Up to 80,000 people are infected with TB every year, and between 65% and 70% of those diagnosed with TB are eventually diagnosed with HIV as well. TB is one of the most common causes of morbidity and the leading cause of mortality in PLWHA. According to the Ministry of Health, an estimated 30% of all deaths among PLWHA are attributable to TB, and about 50% of TB patients are co-infected with HIV.

In 2005, the Ministry of Health developed an HIV/TB Collaboration Programme as well as an HIV/TB policy, leading to the launch of a dual management strategy whereby people diagnosed with TB are screened for HIV as well, and vice versa.

As a result of the policy, diagnostic services were scaled up and an improvement reported in coverage of Community Based Directly Observed Treatment (CB-DOTS). Under the CB-DOTS strategy, TB treatment is done at the home of the patient. When one is diagnosed with TB, a member of the community (usually a friend or neighbour) is selected to oversee his treatment. After sensitization and training, the selected member is given the drugs and the responsibility to give them to and observe the patient take them as and when he/she is supposed to. This strategy is designed to reduce defaults and avoid multi-drug resistance.

The dual management strategy of HIV/TB however still has to overcome some challenges. There is still poor access to diagnostic services due to long distances and understaffing, particularly of laboratory personnel. The quality of CB-DOTS services including follow–up, recording, and reporting is poor. Sputum smear diagnosis in hospitals not a priority. Finally there is a low level of community awareness on TB and weak community mobilization for TB control.

HIV/AIDS TREATMENT FUNDING

Resource requirements

The health sector in Uganda is under-funded, and so is the national response to HIV/AIDS and ART services. Resource mobilization has mainly been at the program and project level. National projections indicate that the country will require over US$2.5 billion to achieve universal access to HIV/AIDS prevention, treatment, and care services by 2012. The Ministry of Health has stated that such investment levels are "unachievable" given that HIV/AIDS is not the only priority Government has to fund, and also because the external sources on which the country's HIV/AIDS response has depended are "unpredictable and unsustainable".

It is estimated that the immediate shortfall in health financing exceeds US$115 million (HEPS Uganda and ActionAid International Uganda, 2006). The Ministry of Health budget (at US$125 million in fiscal year 2003/4) would therefore need to be doubled to achieve sufficient financing for the health sector. But this gap cannot be closed until 2020, even if the health budget were to be increased to 15% of national budget.

The amount of money spent on HIV/AIDS-related activities in Uganda is estimated to have increased from about US$40million in 2000/1 to US$170 million (with 67%, or US$114 million going to treatment and care services) in 2006. The Ministry of Health's budget projections indicate that the HIV/AIDS budget will have to be increased to between US$340-512 million by 2012 if the country is to reverse the epidemic and its effects.

Under-funding of health has of course meant that only limited resources can be invested in the national response to HIV/AIDS, where initially the focus was more on prevention and less on treatment and care. Since the launch of the National Strategic Framework (NSF) for HIV/AIDS Activities (2000/1-2005/6) in 2000, the national focus was rebalanced with equal attention to treatment, care and support services as the number of HIV-positive people increased.

The NSF targeted to provide sustainable ART to about 60% of those eligible, supported by resources from the donor community. The World Bank's US$50 million Multi-Country AIDS Programme (MAP) was launched in 2001 with significant support for treatment services. PEPFAR launched its activities in 2004, with a target to provide ART to more than 70,000 PLWHA in five years. It allocated more than US$50 million (about 43% of its budget for Uganda) on ARV drugs and services and laboratory infrastructure in 2005 alone. In addition, the Global Fund approved a US$70 million grant to support Uganda's HIV/AIDS effort, allocating about US$16 million for procurement of ARV drugs and related logistics.

In spite of the positive response of the donor community to the Government's HIV/AIDS response strategy, the treatment scale-up has achieved only limited success due to, among other problems, the mismanagement of funds by public officials. For example, the Global Fund grant was suspended in August 2005, until May 2006, while Government set up new management structures for the grant. The suspension led to drug stock-outs in government accredited ART service facilities during the period (*Ministry of Health 2005/6 performance Report*).

It should be noted that even with so many external resources flowing into the country to support HIV/AIDS treatment delivery, funding still remains insufficient. Only about 42% of the AIDS patients who urgently need ART are currently accessing it. Facilities, such as infrastructure, laboratories and equipment and other logistics, and personnel (doctors and counsellors) needed for the delivery of ART services are limited. Most districts in Uganda do not for example have functional laboratories, and such essential equipment like CD4 count machines. Second-line treatment is not common in public centres but is available in private units at a cost. Treatment for OIs is available in private clinics and only a few public centres. OI treatment in private clinics is relatively expensive and unaffordable to poor PLWHA.

While some organisations like TASO, AIM and Uganda Cares, among others, are playing an important role in the provision of care and support services, which has helped many PLWHA access ART, they do not have sufficient capacity to reach all AIDS patients. There is a high rate of patients discontinuing ART mostly because they are too poor to afford transport to distant accredited facilities, lack food and other basic necessities to accompany treatment, or become too weak to travel. Yet there is no strong follow-up/outreach programme for patients.

To increase and improve ART service delivery, there is a need for Government and other partners to mobilise and channel more resources into development of infrastructure and facilities, training of human resources, and establishment of a strong support system for HIV/AIDS patients. At the local level, there is need for a health insurance policy to create sustainability of the response effort.

The Global Fund

In March 2003, GoU signed a grant agreement with the Global Fund amounting to US$36.3 million, to finance the scale-up of the national response and interventions against HIV/AIDS in the areas of prevention and care, treatment, impact mitigation, and capacity building. The Fund grants were initially managed and implemented in Uganda by the Ministry of Health through the Project Management Unit (PMU). The Country Coordination Committee (CCM) comprising various stakeholders was the supreme policy organ of the project. The Ministry of Finance was the principal recipient, and PriceWaterhouseCoopers was the Fund Agent.

However, the PMU was disbanded after a PriceWaterhouseCoopers audit revealed its gross mismanagement, and the Global Fund suspended its grant to Uganda. The grant was restored in 2006, after GoU set up a new, interim fund management structure.

The National Strategic Framework for HIV/AIDS (2007/8-2011/2), currently in the final stages of being drafted, is expected to establish a new permanent structure for the management, implementation and monitoring of the Global Fund grants in Uganda. There is a proposal for an "HIV/AIDS Partnership Committee" to assume the role previously played by the CCM, and for a "Partnership Forum" to be in charge of the partnership fund.

PEPFAR

PEPFAR has been supporting Uganda on matters of HIV/AIDS since 2004. PEPFAR has contributed significantly to increasing access to treatment in Uganda. Under the five-year Emergency Plan, Uganda received US$93.3 million in the first year and US$107 million in the second year, in support of enhancing the country's multi-pronged response. PEPFAR's goals in Uganda were stated as: to provide ART to more than 70,000 PLWHA; to support care for 325,000 HIV-infected and affected persons including those orphaned by HIV/AIDS; and to prevent 107,250 new infections. Other activities funded have included the Uganda AIDS Commission (UAC), AIDS awareness campaigns, strengthening of monitoring and evaluation systems, and mapping national services, among others.

The distribution of PEPFAR funding has been instrumental in shaping the government response in general. As far as prevention is concerned for instance, PEPFAR appeared ready to strengthen Uganda's achievements in behavioural change, and provided significant funding for a national Abstain-or-Be faithful campaign (AB Only) spearheaded by the country's First Lady and evangelical rights groups. Condom use was not only down-played but severely attacked with distorted messages, peaking with a critical shortage of condoms in that lasted for almost a year beginning in September 2004. Furthermore, because PEPFAR is the biggest donor for HIV/AIDS in Uganda, civil society recipients have been unwilling to challenge its unwise and unscientific prevention initiatives. As it has turned out, the HIV/AIDS prevalence rate, which had hitherto stagnated at 6.7%, is now rising again, with 60% of new infections occurring among married couples. This situation poses serious a threat to the gains that Uganda has made over the last 20 years.

There have been other weaknesses in the way PEPFAR has been implemented in Uganda. Its HIV/AIDS grant programmes are not integrated in the existing decentralised government structures but run as parallel structures. Some PEPFAR programmes have created competition within health facilities, especially where there is poor coordination and poor integration of services. The sustainability of its programmes is thus questionable, given that government systems are not benefiting by way of capacity development. In addition, stakeholders have complained about lack of flexibility in the grant budgeting and allocation processes that make it difficult for service providers to make adjustments during the course of implementation.

CHALLENGES TO ART DELIVERY AND ACCESSIBILITY

Financial Constraints and Corruption

Financial constraints both at the national and individual levels remain the biggest barrier to sufficient delivery of ART services in Uganda. The resources channelled into the response effort remain far below what is needed to provide ARV's and other care and support services to all patients in need. Over 90% of HIV/AIDS resources currently come from external sources and there has been only a limited effort to increase local financing. The Ministry of Health has lamented that high population growth rates and high HIV prevalence rates call for "unachievable" investment levels if any impact at the population level is to be registered, while dependency on "unpredictable and unsustainable" external resources makes long-term planning difficult. National projections indicate that the country will require over US$2.5 billion to achieve universal access to prevention, treatment and care services by 2012.

Corruption in the management of public funds in recent years has also undermined several health programmes in Uganda, including ART treatment programmes. In 2005, the Global Fund suspended all of its three grants to Uganda after mismanagement was uncovered. This resulted in severe drug stock-outs.

High levels of deprivation among PLWHA

Poverty makes access to the services currently provided even more difficult. In the accredited private ART centres, only ARV drugs are provided free of charge. Except at centres where ART is provide by a few organisations like TASO and Uganda Cares, the routine CD4 count (which costs between US$5-30) and viral load which (which costs between US$80–140), treatment of OIs, and nutritional support are paid for by the patient. Many patients cannot even afford transport to the distant facilities, much less food for themselves and their dependants. Respondents in the private sector where Government is running the free ARV access programme complained that the Government has made no effort to provide resources for follow-up of patients. As a result, many patients are dropping out of care. At one private facility, which was accredited in October 2005, the actual number currently receiving treatment is about 90, yet the centre has been registering 60-80 new patients every month.

> *"When a patient doesn't turn up, it may be because they cannot afford transport or they are too weak. They end up defaulting because we cannot reach them. We usually try to call them at our expense, but some of them don't have phones and there is no one to ensure they take the medicine and don't share it with others or sell it to buy food or alcohol. We need logistical support for follow-ups and for provision of other supportive care"*
>
> —Director, Kadic Hospital

HIV/AIDS treatment has been affected by inability to access the necessary support, such as food supplements. Most people on ARVs are poor and vulnerable with no jobs, or have lost their jobs or partners who have been their breadwinners. The situation is worse in HIV/AIDS affected families where HIV positive children compete for food with their parents.

> *"We don't have enough food supplements to accompany ARVs. The condition of some ARVs require us to eat before taking them. At first TASO used to give us food supplements but they stopped. This puts me on tension all the time especially when I don't have food at home"*
>
> —TASO client

Limited infrastructural support and human resource capacity

Delivery of HIV/AIDS ART services is a challenge that has to be addressed by rapidly expanding infrastructure and assuring adequate human resources. The health system is currently working at the full capacity of its limited facilities and human resources. Because of limited funds, health facilities are unable to provide ART to all who turn up seeking it, much less all those who are eligible for it. Patients are simply turned away at facilities that have reached their maximum capacity. There is especially high staff turnover at the private health facilities, as dissatisfied doctors and nurses constantly leave in search of greener pastures.

The country's high population growth rate of 3.5%, the over 130,000 new infections each year, and the 20,000 PLWHA who become eligible for ART each year, have overwhelmed existing facilities, hindered quick roll-out, and increased drug stock-outs. There are limited personnel to administer ART services. CD4 count machines and ARVs are not available among vulnerable, marginalised and poor people in Uganda. In Kalangala district (an island on Lake Victoria) for instance, patients from Lujjabwa Island have to travel for six to twelve hours by boat (depending on the weather) to the Main Island or to the next district in Masaka to access treatment.

> *"There are very few centres providing ART services in remote rural areas of Uganda especially in the districts of Karamoja, Masindi and Kalangala. People move more than 80km to access ART services"*
> —NAFOPHANU Officer.

> *"We have over 6000 clients some of whom we visit at home and our staff is only 20 counsellors, 7 doctors and 13 field officers"*
> —TASO Mbarara ART team leader.

Shortage and inconsistent supplies of drugs

Drug stock-outs are becoming a big problem. Since mid-2006, Stavudine 40mg has been out of stock and Government has advised service providers to improvise with Stavudine 30mg, which is a retreat for some patients. According to the Ministry of Health, tenofovir or abacavir are supposed to replace Stavudine 40mg, but the National Drug Authority (NDA) is yet to test it several months after it was delivered. At least in one upcountry case in mid-2006, AIDS patients were given expired drugs because of a lack of valid drugs.

> *"I almost cried about drug stock-out during my field visit*
> *to our TASO branches in Masindi and Hoima.*
> *People didn't have ARVs for a week"*
> —Dr Lydia Mungherera, HIV/AIDS Activist

The supply chain of medicine is inefficient. In 2006, stocks of ARV drugs worth US$800,000 expired in stores of National Medical Stores, yet people were in desperate need of them. There have been reports that some drug consignments have been dispatched from National Medical Stores but not been delivered at their destined health centres. Service providers have also complained that the drugs that are delivered to the centre are not according to requisitions, which has left the centres stuck with drugs they do not need and short of drugs they need.
In other instances drugs expire in storage at local centres due to lack of competent personnel while patients are in dire need. A case in point is Buyinja health canter in Bugiri district.

Limited awareness and stigma

Another challenge to ART is limited awareness of ones HIV status. About 70% of the estimated one million infected Ugandans are not aware of their HIV status. Only 13% of adult Ugandans have ever tested and received their results (NHSBS 2005). This limits their chances of accessing life prolonging treatment.

> *"Most people in Uganda don't know their HIV status and by the time they know it's to late. This has affected the planning process of HIV/AIDS service providers and the government of ART treatment to PLWHA in Uganda"*
>
> —Director Planning & Monitoring, Uganda AIDS Commission.

Self-stigmatisation among PLWHA has hindered access to ART services. Many people in couples have failed to disclose their status to their partners or to the public. These people find it difficult to go to public places to access free services; some prefer to pay to access it in privacy. This poses challenges in effective patient management and monitoring.

THINGS THAT ARE WORKING WELL IN DELIVERY OF AIDS TREATMENT

For access to treatment to become efficient and effective many aspects of ART service delivery in Uganda still have to be streamlined, but there is a good base for these improvements.

- Uganda has been able to set up communication channels to reach the population with sensitisation messages through the mass media, posters, community health systems, churches, schools, public dialogues, and a growing numbers of people willing to tell their testimonies.

- There are many players, partners and stakeholders in the response effort, with many willing to work together through sharing of resources, information and responsibilities. The donor community is financing the bulk of the response effort through the Government and NGO's; the Government is working with several NGO's on various components; and the civil society organisations like TASO, Uganda Cares, Uganda Business Coalition, and others are playing a key role in research, advocacy, sensitisation, and providing support to the vulnerable sections of society.

- Uganda has set up infrastructure for HIV/AIDS research, in form of research centres like Joint Clinical Research Centre (JCRC), Mildmay Centre, Makerere University, MU-CWRU Research Collaboration, the Makerere University–John's Hopkins University Research Collaboration (MUJHU), the Uganda Virus Research Institute, International AIDS Vaccine Initiative (UVRI-IAVI), the Makerere University Walter Reed Project (MUWRP), and others undertaking scientific research on HIV/AIDS. There is also a large number of organisations both local and international undertaking social research and generating invaluable information on HIV/AIDS.

CHALLENGES FACING MARGINALISED GROUPS

Marginalised groups in Uganda, such as the internally displaced people (IDPs), refugees, sex workers, MSM, persons with disabilities, orphans, prisoners, fishing communities, and the ignored ethnic groups (pygmies, Karimojong, etc) face many challenges in accessing ART services. The prevalence rate in some of these groups is relatively high or not well known, yet they face many barriers in accessing ART. Some IDP camps, in the conflict region in the North of the country for example, do not have ART delivery centres and people have to travel long distances through insecure areas to access services. Society does not tolerate homosexuality, which is seen as a lifestyle of shame, and MSM find it difficult to openly claim their right to health care, including ART.

> *"Most people in IDPs have little information about ART. Those who are aware have to travel over 80kms to access ART services and there are sometimes no treatment care services like CD4 machines. In Kotido government hospital only one nurse works on out-patients, then PMTCs."*
>
> —NAFOPHANU Officer

The counselling services do not cater for the special needs of the disabled, such as the deaf and the dumb, and most services are not user friendly for the lame, who may have to queue for services. Counselling services are not well suited for children, particularly the orphans who take charge of their lives at a tender age. According to the Ministry of Health, the cumulative number of children orphaned by HIV/AIDS in Uganda is estimated to have reached 2.2 million.

Most of the marginalised groups are not given special attention in the provision of ART services and special delivery mechanisms tailored to their special needs and circumstances.

Judgmental attitudes are still widespread in Uganda and people blame others for the epidemic. Sex workers are looked upon as agents of HIV/AIDS spread and communities are unwilling to give social support to them. Research has identified negative attitudes of family members, particularly towards widows of men who have died of AIDS-related conditions. Rural communities and families ostracise widows and blame them for the death of their husbands.

Recommendations

- **The government must commit increased funds to the health sector and ART services**
- **The government should strengthen management and accountability systems for HIV-related funds**
- **Donors should limit the proportion of funds provided to partners in cash**
- **The government must strengthen national health system capacity through investments in human resources and infrastructure**
- **A major public education campaign is needed to address stigma and encourage social support systems**
- **Greater collaboration among private and public service systems is needed**
- **The government must improve the drug procurement, supply, and delivery system**

RECOMMENDATIONS

1. The Uganda Government needs to mobilise and commit more funds to the health sector, especially ART services, by facilitating the establishment of a sustainable national health insurance scheme. Donors should also commit more funds to ART provision.

2. The Uganda Government should strengthen the management and accountability systems for HIV/AIDS funds. The donor community also needs to limit the proportion of the funds given to partners in cash; a proportion should be directly disbursed to beneficiaries and suppliers. The Government and donors should work together to build the capacity of civil society organisations to be involved in monitoring ART funds.

3. The government needs to strengthen the capacity of the national health system through investment in infrastructure, human resource training and logistics, to facilitate faster roll-out of ART delivery to primary health service units.

4. There should be deliberate efforts by the Government and civil society organisations to educate the public from all angles, including at community levels, in schools and churches, etc., to end stigma and build social support

systems for PLWHA. Donors and Government should provide and allocate resources for support services like feeding and transport, and training more counsellors for PLWHA.

5. The Government and donor community should work together to strengthen collaboration between the private and public service providers, to facilitate the coordination and collaboration through sharing of information, human resources and infrastructure. Government and donors should also improve the coordination of the various funding mechanisms (MAP, Global Fund, PEPFAR) to avoid duplication of interventions, ensure efficient utilization of resources and integration with existing health system to help enhance capacity and sustainability.

6. Government needs to improve the national drug procurement, supply and delivery system to avoid delays, stock-outs and diversions by reducing the bureaucracy involved in importing ARVs. Donors should deliver funds and drugs on time.

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ZAMBIA

By Paul Kasonkomona and Felix Mwanza

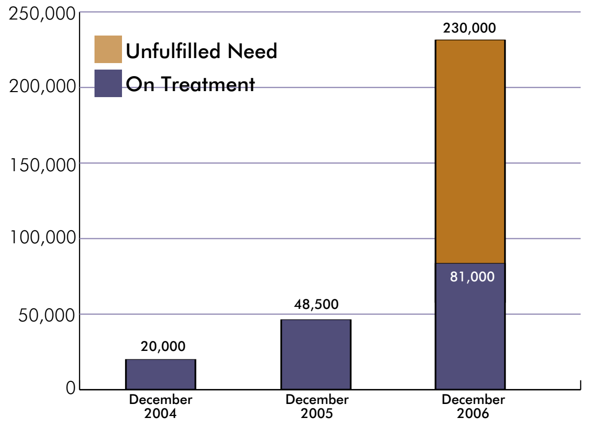
As of early 2007, there were approximately 76,000 to 80,000 people on ART in Zambia, of whom some 30,000 were children. More than half of all receiving ART were doing so in the capital of Lusaka. In a recent interview, a senior staff person with the Ministry of Health estimated that one quarter of the 1.6 million Zambians living with HIV are in urgent need of ART, which means that fewer than one-quarter are being reached.

Although exact numbers are not easily available, more women than men are on treatment in Zambia. Among the reasons for the greater uptake among women are, firstly, that far more widows than widowers are among the recipients of ART, and secondly, that men are more likely than women to be in denial about possibly having HIV (and thus they refuse to be tested).

Changes and trends in art availability and uptake

There were approximately 33,000 people on ART by June 2005 and about 43,000 as of December 2005. The total one year later, in December 2006, was slightly more than 60,000. This increase is less than what might reasonably be expected considering the amount of donor aid that Zambia receives, especially in comparison with neighbouring countries. Part of the problem seems to be that policymakers may operate less from a plan than on the basis of individual discretion and whims. This greatly hinders efficiency.

AIDS Treatment Access in Zambia



Note: all numbers based on WHO AIDS treatment update reports, 2005, 2006,and 2007

- **Treatment access has reduced HIV-related mortality and productivity losses, and helped address AIDS-related stigma**
- **Serious inequalities exist in access between urban and rural areas, and most people in rural areas are forced to travel long distances for care**
- **Limited access to diagnostic tools, such as PCR testing**
- **Paediatric formulations not widely available**
- **Health care workers receive very low pay and often are forced to work in appalling conditions**
- **Drug stock-outs and inadequate supply of basic tools compromise provision of care**
- **Marginalised groups face unique challenges in accessing care: sex workers have been harassed in medical settings, and refugee programs struggle with limited drug supplies**
- **PMTCT largely unavailable in rural areas**

In Mongu, for example, a hospital stopped enrolling patients for ART because demand greatly exceeded the supply promised by health officials. Many people had to wait months before initiating treatment.

The lack of meaningful civil society engagement has contributed to the slow speed and complications related to ART roll-out to date. Plans and policies were developed without extensive participation of stakeholders who work with grassroots communities and are able to challenge government decisions. The involvement of local civil society organizations is crucial because they know the primary needs of those living with HIV. Moreover, they recognize that most statistics published do not reflect the true picture of what is happening on the ground. Unfortunately, organizations such as the Network of Zambian People Living with HIV/AIDS (NZP+) have yet to play a meaningful role in this process. NZP+, which seeks to serve as the voice of PLWHA, receives enormous financial and material support from different players, including the government. Perhaps for this reason, its leaders rarely challenge government decisions and have little interest in seeking to reflect the concerns and needs of most PLWHA.

- **Few able to access second-line treatment and most local clinics do not have drugs to treat OIs**
- **Many live on desperately low incomes and cannot afford travel to clinics or other treatment-associated costs**
- **Multilateral organizations work closely with the government but have inadequate interaction with genuine civil society organizations**
- **PEPFAR is making major contributions to treatment delivery but must expand services to more districts and dedicate increasing resources to health care worker training**
- **Numerous instances of conflict of interest in management of Global Fund monies**
- **Greater priority needs to be given to appropriate prevention strategies, especially for marginalised populations**

Transparency regarding ART roll-out is in short supply among all stakeholders. The government's ART access targets are not known. As a result, it is difficult if not impossible to know when (or if) the government plans to achieve universal access, and, consequently, there is no way to monitor progress. A major contributing factor is that local offices of UN agencies seem reluctant to point out weaknesses in the government's response.

Policies related to TB and HIV/TB co-infection also contain no treatment or care targets, and the government does not seem to have a policy on what to do in response to the growing rates of multidrug-resistant TB (MDR-TB) and the even more serious extensively-drug-resistant strains (XDR-TB). Research indicates that little is done to help those infected with either MDR-TB or XDR-TB, and so nearly all of them are dying.

RESEARCH METHODOLOGY

The research for this report consisted of the following:

- a review of policy documents, national strategic plans, national development plans, conventions, and declarations of commitments;
- in-depth interviews with key stakeholders;
- focus group discussions to ascertain knowledge and awareness about HIV and information about behaviours. Discussions were conducted with both PLWHA (often through support groups) and community members not living with the virus; and discussions and interviews with commercial sex workers at and near places they work.

FINDINGS

HIV treatment, care, and prevention services are not readily available across the entire population; in general, the inequities in access to such services between urban and rural areas mirror those in the provision of general health care services. For example, in urban areas, 99% of households are within five kilometres (3.2 miles) of a health facility compared with 50% in rural areas. Long distances, cost, and lack of transport contribute to difficulty in accessing treatment, care, and prevention services.

Comprehensively assessing public opinion regarding government efforts at care, support and treatment is difficult if not impossible. Researchers did, however, ask many respondents what they thought could be done to improve care for PLWHA and their families in towns and communities where treatment is not available. The most common response was that medicine should be provided (65%). Other responses were to provide financial assistance and for those in need to be admitted to hospitals (48% and 42%, respectively); better care from the family (22%); home visits from care providers (14%); setting up hospices (24.7%); improved educational opportunities for AIDS orphans and children from homes affected AIDS (14%); support groups (8.6%); and improved access to care from traditional healers (8.6%). From these responses, it is clear that there is a need for improved access to medicines and better health care, and that many families are in need of financial assistance. Having a family member who is ill not only increases expenses in general but also increases the workload of family members who remain healthy. In many cases, the ill family member would otherwise have been a wage earner. Informants also were asked to name the places where people could go if they wanted to know whether they had HIV. Although there are many stand-alone VCT centres, almost all respondents (93%) mentioned health centres, and only 28% mentioned a VCT centre.

Key barriers to effective HIV service delivery include the following:

- Diagnostics are limited in the run-down health care system. For example, no polymerase chain reaction (PCR) tests are available to determine the HIV status of a child younger than 18 months.
- For the most part, paediatric formulations of ARVs are not available at all, thereby limiting effective treatment options for children.
- Health care workers are paid meagre salaries and work in appalling conditions, thereby limiting their motivation. Often their facilities have stock-outs of key supplies ranging from reagents to disposable gloves.
- Most people, especially in rural areas, must travel long distances to find a health centre. Doing so can be difficult for those with little money for transport or with significant responsibilities at home (such as taking care of children).
- The vast majority (80%) of Zambians live on less than one US dollar a day. Travel can be difficult for those with little or no money for transit. (Typically, people have to pay about ZMK60,000 [$14.46] in transportation fees to access treatment at health centres.)

What is working well

The government's decision to make ART free to all that need it is a step in the right direction. The problem is that although most people in rural or semi-rural areas have heard about ARVs, often they cannot obtain them because they live too far from health centres.

Lessons learned from art roll-out to date

The provision of treatment in a number of centres has proved to be a factor in reducing the number of deaths, the number of work hours lost to sickness, and the number of broken families headed by single parents or grandparents. In turn, these developments have helped reduce stigma and discrimination because HIV and AIDS are no longer necessarily perceived as a death sentence.

Advocates' successful push to supply ART in prisons has precipitated a decline in deaths among inmates, according to the head of a prisons-based NGO.

Where treatment and food rations have been made available, there is proof of improved treatment adherence and greater willingness among community members to be tested for HIV. Working in collaboration with the World Food Program, staff at the Lusaka Centre for Infectious Disease Research, Zambia (CIDRZ) issue food supplements to hundreds of people on treatment. Such initiatives may seem simple but have extremely positive effects. Numerous PLWHA interviewed for this report including men and women from Kafue and Kabangwe districts said that they find it difficult to take ARVs without food and that they have therefore missed dosages at lean times.

A major problem is the persistent shortfall in trained health care workers. No sustainable progress in ART roll-out can be made unless this problem is addressed adequately.

Marginalised groups and access to treatment

Commercial sex workers

There are an estimated 35,000 sex workers in Zambia, with 10,000 in Lusaka alone. A study conducted in Ndola, a city in the copper belt, found that 68% of sex workers were HIV-positive. A Lusaka-based NGO called Tasintha (meaning "we have changed") operates a notable program for sex workers in high transmission areas throughout the country by improving negotiation skills among sex workers to increase condom use and other safe sex practices.

Some have argued that sex workers cannot be stigmatized at health service facilities because no one asks whether one is involved in the trade or not. Yet research indicates that sex workers usually prefer to use private clinics because of harassment by health care providers in the public health centres, where many staff regard them as sinners and dirty.

Refugees

Due to the political instability in several neighbouring countries, there has been an influx of refugees into Zambia in recent years. Multisectoral task forces on HIV/AIDS have been established in all refugee camps to organize a range of prevention and care activities. However, programs have been constrained by shortages of essential drugs, including treatments for sexually transmitted infections, and limited human resources. In most camps, only one ART medicine is available the triple-combination drug Triomune (which contains d4T, 3TC and nevirapine).

Prisoners

In 2003, the Zambia Prison Service (ZPS) developed an HIV/AIDS policy, recognizing that prisoners are an important high risk and yet marginalised group requiring urgent attention. The national policy includes provisions on preventative care and support services in prisons and articulates procedures for the implementation of these policies and mechanisms for monitoring and review. Inmates are also guaranteed access to ART. However, implementation of services remains weak. For instance, condoms are not available in prisons for the reason that condom promotion among inmates is viewed as support for abnormal sexual behaviour.

Data from the past decade clearly indicate the great need in prisons. One study conducted in 1999 estimated that 27% of inmates were HIV-positive. Between 1995 and 2000, nearly 2,400 prisoners and 263 prison staff died of HIV-related causes.

Findings also suggested that TB in prisons is becoming a major cause of morbidity and mortality, largely as a result of overcrowding, poor ventilation, and poor nutrition. TB incidence in prisons was reported at 5,000 cases per 100,000 in a study conducted in July 2006. The study also revealed that nearly 4% of the inmates interviewed were involved in same-sex relationships that were sometimes linked to lack of proper nutrition; prisoners who are privileged to serve in the kitchen often solicit sex in exchange for larger rations. Other HIV risk behaviours among inmates include tattooing and sharing of razor blades.

On paper, prisoners are guaranteed access to ART; in practice, however, this ability is at the discretion of authorities at individual prisons. During researchers' visit to a hospital in one town in the Southern province, a number of prisoners there said they had only been able to receive HIV tests after their families had made special arrangements with prison officials.

According to one prisoner interviewed at that hospital, "Most of our friends are dying inside there both of TB and HIV because they cannot be brought out here to access treatment. Some are taken to the hospital when it is too late and they die of hunger after beginning treatment. The authorities don't care because they don't feel sorry about a person who to them is just another statistic."

PMTCT

PMTCT services are not offered to all pregnant women even though the HIV/AIDS policy states that all pregnant women should have access. The only fortunate women are those in urban settings. Most rural dwellers have no access at all and usually do not even receive information about how HIV can be transmitted to their children.

Second-line ART

Second-line ART is only available in about seven districts, with slightly greater access in Lusaka. Drugs are only available at ART sites where the government is partnering with donor organizations such as PEPFAR, MSF, and CRSP. As a result, there are less than 400 people on second-line regimens and sources within government state that there are no immediate plans to widely provide them because of the prohibitive expense. Treatment of OIs is not widely available either, although cotrimoxazole is sometimes available in Lusaka. The situation is similar in regard to TB treatment.

Most local clinics, meanwhile, do not have drugs to treat OIs, so they refer patients to regular hospitals. People continue to die due to lack of fluconazole and other essential drugs in rural areas. Post-exposure prophylaxis (PEP) is only offered at Zambia's largest health institution, the University Teaching Hospital in Lusaka; only health care providers at local clinics can receive it.

The true cost of accessing treatment

ART is available free of charge at a few selected points of service only. Yet transport to and from these widely separated facilities is not free, and often the cost of transit drains what little extra money is available to a family. Other drugs, including cotrimoxazole, multivitamins (MVT), ferrous sulphate, and folic acid, are free but only for a few months. Patients are required to pay for X-rays.

Some 40% of the people in a focus group discussion in the Kabangwe area, six miles from Lusaka, reported that they are living with OIs or drug side effects, but they cannot afford to pay medical costs of about ZMK1,000,000: (US$238). A number of interviewees have been asked to pay this amount at the University Teaching Hospital for treatment and diagnosis of OIs. Many participants in a focus group discussion in Kitwe in the Copper Belt reported that CD4 tests were available only at the city's central hospital, and for a fee (which the patient must pay) of about ZMK170,000 (US$40).

Integration with TB services

Only those HIV-positive people who exhibit symptoms are screened for TB. Patients usually have to pay for TB tests   in some cases they are even required to buy specimen containers. Poor health service integration makes things worse: Currently, counsellors at VCT centres only do HIV counselling, while staff in TB sections only discuss TB. Often they are unfamiliar with the other diseases. TALC is seeking to have health care providers trained to discuss and treat the two diseases simultaneously, a useful step because they are usually linked.

The work of multilateral agencies

Numerous agreements have been signed with multilateral agencies, but little evidence of that exists on the ground. For the most part, the agencies are visible when they are officiating at launches. They comply with government to suppress the criticisms by the general public as well as the opinions of genuine civil society representatives. It is clear that organizations that speak out against government do not benefit from most UN or other funding agencies. The multilateral agencies work closely with government organized non-governmental organizations (GONGOs); these entities fail to report on or address what is really happening on the ground.

PEPFAR

In Zambia, PEPFAR programs are not strongly perceived as working on treatment directly (PEPFAR is deeply involved in prevention activities in Zambia). This was reported by observers on the ground and in interviews with people in different communities. Programs supporting treatment are at the Centre for Infectious Disease Research, Zambia (CIDRZ), which dispenses ART in 16 clinics in Lusaka, and hospitals in Mongu and Sesheke in western and Kafue Lusaka provinces, respectively. This program has the largest number of people on ART (more than government and any other provider of ART), but there is concern about sustainability given that the agreement with government ends in December 2008. There is no information about whether the contract will be renewed, a situation that makes some people reluctant to enrol on ART. Their concerns are not baseless. For example, MSF-Holland recently announced that it would depart (and close its ART facility) when its agreement with the government ends in December 2007. Some are concerned about the transition because they fear MSF has not capacitated enough health care workers; indeed they have taken sizeable number of health workers from the already understaffed institutions and employed them. Unfortunately this has caused mixed feelings in the communities because, once health care providers go to work for an NGO, they don't go back to work in public hospitals.

The Global Fund

The Global Fund's impact has been plagued by numerous instances of conflict of interest with how the funds are disbursed in Zambia. Staff from the Global Fund Principal Recipients also hold top positions in the country coordinating mechanism There is unavoidable conflict of interest when an organization that is a principle recipient has seat on the CCM where they report their implementation programmes (CCM). Power and influence are highly concentrated in general in Zambia, thereby limiting extensive and useful consultation among people at the grassroots level.

Area of special focus

Despite the fact that women and girls are particularly vulnerable to HIV infection, the national policy fails to directly address them. It was noted with sadness that for women, marriage has now become a major risk factor for HIV infection in Zambia. As in many places in the world (and especially in sub-Saharan Africa), more women than men in Zambia are being infected with HIV, and women account for an estimated 54% of all PLWHA. In addition, HIV prevalence among 14–19 year-old girls is six times higher compared with boys in the same age group. This scenario clearly indicates that the National Policy has not placed enough priority on appropriate prevention strategies, especially for the most vulnerable populations.

The National Policy also does not adequately address geographical disparities in care. The poor in remote parts of the country do not have sufficient access to ART. In most parts of rural Zambia, there is no infrastructure for providing ART such as refrigeration for syrup formulations and electricity for CD4 machines (even if they themselves were available). Possible means to address this have been proffered including the provision of mobile ART services. Rural electrification is also viewed as essential for provision of widespread ART services.

Recommendations

- **The government must speed up and expand implementation of health care worker training and retention, and provide salary increases**
- **The government must address the need for better transportation to and from health clinics, and consider utilizing mobile ART clinics**
- **Policy makers must partner with genuine civil society organizations working on the ground to serve PLWHA**
- **Expanded access to PMTCT services must be a top priority**
- **Government and partners must act to expand treatment access in rural areas and make second line treatment more readily available**
- **Multilateral organizations must help local institutions take over provision of services**
- **Civil society must be independent watchdogs of service delivery, and community groups must be more closely involved in setting Global Fund and other AIDS-related policy**

RECOMMENDATIONS

- Shortage of health care workers. The government should speed up the health workers' retention scheme if the country is to meet universal access goals.
- Transport problems. The government should address the problems related to unaffordable and time-consuming transport to and from clinics providing ART. One solution would be mobile ART clinics.
- Priority-setting. The government's ability to set appropriate priorities in HIV prevention, care, and treatment would be improved if policymakers worked more closely with genuine civil society organizations that are doing work on the ground.
- Financial concerns. To help address ongoing and critical financial shortfalls, the government should create a reserve account that will be used to motivate health care workers by providing salary increments and allowances. Moreover, donors should stop dictating how the money they donate should be used; instead, they should sit down with country teams to hear what the priority areas are. Currently, health care officials often have little or no say when it comes to the way donor money is used.
- There is a need to economically empower people in order for them to be able to acquire sufficient food while they are on ART. This undertaking should be initiated by both government and NGOs that have mandates to do so.

- Advocacy movements should continue to put pressure on NGOs that operate as though they are for-profit entities with the goal of making money at the expense of PLWHA. Many of these organizations should be investigated thoroughly by public- and private-sector monitors to determine how they allocate their funds.
- PMTCT. Far too little is available in the way of PMTCT services and treatment literacy information. The latter was evident in the large number of people interviewed who did not understand it was possible for an HIV-positive woman to give birth to a negative baby. All stakeholders in HIV prevention, care, and treatment should make improved PMTCT availability a key priority.
- Urban–rural gap. There is a need for public-sector policymakers to focus on greater provision of ART in rural areas, where people are comparatively poorly served. They also have far less access to treatment literacy information.
- Second-line treatment. The growing signs of treatment failure offer proof that the government must focus on providing greater access to second-line treatment. Policymakers should work closely with donors to ensure affordable access to available drugs beyond those in the first-line regimen.
- Training of health care workers. Greater resources and attention must be focused on training all health care workers in the management of both HIV and TB, as well as in other common OIs. Some such initiatives have been taken in this regard; for example, there is now HIV group counselling required for all pregnant women during antenatal clinic (ANC) visits. Yet in general, much more remains to be done especially regarding the training of nurses who do not work on HIV issues directly. They must be provided greater information about HIV and ART.
- Ensuring sustainability. Multilateral agencies should meaningfully empower government-owned health institutions and staff to take over ART and other HIV-related services when donors leave and/or the programs fold.
- Monitoring and evaluation. Civil society organizations should conduct independent monitoring and evaluation efforts to ascertain how government resources are being used. Often they can apply for and receive such training from donor organizations.
- Involve community groups more extensively and directly in all Global Fund processes. Community groups should be more directly involved in setting priorities for Global Fund assistance. They should also be able to hold national Global Fund policymakers accountable for ensuring that the funds are allocated appropriately. Community members can and should be involved in all aspects of how Global Fund assistance is administered and managed. There is a need to set up a functional community advisory body that determines funding priorities instead of relying on one executive director and his or her loyalists.

ZIMBABWE

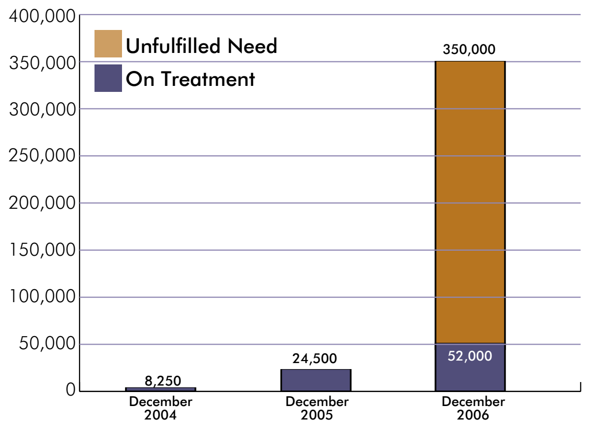
By Matilda Moyo, Caroline Mubaira, and Martha Tholanah

Adult HIV prevalence in Zimbabwe has declined steadily in recent years, from 24.6% in 2003 to 20.1% in 2005 and 18.1% in 2006. However, the HIV burden remains very high compared with most other countries. About 3,500 people die of AIDS-related illnesses weekly, a situation health experts attribute to lack of treatment.[1]

Although there has been a gradual increase in the number of people receiving treatment over the last three years, the figure remains exceptionally low considering the need. For example, UN estimates placed ART coverage in Zimbabwe in 2005 at 8%, with 27,000 people receiving treatment. By July 2006, some 46,000 were on treatment, a number that increased to 60,000 in December 2006 and 66,253 by the end of March 2007.[2] However, an April 2007 WHO report says 52,000 people were receiving ART, representing an estimated 15% coverage, while 230,000 were in need of treatment.[3]

In May 2007, Health and Child Welfare Minister Dr. David Parirenyatwa estimated that 82,000 PLWHA in Zimbabwe were on treatment. The vast majority receive ART through 78 government-supported public and church-run mission health facilities, with the remaining 10,000 individuals obtaining HIV medicines through the private sector.

AIDS Treatment Access in Zimbabwe



Note: all numbers based on WHO AIDS treatment update reports, 2005, 2006,and 2007

- **Treatment access increased in recent years, but remains far below need**
- **Inadequate treatment literacy undermines ART delivery**
- **Costs for AIDS drugs soaring at private pharmacies**
- **Long waiting lines for subsidized services through the government program**
- **Hyperinflation severely erodes the purchase capacity of the Global Fund and other programs**
- **Deteriorating economy has lead to reduced capacity at government generic production facility as raw materials have become prohibitively expensive**
- **Overall health care system is suffering as the government reduces social spending**
- **High attrition among health care workers who must work with outdated equipment, shortages of diagnostic machinery, and inadequate supplies of medicines**

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[1] IRIN, January 2007

[2] MoH&CW, 2007

[3] WHO Report. April 2007

- **Stigma against PLWHA widespread across the country**
- **Growing political isolation leads to reduction in multilateral support**
- **Multilaterals providing inadequate assistance on treatment barriers and brain drain; should work more directly with civil society**
- **Women, children, the disabled, and other marginalised groups face extra challenges in accessing appropriate care**
- **Second-line drugs prohibitively expensive for many, and drugs to treat OIs not readily available in public institutions**
- **Management problems with Global Fund monies delay services**

The government aims to place 120,000 people on treatment by the end of 2007 as part of its goal of universal access, a reduction from 160,000 announced by Parirenyatwa at the beginning of the year. However, that number would still represent only about 36% of the conservative estimate of 342,000 PLWHA in need,[4] and just 24% of the more widely accepted unofficial figure of 500,000[4] people in urgent need of ART. It is believed that many people are turned away from treatment sites without being added to the waiting list to keep official figures low; hence the higher estimate by activists. There are about 1.8 million PLWHA in Zimbabwe.[5]

Research method and techniques

Research in Zimbabwe was conducted by a three-member team using various methods and techniques. These included key informant interviews with stakeholders such as civil society, activists, PLWHA, medical practitioners, government officials, and pharmacists using a standard questionnaire. Some information was obtained through strategic national workshops that focused on treatment. In addition, the team reviewed authoritative research documents and monitored statements and announcements by stakeholders, particularly government officials, in the local media.

BARRIERS TO EXPANDED ART DELIVERY IN ZIMBABWE

Inadequate treatment literacy

Numerous facilities provide voluntary counselling and testing (VCT). Yet neither the government nor civil society has followed through by extensively publicizing the existence and effectiveness of both ART and treatments for OIs. There is still limited information about treatment for PLWHA, including what it is, where to get it, when to seek it, and how to access it. These gaps are particularly wide in rural areas where the majority of the population lives.

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[4] Interview with Dr. Owen Mugurungi, Head of AIDS & TB Unit in the MoH&CW

[5] MoH&CW

Limited access to ART

Treatment options for Zimbabweans include purchasing drugs from pharmacies or enlisting in government programs. The former option, self-sponsorship of treatment, is an increasingly difficult challenge due to soaring costs of medicines as a result of the hyperinflation (at 3,700% May 2007) in the past two years. Meanwhile, the government program is over-subscribed; at the end of March 2007, for example, a total of 32,224 people nationwide were waiting to be placed on treatment. The government program also experiences regular stock outs. For instance, Kotwa district hospital had no ARVs between March and May 2007[6]. On the other hand, mission hospitals were more reliable and as a result, people would travel long distances to such institutions where treatment was guaranteed. For example, patients were travelling about 200Km from Harare to Karanda hospital in Mashonaland Central province to access treatment. Even as more sites get approval to provide ART, delivery of medicines from government stores is sometimes delayed. For example, Nyanga District Hospital in Manicaland Province was approved in January 2007, yet by May, the government had not supplied ARVs, and drugs were being occasionally provided by Mutambara Mission Hospital in Chimanimani District, which is a Global Fund site.

Economic challenges

Although Zimbabwe has adhered to the Abuja Declaration, committing 15% of its 2007 budget to health care, the hyperinflationary environment limits resources and hinders the government's ability to cater for patients in need of treatment. Financial assistance from the Global Fund and other sources is eroded by the artificial official exchange rate of US$1:Z$250[7] which is causing foreign currency shortages. Zimbabwe can produce generic ARVs through a local pharmaceutical company, Varichem, but the deteriorating economic situation has reduced the company's production capacity because it requires US$1 million in scarce foreign exchange every month to import raw materials for drug production.[8]

Although there was rapid ART scale-up initially, with 4,000 new people being placed on treatment monthly in 2006, this ceased in February 2007 due to uncertainty of drug supplies. As a result, many people die while awaiting treatment.

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[6] PLWHA in the community

[7] The official exchange rate is US$1:Z$250. However, in April 2007, Reserve Bank of Zimbabwe (RBZ) governor, Gideon Gono announced that a rate of US$1:Z$15, 000 could be used under the drought mitigation scheme. The parallel market rate changes daily and rose from US$1: Z$40, 000 to US$1: Z$96, 000 between mid-May and early June 2007. For this research,Z$50 000 shall be quoted as the parallel market rate.

[8] IRIN, January 2007.

"My niece died on the 21st of May after waiting for more than a year to commence treatment. Although I am a treatment activist, I could only watch helplessly as her life sapped away. Ironically, it was during the global week of action," an activist lamented during an interview.

Inadequate fuel supplies exacerbate transport problems resulting in failures by hospitals to collect medicines and clients to reach sites designated for treatment access. For example, some district hospitals in Mashonaland Central province had stock outs for four months because they lacked fuel to collect the drugs from the central distribution points. Power shortages also affect treatment delivery and limit the use of laboratory equipment and other systems; some hospitals request patients bring candles and matches for lighting upon admission. Although most hospitals have fuel-powered generators, these cannot be used due to fuel shortages.

A reduction in social spending by the government has resulted in the deterioration of the country's health delivery system. The consequences are shortages in medical equipment and in personnel, who have migrated in search of better salaries and living conditions. The year 2007 began with a strike by junior doctors at government hospitals — later joined by nurses — all demanding 1,000% salary increases. The strike lasted from January to March, then resumed from May to June, after inflation eroded the reviewed salaries.[9]

The high attrition rate among personnel is attributed to inadequate medicines to treat people; anachronistic equipment; shortages of diagnostic machinery and reagents; poor working environments in general; and low wages that are further eroded by the prevailing hyperinflationary economic environment. In May 2007, a municipal nurse earned Z$1,300,000 (US$26 at parallel market rate) while junior doctors earned less than US$100 per month. Most health workers have fallen below the official poverty line.

The staff shortages have affected treatment delivery. Few nurses are being trained in ART administration, resulting in long queues at clinics and forcing personnel to resort to group counselling, thus compromising service quality. The doctor/patient ratio is reportedly 1:12,000[10] while the nurse/patient ratio is estimated at 1: 1,000.[11] Some hospitals in rural areas share personnel, with doctors covering a number of districts that are more than 100Km apart. As a result, patients have to wait from weeks to months before receiving doctors' attention. Clients are often forced to visit the clinic a number of times before receiving a service, which is both exhausting and financially taxing because most people cannot afford the high transport costs.

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[9] The Herald. June 2007

[10] ChangeZimbabwe.com, June 2007

[11] Interview with Blessing Chebundo. Chairperson of the parliamentary portfolio committee on health. June 2007.

Political isolation

The current regime's policies have led to political isolation and resulted in the reduction of support by multilateral institutions that would have provided much needed funding for treatment programs. Zimbabwe is currently under "targeted sanctions" by Western countries. However, while these are aimed at punishing the ruling elite, they are negatively affecting the ordinary person.

Stigma

Although much has been done to fight it, HIV-related stigma remains widespread throughout society. Stigma hinders access to treatment because some people would rather die in denial than face the consequences of knowing or having other people know – their HIV status.

Successful Aspects of Treatment Delivery in Zimbabwe

Despite the massive challenges affecting treatment delivery efforts in Zimbabwe, some aspects of the program are working well as the country attempts to fulfil the Millennium Development Goals (MDG), particularly goal 6, which is "to combat HIV/AIDS, malaria and other diseases."

Zimbabwe has a national AIDS policy and sustainable financing for HIV/AIDS programs through a 3% national AIDS levy on all employees that was introduced in 2000 and is administered through the National AIDS Council (NAC).[12] Currently, NAC uses 50% of the National AIDS Trust Fund (NATF) to procure ARVs, which are dispensed for a nominal fee by the Ministry of Health and Child Welfare (MoH&CW) through public health institutions.

ART has been decentralized to all provinces. The concept is sound because it promises to bring treatment closer to the people who need it most. However, the effort has not been entirely successful because of a lack of laboratory machines, infrastructure, human resources, and availability of ARV drugs. Furthermore, the ART sites are still inaccessible to most people in villages given the long distances and transport costs.

Internal manufacturing of ARVs by Varichem, albeit at high cost and on a small scale, has enabled access and significantly reduced the price of treatment.

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[12] Zimbabwe National Health Sector Budget Analysis and Equity Issues 2000 – 2006. ZIPARU & TARSC. October 2006.

THE ZIMBABWE NATIONAL HIV AND AIDS STRATEGIC PLAN (ZNASP)[13]

Zimbabwe is implementing a comprehensive multi-sectoral response to HIV and AIDS, known as the ZNASP 2006–2010. "While full coverage with prevention, treatment, care, and support during the planning period remains unrealistic, the ZNASP aims to scale up services to come as close as possible to providing universal access for all those in need," said Dr. Tapuwa Magure, chief executive officer of NAC.

To achieve its goal of reducing the spread of HIV, improving quality of life for those infected and affected, and mitigating the socio-economic impact of the epidemic, the ZNASP will focus on four strategies:

- HIV prevention to reduce the number of new infections, with a focus on behaviour change promotion;
- Increased access and utilisation of treatment care services;
- Improved support for individuals, families, and communities, including orphans and other vulnerable children infected and affected by HIV and AIDS; and
- Effective management and coordination of the national HIV and AIDS response (including resource mobilisation).

The ZNASP strategy for treatment focuses on accelerated enrolment of patients at registered sites; basic laboratory services; and affordability of AIDS treatment and regular supply of ARVs, including paediatric formulations and drugs for OIs. The overall objective of the strategy is to ensure access and utilisation of treatment and care services by 2010 for a minimum of 75% of those who need them. For children, the 2010 national target is 100%.

Treatment Access to Marginalised Groups

The ZNASP recognizes women, youth, and children[14] as marginalised groups, although it excludes people with disabilities[15]. Sadly, few HIV/AIDS interventions target disabled people despite their vulnerability, which is attributable to poverty, lack of education and social discrimination.[16]

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[13] Presentation by Dr. Tapuwa Magure, chief executive officer, National AIDS Council (NAC). Universal Access Target Setting Workshop hosted by MoH&CW, NAC, SAfAIDS, OXFAM Australia, UNAIDS, 28 –30 May 2007.

[14] For the purposes of this study, according to the researchers, children are those below the age of 10 and youth below 24 years.

[15] This covers physical and mental disability.

[16] Presentation by Gladys Chawora, executive director of Disabled Women Support Organisation (DWSO) Universal Access Target Setting Workshop hosted by MoH&CW, NAC, SAfAIDS, OXFAM Australia, UNAIDS, 28 –30 May 2007.

Women lack access to treatment because they are often dependent on men for money, including transport fare to get to the clinic or pay the user fees. The long queues at health centres offering ART deter women from accessing the drugs because they have to balance their family responsibilities[17] and treatment requirements. Many women cannot afford to repeatedly visit health centres and spend time in queues without the guarantee that they will obtain treatment; yet private-sector facilities are not an option for women and youth because of the costs.[18]

Limited exposure to information affects women's access to treatment. Despite a 95% nationwide basic literacy rate, rural-based women have difficulty obtaining information because treatment literacy materials are largely distributed in urban centres and may not be appropriately written to meet their needs. The patriarchal nature of society, which limits women's choices and opportunities, also affects their ability to make decisions concerning their treatment options. Further, there is a dire shortage of materials in Braille for the visually impaired and messages in sign language for the hard of hearing.

Also of concern is the non-existence of treatment programs targeted at young people, whether through tertiary institutions such as universities and colleges or out-of-school initiatives carried out at community level. The deterioration of social amenities at tertiary institutions creates the need for new structures and systems to cater for students. Meanwhile, new, concrete plans are required for out-of-school youth.

Civil society representatives feel the ZNASP does not adequately cater for these vulnerable groups. The ZNASP aims at 100% provision and uptake of paediatric treatment, but is silent on targets for women and youth, despite acknowledging their marginalization.

There is need for deliberate attempts to ensure that women and children become the majority of recipients in government treatment programs, given that they are at the bottom of the economic ladder. By end of March 2007, a total of 30,232 women and 4,794 children were on treatment, representing 46% and 7% respectively of the total of 66,253 receiving ART.[19] These figures are negligible in proportion to the number of infected women and children that require treatment. There is need to cater for women in rural areas and the urban poor while increasing the number of children on treatment and targeting disabled people. Similarly, treatment programs for youth should be initiated urgently.

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[17] Childcare, housekeeping, growing and cooking food, etc.

[18] Presentation by Mary Sandasi, director at the Women and AIDS Support Network (WASN), Universal Access Target Setting Workshop hosted by MoH&CW, NAC, SAfAIDS, OXFAM Australia, UNAIDS, 28 –30 May 2007.

[19] ART March 2007 Progress Report by Province, MoH&CW.

PMTCT

In 2005, Zimbabwe had 1,383 antenatal care (ANC) centres, 1,369 of which were PMTCT sites. Under the ZNASP, the target is to expand the number of both ANC and PMTCT sites to 1,400 and aim for 100% uptake of services offered.[20]

Although accessibility of PMTCT centres has improved with a gradual roll-out from 800 sites in 2004 to 1,369 in 2005 and subsequently 1,400, uptake has not reached the optimum level. Stigma and inaccessibility remain some of the challenges hindering the success of PMTCT programs.

The system caters for eventualities such as the likelihood of giving birth at home. For example, women are given a tablet of nevirapine near the time they are due and encouraged to take it when they go into labour. Enrolment in the program, however, remains voluntary and indications on the ground reflect low uptake as noted, for example, by NAC with regard to GFTAM-funded PMTCT programs. Table 1 reflects the scenario at a local district hospital in Kotwa, where only 45% of HIV-positive women and 25% of exposed infants received nevirapine prophylaxis despite exposure, testing, and counselling. The table compares uptake at the inception of the PMTCT program in March 2006 and May 2007. The WHO April 2007 report pegged the proportion of pregnant women on PMTCT+ in Zimbabwe at 9%.

Table 1: A Comparison of PMTCT Uptake at Kotwa district hospital ANC for May 2006 and March 2007

Indicator	*May 2006*	*March 2007*
ANC first time visits (pregnant women seen for first time during current pregnancy)	306	478
Pregnant women pre-test counselled without partners	262	516
Pregnant women tested for HIV	190	340
Pregnant women tested HIV-positive	27	55
HIV-positive women post-test counselled	27	55
HIV-positive mothers dispensed nevirapine during ANC and in labour ward	27	25
HIV exposed infants swallowed nevirapine or other ARV	27	14

In the private sector, the onus to offer PMTCT rests on the obstetrician or general practitioner, unlike in the public sector where the choice lies with the patient. Although statistics are not available, it is believed that uptake of PMTCT is high at

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[20] MoH&CW PMTCT Indicators. Universal Access Target Setting Workshop hosted by MoH&CW, NAC, SAfAIDS, OXFAM Australia, UNAIDS, 28 –30 May 2007.

private, urban clinics because general practitioners and obstetricians insist on an HIV test before taking on clients. PMTCT is free at public health institutions but not in the private sector.

Children and ART

Paediatric treatment remains a major challenge, as ARVs are not reaching most children in need. In 2005, a total 115,182 children were living with HIV. Of these 17,277 required ARVs but by end of March 2007, only 4,794 children, representing a meagre 27% of those in urgent need, were receiving treatment through the government program.

Further, paediatric formulations were not readily available. Some hospitals sought to address the shortfall by administering adult medications in small doses – for example, by giving children half a tablet intended for adults. The use of this imprecise option reflects the crisis surrounding paediatric formulations.

However, despite these shortcomings, government and mission hospitals were reportedly the best sources of paediatric ART. Drugs were supplied by Aspen Pharmaceuticals while the Elizabeth Glaser Foundation and the Clinton Foundation provided technical and financial support. MSF and Medicins Du Monde (MDM) also had programs for paediatric ART.

Interviews revealed that pharmacies generally did not sell paediatric formulations and only stocked them occasionally – a recipe for drug resistance. When available, the drugs were very expensive because they were brand-name medicines procured from multinational pharmaceutical companies such as GlaxoSmithKline.

Second-line ARV Therapy

Availability and accessibility of second-line treatment remains a major challenge in Zimbabwe, largely because of prohibitive costs. As a result, most patients use first-line regimens; 95% of those on ARVs are on first-line treatment while 4% are on alternative first-line treatment. About 1% of the people receiving treatment by end of March 2007 were on second-line treatment, largely through the public health system. It is however, worrying that the ZNASP is silent about rolling out second-line treatment.

At private pharmacies, meanwhile, supply of second-line medications is erratic and they are usually extremely expensive. In May 2007, for example, a monthly supply of Kaletra (when available) cost about US$100, well above the average monthly salaries of less than US$50[21]. "Given the costs of second-line treatment, the question is, how can people afford it when they cannot afford first-line treatment?"[22]

Treatment for OIs

Treatment for OIs is generally available at major government and mission hospitals where ART is administered. According to the MoH&CW, 70% of admissions to medical wards are due to HIV and AIDS and its related OIs, mostly TB and pneumonia, for which treatment is available. The most common causes of death among PLWHA are TB, oral thrush, and diarrhoea.[23]

Some medicines for OIs are not readily available in public institutions, yet it is possible to find them in private pharmacies where they are expensive. For example, cotrimoxazole, a prophylaxis for *Pneumocystis* Carinii Pneumonia (PCP) is available at some health centres, though supplies are erratic. In June, a month's supply of the medicine cost about Z$148,000 at a private pharmacy. During the counselling sessions to prepare clients for ART, cotrimoxazole prophylaxis is used as an indicator for adherence behaviour. Diflucan, used to treat *Cryptoccocal Meningitis* cost Z$600,000 in June 2007. Private pharmacies do not stock TB treatment because it is available free of charge through the government TB program.

Respondents also raised concern at claims that OI medications were being sold on the parallel (illegal) market by unauthorized dealers. This is problematic because it could fan drug resistance. Under the prevailing economic environment, the parallel market has become a steady source of scarce commodities in Zimbabwe, including drugs.

Cost of Treatment

The government treatment program, initiated in 2003, is highly subsidized and is supposed to be at no cost to patients. However, varying user fees are charged for the program, which covers ARV drugs and basic diagnostics (CD4 tests and liver and kidney function tests). User fees range from Z$50 to Z$8,000 depending on the hospital. Viral load tests are not commonly available in the country.

However, there are other financial and non-financial costs that patients incur, such as transport and time loss due to queues. In addition, women's rights advocates argue that while the user fee may be nominal, it constitutes a barrier to treatment for those without a source of income, particularly women.

Further, due to constant breakdowns and a limited number of laboratory machines in the public sector, patients have to contend with long queues and waiting lists for diagnostic tests. The waiting period can stretch up to six months for a CD4 test and another three months for the results, despite the option of the WHO clinical staging.

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[21] In May 2007, the parallel market exchange rate was US$1: Z$50 000

[22] Itai Rusike, Executive Director, Community Working Group on Health (CWGH).

[23] Interview with members of Hope In AIDS Support Network.

"One of our comrades who required a CD4 count test died while waiting in a queue. She booked the test in December 2006, but the earliest date she could get to undergo the test was in June 2007. Her life could have been saved if health personnel had resorted to the WHO clinical staging," Jimmy Wilford, National Coordinator of the Students and Youth Working in Reproductive Health Action Team (SAYWHAT) said in an interview.

To circumvent the waiting period and queues in the public system, some patients opt to undergo diagnostic tests at private laboratories that are more reliable but charge exorbitant fees. For example, a CD4 count test at a private laboratory in May 2007 cost about Z$1.5 million (US$6,000 at the official exchange rate and US$30 at the parallel market rate).

In the private sector, treatment is at cost. Charges are either borne fully by an individual or partially by the medical aid/insurance, depending on the scheme one subscribes to. Local pharmacies mostly sell generic ARVs by Cipla and Ranbaxy (both from India) and Varichem (Zimbabwe), which supplies Stalanev (a first-line, fixed-dose combination of stavudine, lamivudine, and nevirapine). Because of government policy, the mark-up on ARVs is low, at about 30% compared to 60% for all other medicines. Few pharmacies have systems that allow account holders to pay for their drugs in instalments. Some medical aid/insurance schemes cover ARVs, although most do not offer full cover so clients have to pay for the shortfall. While other drugs are available, Kaletra is the most difficult to obtain and is extremely expensive.

Table 2: Cost of ARV drugs at two private pharmacies in May 2007

Pharmacy 1		**Pharmacy 2**	
Drug	**Price Z$**	**Drug**	**Price Z$**
AZT & lamivudine	1,026,000	Triviro 30	765,000
Stalanev 30	830,000	Triviro 40	785,000
Stalanev 40	868,000	Lamivudine	550,000
*Stockrin	986,000	Stavudine 30	550,000
*Videx 100mg	1,300,000	Stavudine 40	550,000
*Videx 150mg	1,800,000	Efavirenz	550,000
*Indinivar	3,480,000		
*Kaletra	4,020,000		

**Medicine used in second-line treatment.*

+ Exchange rate: Official = US$1:Z$250; Parallel = US$1:Z$50,000

By June 2007, prices had increased and were expected to continue soaring. For example, Stalanev 30 cost Z$1,800,000; Stavudine 30 cost Z$700, 000; Stavudine 40 was Z$ 800,000 and Efavirenz was Z$2, 500, 000.

HIV and TB

"Fighting HIV and AIDS requires a stronger integrated response to tuberculosis and other AIDS-related diseases," health minister, Dr. Parirenyatwa recently said, acknowledging the urgent need for joint surveillance of HIV/TB to reduce the burden of TB among PLWHA and vice versa.

Dr. Owen Mugurungi, head of the AIDS and TB unit in the MoH&CW said the MoH&CW had put in place a policy to link TB and HIV services. All people with TB are screened for HIV and vice versa. The program is designed to ensure that clients get all the necessary services from one point.
According to Dr. Karin Hatzold from Population Services International (PSI), all new clients at the organization's Post-Test Support Service Centres receive symptomatic TB screening through a standard questionnaire. If suspected of having TB, patients are referred to a TB diagnostic centre for further clinical investigations through sputum analysis, clinical examination, and chest X-ray. Approximately 14% of PSI's HIV clients are referred for further tests. PSI, which covers about 45% of VCT services in Zimbabwe through its New Start Centres, tested about 84,097 people between January and April 2007, compared with 68,971 during the same period in 2006.

Sandasi added that TB clients receive HIV counselling and voluntary tests. If HIV-positive, they are usually given cotrimoxazole prophylaxis.

Integration of HIV-Related Services with Other Health Services

Although there is a policy framework for the integration of HIV-related services with other health services, implementation varies at different institutions. A number of institutions offer integrated services but some cannot because of limited resources. There is need to ensure standardization of integrated services at all health centres.

Work of Multilateral Agencies

Due to the prevailing political and economic situation in Zimbabwe, most multilateral agencies have reduced their funding and are offering limited support.

While it is acknowledged that WHO is providing support, activists felt its assistance could be more relevant, for example, by addressing barriers to treatment by building health care systems and curbing the brain drain among health professionals. The agencies' impact is also limited because they are bound by multilateral agreements to work with NAC instead of civil society organizations.

Yet civil society representatives interviewed said they believed WHO and UNAIDS have done well in producing modules on community involvement in treatment scale-up. For example, they pointed to the pivotal role played by UNAIDS in rebuilding the capacity of the Zimbabwe National Network of People Living with HIV (ZNNP+) to represent communities. UNAIDS has also played an important role in supporting the Zimbabwe Words to Action Committee (ZWAC), which has brought together AIDS Service Organisations (ASO) and PLWHA in joint advocacy effort.

However, a partnership for resource mobilization, known as the Expanded Support Program (ESP) has been established to enable multiple bi-lateral donors to support the national HIV/AIDS response in Zimbabwe. Donors include the United Kingdom's Department for International Development, CIDA, SIDA, Irish Aid and Norway Aid, who have pledged US$40 million over three years. Components are aligned to Global Fund priorities in Zimbabwe.[24] For example, under the partnership, the US has committed US$18 million to treat 40,000 PLWHA and purchase rapid test kits over a three year period.[25]

Role of PEPFAR in Treatment Scale-Up

Although Zimbabwe is not a target country of PEPFAR, it has benefited indirectly from funds injected through civil society. In 2006, PEPFAR, through the CDC, supported the Zimbabwe Association of Church Hospitals (ZACH) in training 300 primary care counselors. [26]

Role of the Global Fund in Treatment Scale-Up

Zimbabwe has been successful in obtaining funds for HIV/AIDS programs in two of the six rounds of GFTAM grant applications. According to the new Principal Recipient (PR) for GF grants, NAC, the two rounds are being implemented concurrently. The total approved Round 1 grant was US$10,300,000 while that for Round 5 was US$32,742,685[27] The goal of the HIV and AIDS component is to improve quality of life and reduce mortality among PLWHA. The main strategy will be a decentralized, district-level response to ART roll-out. Both grants have a strong focus on ART and PMTCT, and funding will support the ZNSAP.

Challenges experienced during implementation of Round 1 included:

- delays in the disbursements by the Global Fund;
- continued fluctuations of the Zimbabwe/US dollar exchange rate and the prevailing hyperinflationary economic environment affecting budgets and cost estimates for goods and services at implementation levels;

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[24] Presentation by Patricia Darikwa, ESP Coordinator, Universal Access Target Setting Workshop hosted by MoH&CW, NAC, SAfAIDS, OXFAM Australia, UNAIDS, 28 –30 May 2007.

[26] Stories of Hope. 2006. http://www.state.gov/documents/organization/70373.pdf

[27] Presentation by Rose Kona, ESP Coordinator, Universal Access Target Setting Workshop hosted by MoH&CW, NAC, SAfAIDS, OXFAM Australia, UNAIDS, 28 –30 May 2007.

- delays in the procurement of planned second year non-medical and medical commodities, particularly ARVs, test kits and the laboratory equipment;
- institutional capacity constraints of sub-recipients in some of the components;
- delays in the submission of quarterly returns for the disbursement requests; and
- insufficient program funds until November 2006. This caused lowered staff morale and poor motivation, and resulted in premature contract terminations and increased staff attrition in the absence of monthly salary payments.

Promises Made by Country Leaders on AIDS Treatment

1. In 2006 the Reserve Bank governor, Dr. Gideon Gono, pledged to allocate US$1 million for ART on a monthly basis. This has not been done.

2. Although the government of Zimbabwe has noble intentions and sets annual treatment targets, it has repeatedly failed to meet them. In 2005, the government pledged to place 110,000 people on treatment, but only managed 27,000. In 2006, the target was 70,000 but only 46,000 were placed on treatment. This year's target is 120,000, and it is unclear whether it will be fulfilled.

3. "Health for all by 2000" has remained a slogan and an empty promise.

Area of Special Focus

Treatment for marginalised groups, particularly women and children, using prevention of parent-to-child transmission PPTCT as an entry point, thereby capturing families rather than individuals. The program name should be changed from prevention of **mother-**to-child transmission (PMTCT) to prevention of **parent-**to-child transmission (PPTCT) so that both parents feel responsible. The current scenario places the burden of protecting the unborn child solely on the mother while treating her as a vector of transmission and absolving the father from responsibility. Further, most HIV-positive women are captured during antenatal care, therefore introducing such programs would cater for whole families.

Treatment in rural areas. More than 75% of Zimbabwe's population live in rural areas where there is limited access to treatment. It is important to introduce programs that provide treatment literacy thereby ensuring access to ART for this highly marginalised population.

Treatment from a gender perspective. Where resources are limited, women are sidelined and there is need for programs to cater for this vulnerable group and empower them to demand their right to treatment and health.

Treatment for youth. This group is very sexually active and extremely vulnerable to infection, yet there are no programs that target them. There is need for programs for youth both in and out of school.

Recommendations

- **The government and other providers should utilize the expertise of PLWHA in counseling and treatment literacy services**
- **The government must train more health care personnel**
- **The government must work to decentralize access to ART services**
- **The government must use new approaches to encourage uptake of prevention of mother (or parent) to child transmission**
- **Global Fund and other funding sources should provide increased resources for PMTCT and paediatric treatment. Funding is also needed for mobile clinics and fuel coupons**
- **The Reserve Bank of Zimbabwe should allocate foreign currency for purchase of ARVs and to support ARV production**
- **The National AIDS Council should increase the allocation for treatment from 50% to 60% of total funds**
- **The government must improve relations with global partners to increase outside support**
- **The government must work more closely with civil society and other partners in providing HIV services**

RECOMMENDATIONS

WHO

- PMTCT and paediatric treatment would be more successful with support from both parents. The program should be changed from PMTCT to prevention of parent-to-child transmission (PPTCT) so that both feel responsible. PMTCT stigmatizes the woman as the mode of transmitting HIV to a child and places the sole responsibility of prevention on the mother – yet both parents should share it.

MoH&CW

- A radical approach such as Provider Initiated Counselling and Testing (PICT) for public institutions to promote PPTCT would go a long way in encouraging uptake of services and would compliment VCT.

- Use expert patients to assist health service providers in a voluntary capacity to mitigate the impact of staff shortages. Hospitals can make use of PLWHA in the areas of counselling and treatment literacy among other services. It is reported that the Zimbabwe Red Cross Society has started rolling out ART and is using affected communities, an approach that has proved effective at Mt. Darwin and Chivi hospitals.

- Train more health personnel; decentralize ART to clinics and stations, which are run by nurses only;

- Use mobile clinics to reach more people by reducing transport costs and distance travelled to access ART services. Global Fund funding could be used to purchase fuel and vehicles for mobile facilities.

- Decentralise PPTCT and ART sites to local council clinics for easy accessibility.

GFTAM and Multilateral Agencies

- Allocate more resources to PMTCT and paediatric treatment, including mobile clinics and fuel coupons to ensure greater access to services.

- Timely disbursement of Global Fund funds is essential to enable smooth operations.

- Countries are the drivers of these programs; therefore, the Global Fund should be flexible in respecting the country's decisions as long as they are justified and approved by the country coordinating mechanism (CCM).

Reserve Bank of Zimbabwe (RBZ)

- Allocate foreign currency for the purchase of ARVs and to support local ARV production, as promised.

NAC

- Increase allocation for treatment from 50% of total funds to 60%.

Government of Zimbabwe

- Improve relations with other countries, multilateral agencies, and international donors to ensure increased funding and support.

- Seek to work closely with civil society and other partners instead of isolating and treating them with suspicion.

Updates from Previous Focus Countries

DOMINICAN REPUBLIC

By Eugene Schiff and Felix Reyes

In the eight months since the last Missing the Target report was published in November 2006, an additional 2,000 PLWHA in the Dominican Republic now have access to ART. The government has expanded the network of clinics providing treatment to more than 40 nationwide. ARV drugs dispensed by these clinics are purchased almost exclusively through a Global Fund grant. As of May 2007, a total of 6,229 people were receiving ART through the public and NGO sectors, nearly twice as many as one year ago. Health officials indicated that in addition to these 6,229 receiving ARV drugs, nearly 10,000 more individuals are registered and in clinical follow-up in hospitals and clinics providing care for PLWHA, but have yet to start treatment. It is not clear how many of these 10,000 also need but cannot access appropriate testing and lifesaving drugs. WHO estimated that 14,000 people needed ARV drugs in the Dominican Republic at the end of 2006, and documents provided by the local office of the Pan American Health Organization indicated a serious shortfall or treatment gap with as many as 6,100 people who may have died of AIDS last year as result of lack of care and medicines.

Despite significant progress, many challenges remain. Field visits revealed persistent limitations in access to medicines for OIs through the public sector. This is in contrast to statements made by some officials, and offers a sobering reminder that effective distribution of drugs for OIs have not been prioritized or effectively managed. Physicians regularly must refer PLWHA to private pharmacies to purchase the drugs they need, but sometimes cannot afford.

Another concern expressed by PLWHA at public treatment centres was the limited and inconsistent access to viral load tests. It is unclear if sufficient resources are available to offer and coordinate yearly viral load tests for all PLWHA on ART or in clinical follow-up (totalling more than 15,000 people altogether). Some have claimed that decisions on who can receive these important tests are not always based on consistent guidelines or clinical criteria.

Basic infrastructure has been found to be lacking in a variety of areas. For example, for a period of several months there was no working phone line in one of the government's largest public treatment clinics. Furthermore, with a few exceptions it seems that the clients, staff, and administrators in provincial health centres typically receive less attention and have fewer resources than NGO sites and public sector counterparts at the dozen treatment sites in the capital of Santo Domingo. Even in the capital, it remains difficult for PLWHA to be admitted for in-patient hospital care.

Local prevalence studies with data by region are still hard to access and are frequently out of date. Yet the epidemic shows few signs of abatement. Conservative estimates indicate that 60,000 to 80,000 Dominicans are living with HIV. At least 6,000 additional people therefore require ART each year, even without taking into account significant numbers of undocumented Haitian migrants living in and continually migrating to the Dominican Republic. Despite these considerable current and future needs, there are shortages and signs of stagnation. Administrators at some treatment centres warned they were currently "full" (due to lack of adequate staff) and at least one claimed to be no longer accepting additional clients to receive ART.

Particularly prominent in recent months have been expenditures on a host of activities –- highly staged "community forums" and lavish galas that seem to serve more to advance political and institutional agendas than improve the lives of PLWHA. Such events contrast greatly with often poorly managed, overcrowded, ill-equipped and short-staffed public hospitals and clinics nationwide. Grassroots community groups and PLWHA frequently feel left out and marginalised, but many are unable to risk financial support by speaking out and actively challenging the strategies of relatively powerful, politically connected administrators now managing millions of dollars in foreign aid for HIV/AIDS each year.

Recently, several workshops have been organised and agreements have been signed announcing plans for a new Bi-national HIV/AIDS Strategy between Haiti and the Dominican Republic. However, hundreds of thousands of Haitian workers and many children of Haitians migrants born in the Dominican Republic still lack legal documents and face exclusion, barriers to accessing essential services, and increased stigma and blame surrounding HIV/AIDS in their communities and nationwide. While concrete incremental improvements deserve to be supported, it is very likely that the current HIV/AIDS prevention and control strategies will fail, and the treatment gap will become even greater without effective new policies to significantly impact and address politically sensitive issues such as widespread poverty, inequality, migration and tourism, discrimination, and poor working and living conditions of Haitians and the majority of Dominicans on the island.

Key results, advocacy initiatives, and issues in recent months include the following:

- ITPC's entire Missing the Target #3 report was translated into Spanish. The Spanish version of the Dominican Republic chapter was circulated to thousands of PLWHA at treatment centres as well as to counsellors, physicians, and decision makers throughout most of the country. The report and several key issues outlined in the report were subsequently featured in the local press and online publications.

- There are signs of greater interest and willingness on the part of the press to expose instances of corruption within the HIV/AIDS bureaucracy and to question resource allocation and the effectiveness of projects being funded by international donors.

- Some important new initiatives have been introduced, such as highly publicised free HIV testing campaigns. However, closer investigation in many clinics and regions suggests there is still no or only limited availability of free HIV counselling and testing for the general population at hospitals, clinics, or elsewhere.

- Despite new resources and numerous projects by COPRESIDA, the need remains for more independent community-based advocacy.

- There has been little recognition of or coherent strategy to address the needs of IDUs or to implement harm reduction interventions.

- There have been several important price reductions globally, but more local discussions are needed related to the government purchasing and the pricing of drugs. The need for second-line medicines will likely become much greater in the future as individuals develop resistance to first-line drugs.

- The new Social Security System still discriminates against PLWHA and excludes ARVs from the new national insurance plan.

INDIA

By Abraham KK, Celina D'Costa, Elango Ramachandar,
Murali Shunmugam, Dr. Venkatesan Chakrapani
Indian Network for People living with HIV (INP+)

According to UNAIDS, about 5.7 million individuals in India were living with HIV at the end of 2005, thereby making it the country with the world's largest number of PLWHA (UNAIDS, 2006). At the end of April 2007, a total of 70,782 PLWHA—42,604 men, 22,957 women, 5,113 children, and 108 individuals classified as transgender—were receiving treatment through the 107 ART centres supported by the National AIDS Control Organisation (NACO). An additional 4,442 PLWHA were receiving ART outside of the core public sector program. Global Fund assistance is directly responsible for ART provision to some 56,130 of PLWHA in the public sector system and 1,963 in a separate program (Global Fund Round-II non-governmental centres).

According to WHO estimates, some 785,000 PLWHA in India needed ART by the end of 2005. Targets set at the end of the third phase of the National AIDS Control Programme (NACP-3) are for 300,000 adults and 40,000 children to be on ART in the public sector by the end of 2012. The interim target is to have 100,000 on ART by the end of 2007. Clearly, therefore, only a fraction of those needing treatment are receiving it now or can hope to receive it in the next half decade.

Status of previous key recommendations to NACO

1. Develop a plan to provide second-line ARVs through national ART program

Follow-up:

All PLWHA (including children) in the national program are provided only first-line ARVs; second-line ARVs are not currently available in the national program. The director general of NACO has announced that NACO would start providing second-line ARVs once the treatment access target of 100,000 is reached. It is expected that NACO will meet this target by December 2007. The government has plans to seek funding from international sources for procuring second-line drugs.

2. Provide paediatric formulations for ART

Follow-up:

The National Paediatric HIV/AIDS Initiative was launched in November 2006 by NACO in collaboration with the Indian Academy of Paediatrics, UNICEF, WHO, and the Clinton Foundation. Plans are to implement it in a phased manner with the goal of providing ART to 40,000 children by 2012. Meanwhile, national paediatric ART and dosing guidelines have been released. (Currently, all children are on first-line ART. However, paediatric formulations [syrup forms] are not available in all ART centres.)

3. Develop a policy to ensure equity in ART access to members of vulnerable groups

Follow-up:

No information is available on how many MSM, IDUs, and sex workers all members of vulnerable groups are receiving ART through the national program. However, the numbers are likely to be very low because of actual or perceived discrimination.

In Mumbai, MSF has started a treatment program open only to PLWHA who have been excluded from the government program for one reason or another. MSF states: "Most of MSF's patients come from marginalised groups such as transgender women (*hijras*), MSM, commercial sex workers, migrant workers, and those living in poverty. Started in February 2006, the clinic had approximately 200 patients by July 2006. Some 500 patients should be receiving ARV treatment through our program in 2007."[1]

Initiatives such as this one are invaluable, yet they cannot absolve the government of its responsibility toward all people. There is a need for a national action plan to ensure that marginalised populations living with HIV are not excluded from the national ART program.

4. Establish enough ART centres across the country to help facilitate universal access

Follow-up:

NACO's target is to have at least 188 public-sector ART centres by December 2007, up significantly from the current total of 107.

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[1] See www.msfindia.in/msf-in-india.html#mumbai.

KENYA

By James Kamau

- The number of people receiving HIV treatment and care in Kenya reached 135,000 by the first quarter of 2007. This number is projected to increase to 181,000 by the end of the FY 2007/08.

- The government and its development partners have undertaken a costing for HIV/AIDS commodities for the next three years (2007/08, 2008/09 and 2009/10) to ensure that people already on treatment and care, as well as those newly enrolled, have sustained access to ARVs and other HIV/AIDS commodities. This exercise will improve planning for program needs and for the procurement of HIV/AIDS commodities in order to avoid shortages.

- The Clinton Foundation has undertaken to fund treatment for all paediatric cases in the country. The Foundation has hired over 200 nurses to assist in implementing the programme. The Foundation will also support children who were formerly being treated by MSF.

- It is projected that PEPFAR will put another 80,000 more people on ARVs to reach a target of 200,000 people on treatment by July 2008.

- The number of people earmarked for treatment with support from the Global Fund increased from 42,000 to over 48,000 people, although the funding was intended to cover only 40,000. The number was overshot because of the increased government campaign to put more people on ARV.

- The government has also factored into the budget for the FY 2007/08 a line item for ARVs amounting to Kshs. 500 million. This is supposed to cover people who were formerly being supported by MSF and whose funding is ending at the end of the current financial year.

Challenges

- The main challenge to ensuring sustained access to treatment is the shortage of funding for HIV/AIDS commodities. For example, it is estimated that an additional US$3.3 million, US$29 million and US$170.7 million will be needed during the years 2007/08, 2008/09 and 2009/10, respectively. The second challenge is that most hospitals, especially those in the rural areas, lack equipment for CD4 count testing. Also, the lack of qualified personnel, especially in the rural health facilities, hinders access to treatment.

NIGERIA

By Olayide Akanni

At the end of 2005, an estimated 2.86 million Nigerians were living with HIV, of whom 507,500 (412,500 adults and 95,000 children) required ART.

According to the Federal Ministry of Health, as of the first quarter of 2007, 124,567 people were on ART, including 5,279 children. There are a total of 211 treatment sites and there are plans to scale up to 240 sites by the end of 2007[1].
However, treatment centres are still largely concentrated within urban areas. A more equitable distribution of treatment centres across the country is one of the key areas that the National AIDS and STIs Control Programme is expected to focus on this year.

While ART coverage is generally low overall, the proportion of paediatric patients receiving ART remains extremely low. One of the major reasons identified for this is the low level of awareness about the availability of paediatric ART and challenges encountered in identifying HIV positive children. This is further compounded by the often fatalistic attitudes of parents or guardians regarding HIV positive children[2].

The Treatment Information Technical Working Group has been instituted, composed of the National Agency for the Control of AIDS (NACA), the Clinton Foundation, and civil society groups. The Working Group will be responsible for communicating treatment information and updating the public on the availability of paediatric treatment services.

Expanding the scope of access to paediatric services is also one of the country's focus areas in the development of the Global Fund Round 7 HIV/AIDS grants. In April 2007, NACA convened a National Summit which drew participation from key stakeholders across the country. The meeting provided an opportunity to discuss the challenges in scaling up HIV/AIDS prevention, treatment and care services and to identify best practices and opportunities. Outcomes of the meeting are to inform the implementation of the HIV/AIDS response in Nigeria.

At the first Expanded Theme Group Meeting convened by NACA in February, 2007, the various partners implementing treatment stated that as part of their activities planned for the year they will focus on health care workers capacity, PMTCT, and ART.

Laboratories with adequate infrastructure for monitoring ART are few, and disparities exist between the laboratory facilities of some donor-funded treatment programmes and those of Government of Nigeria-supported programmes. The capacity of all laboratories must be developed and quality assurance programs implemented. Laboratory tests that monitor ART should be free to avoid the development of drug resistance in the population.

Update on Country Team Advocacy Activities

In January 2007, the country team organized a Treatment Stakeholders Forum in Lagos, which aimed at sharing the findings of *Missing the Target #3* and sharing them with stakeholders. The forum was organised as a medium for care providers, policy makers, members of civil society, the media, as well as other stakeholders. The goal was that participants would not only express their fears and concerns, but also generate ideas and solutions that those at the helm of affairs of the nation's treatment programme could adopt and implement, with the goal of making the process more efficient.[3]

Recommendations for expanding treatment access:

- Strengthen or upgrade laboratory infrastructure in treatment centres;
- Subsidise cost of monitoring tests;
- Upgrade rural infrastructure to support rapid scale-up of treatment;
- Implement comprehensive care for PLWH, including access to treatment for OIs, nutritional support, and psychological care
- Find and maintain balance between "rapid treatment" and "qualitative care"

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[1] Presentation by Dr Annette Akinsete, Coordinator of the National AIDS and STIs Control Programme (NASCAP) during the 4th National AIDS Summit (April 1-4 2007)

[2] Comments by Prof Kikelomo Osinusi of the University College Hospital (UCH)

[3] Issues Towards Achieving Nigeria's Aids Treatment Target in 2007 by Florence Udoh; Daily Champion Newspapers, March 1 2007

RUSSIA

By Shona Schonning, Gennadiy Roshchupkin, PHD Consulting, Raminta Stuikyte, Central and Eastern European Harm Reduction Network (CEEHRN)

The number of people receiving ART in Russia continues to rise, reaching about 19,000 as of May 2007. Yet at the same time the number of those in need is growing even faster, to 140,000 in April 2007 (as per WHO's median estimate) from 100,000 a year earlier.

The main barriers to access continue to be:

- low public awareness of ART availability;
- underinvestment in targeted programs for vulnerable groups (notably IDUs, MSM, and sex workers);
- HIV-related stigma and discrimination, particularly toward members of vulnerable groups;
- lack of client-centred services and the continued delivery of HIV services through a vertical structure;
- Limited support (training & salaries) for heath workers
- problems with pharmaceutical purchases and ensuring uninterrupted supplies;
- low levels of access to harm reduction services (such as needle/syringe exchange for IDUs); and
- limited treatment services for IDUs, who comprise the majority of those in need of ART. IDUs also face challenges stemming from the lack of opiate substitution therapy, which is still illegal in Russia.

Advocates originally were hopeful in the wake of the creation of a national multisectoral Commission on HIV/AIDS with decision-making power. So far, however, the commission has been ineffective. An appeal by Russia's Union of PLHIV to include a representative on the commission was rejected. The group has met only once and has not been involved in key decisions, including those concerning the HIV component of the Federal Program on Prevention and Struggle with Socially Significant Diseases for 2007–2011, which was approved by the government in May 2007.

The Federal Program includes only two key indicators on HIV: a lower number of new registered cases of HIV per year, and a higher level of access to PMTCT. Yet these indicators of success only tell part of the real story. For example, the number of newly registered cases has been declining largely because testing uptake remains low, a situation that does not reflect the real number of PLWHA. The second indicator, on PMTCT access also does not reflect priorities in terms of reducing morbidity and mortality given that access to PMTCT is already around 90% in Russia. More striking is that an indicator reflecting access to ART is not included. Universal access targets have not been linked to the program nor have they been approved by the national commission.

SOUTH AFRICA

By Fatima Hassan, senior attorney at the AIDS Law Project (ALP)

Civil society and treatment access activists spent the first half of 2007 working closely with senior government officials as well as labour, business and other sectors in finalizing and launching the new *National HIV & AIDS and STI Strategic Plan for South Africa, 2007–2011* (NSP).[1] Activists are hopeful that this effort and the restructuring of the South African National AIDS Council (SANAC) will help strengthen coordination among all sectors of civil society involved in treatment, care, and support activities. Moreover, for the first time a civil society representative has been selected as deputy chair of SANAC.[2] This is an important development because the last few years have been characterized by conflict between government and civil society regarding nearly all aspects of HIV/AIDS policy.

The new NSP offers numerous challenges as well as an opportunity for civil society to work with other sectors (i.e., business and labour) and the government to ensure that its targets on prevention, care and treatment are reached.[3] According to the new deputy chairperson of SANAC, "It marks a new chapter of national consensus in respect of the objectives of HIV prevention and treatment programs as well as the strategies, policies, and laws that are required to reach these objectives".[4]

Ensuring that all sectors contribute to the effective implementation of the NSP is critical, especially because South Africa continues to fall far short of treating the thousands of people who are still in need of treatment. According to data provided by the head of the HIV/AIDS Programme, as of April 2007 a total of 257,108 patients were accessing ART in the public sector.[5] However, according to government reports, approximately 30,000 people are on official waiting lists. Data collected by the AIDS Law Project indicate that between 100,000 and 110,000 additional people are on treatment in the private and not-for-profit sectors.

Given that the NSP aims to increase the number of new adults initiating ART from 24% of new AIDS cases in 2007 to 80% of new AIDS cases in 2011,[6] South Africa has a long way to go toward meeting these and other important targets.

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[1] The cabinet approved the NSP as a strategic framework that will guide the national response to HIV and AIDS over the next five years. Information available online at: http://www.gcis.gov.za/media/cabinet/070503.htm

[2] Mark Heywood, ALP director's and the national treasurer of the Treatment Action Campaign (TAC), was elected deputy chairperson.

[3] The NSP proposes that by 2011, 70% of people in South Africa should have tested voluntarily for HIV—(page 83); by 2011, 95% of all public and private facilities in South Africa will routinely offer HIV testing services (page 82); and by 2011, 80% of adults needing ART should be receiving it. According to the NSP's targets, this means that about 1.625 million adults should have been initiated on ART by 2011 (page 85). Implementing the NSP is expected to cost 45 billion rand ($6.2 billion) for the first five years.

[4] Interview with Mark Heywood, SANAC deputy chairperson.

[5] Donors such as PEPFAR, ARK (Absolute Return for Kids), and MSF support about a third of these patients.

[6] Amounting to an additional 1.375 million adults initiated on ART within the next five years and taking the total number of people on ART to beyond 1.7 million.

Short Summaries from Other New Countries

ARGENTINA

Dr. María Lorena Di Giano

Background

The fight against HIV/AIDS was declared a national priority for Argentina in 1990 and the National Health Ministry was authorized to implement a comprehensive response. The National AIDS Program, established in 2000, invests the majority of its allocated resources in treatment (the purchase of drugs and supplies) with a much smaller amount invested in prevention (primarily for the purchase of condoms).

According to the latest statistics published in the Bulletin of the National HIV/AIDS Program in December 2005, in agreement with UNAIDS estimates, there are 127,000 people living with HIV in Argentina, with 60% thought to be unaware of their status.

The Argentinean AIDS epidemic increasingly affects women. In 1987, when the first woman was diagnosed with AIDS in Argentina, the ratio of men to women with AIDS was 92:1; by 2005, this ratio had dropped to 2.4:1. HIV infection among both genders is concentrated in the 20–39 age range.

Issues related to treatment access

According to information supplied by national health authorities, there is broad access to ART (including extensive access to second-line medicines) and treatment for OIs in Argentina. UNAIDS estimates coverage reaches about 95% of those who have been diagnosed and need treatment. However, PLWHA organizations have identified problems in national and regional treatment programs, including inadequate logistics and supply systems. The deficiencies vary widely by province; some provincial governments have demonstrated the necessary political will, while others have evinced a marked lack of resources and a lack of interest in solving treatment access problems.

Moreover, because of a shortage of specialized doctors, health services for PLWHA in most provinces are concentrated in the larger capital cities. Many patients must travel hundreds of kilometres to receive care and treatment.

Stigma and discrimination toward PLWHA — particularly against transvestites and drug users — are still in evidence in most care centres, which serves to delay or limit ART access among members of these groups. Many health care professionals refuse to provide care to PLWHA and show no interest in participating in programs designed to increase HIV awareness and sensitivity.

RECOMMENDATIONS

- Create an intersectorial and interministerial country committee that is transparent, democratic, and representative of diverse sectors—both governmental and non-governmental—in which the participation of affected groups is guaranteed. The goal is to design more effective national public policies in the area of HIV/AIDS that are recognized and complied with across the country.
- Establish a national strategic plan for 2008–2010 that clearly defines the goals related to UNGASS commitments. The plan should also focus on prevention strategies from a human rights perspective.
- Articulate and create ways for the National AIDS Program and local programs to work together, share responsibilities, and provide effective solutions to overcome operational barriers.
- Work to improve data collection systems and epidemiological surveillance, focusing primarily on vulnerable groups including transvestites, sex workers, and IDUs
- Increase resources and capacity for HIV diagnosis and strengthen counselling and testing centres. Particular attention should be paid to bringing in members of vulnerable groups.
- Generate and implement stigma-reduction programs to train health workers how to care for PLWHA with sensitivity.

BELIZE

By Caleb Orozco, President, United Belize Advocacy Movement

As of December 2006, a total of 3,805 HIV cases have been reported in Belize. According to UNAIDS, the adult HIV prevalence rate stands at about 2.4% and the epidemic has become generalized. Data from the National AIDS Coordinator indicate that 494 PLWHA were receiving ART as of December. The health care system offers seven different first-line regimens for adults as well as an additional one, containing Kaletra, for children who have developed drug resistance. With the assistance of money from a Global Fund grant, HIV treatment services are available free of charge.

The Ministry of Health reports that in 2006, 93% of HIV-positive pregnant women received single doses of nevirapine as *PMTCT therapy*. That year, however, guidelines were changed and nevirapine was phased out in favour of a regimen of zidovudine and lamivudine to begin at 14th week of pregnancy.

HIV prevalence is thought to be higher than average among many *vulnerable groups* such as inmates (calculated as 4.9%). Comparable data for sex workers and MSM are incomplete. Government officials do not collect data on these groups and consequently give low priority to reducing the social stigma and discrimination that limits their access to key health services. There are too many stop gap strategies currently in place that inadequately provide HIV prevention and treatment information to vulnerable groups in the public health system.

The main challenges to Belize's HIV/AIDS response, as summarized by the technical director of the National AIDS Commission in a 2006 report, include the following:

- limited human resources in support of critical HIV/AIDS services and programs;
- insufficient engagement and monitoring of the private sector in offering services;
- poor integration of services at the primary level;
- a highly centralized system of care and treatment;
- insufficiently extensive referral systems to relevant services, which would help strengthen a long-term case management approach to care;
- limited roll-out of nutrition programs to support adherence; and
- lack of home-based care for persons who wish to remain anonymous for fear of stigma and discrimination.

RECOMMENDATIONS

The following recommendations are designed to help promote an improved HIV/AIDS response in Belize:

- a greater degree of community-based dialogue and programming needs to take place so that marginalised groups are involved in care, treatment, and prevention efforts;
- an independent watchdog (such as an ombudsperson) should be established to train staff from media outlets regarding key HIV-related health and human rights issues. This would help ensure that reporting is accurate and non-discriminatory, especially in regard to vulnerable groups;
- monitoring and evaluation systems should be strengthened to consider how condom distribution takes place and to recommend changes if necessary;
- data collection for MSM, sex workers, and other vulnerable groups must be more extensive and regularized;
- community members should be directly involved in strategy development;
- PLWHA should be directly engaged in policymaking at all levels, and among all stakeholders, in regards to HIV/AIDS issues. This will help ensure that policies are appropriate and humane and should also help reduce stigma and discrimination;
- issues specific to HIV and AIDS should be integrated into poverty alleviation programs. This is important for numerous reasons; including the fact that ART adherence is improved by access to decent nutrition.

CAMEROON

By Mrs Wendi Losha Bernadette, Dr. Oliver Birnso Verbe

According to data provided by the Cameroon Ministry of Public Health, some 500,000 people in the country are living with HIV (although this number may be much larger since many at-risk individuals shun HIV services due to fear and stigma). Of these, only 31,200 are currently on ART. Two-thirds receive treatment at accredited public hospitals and one-third from accredited private health facilities.

Recently the Cameroon government has pledged to provide free treatment by the end of 2007 to an additional 12,000 people who have already qualified but have not started ART because they cannot afford fees for tests or registration. This effort should bring the number of people on ART to 43,000.

The cost of ART has fallen sharply in recent years through the intervention of the Cameroon government and support from donors including the Global Fund. As of May 1, 2007, ART was declared free of charge to all who need it. However, that statement is misleading because a registration fee of US$3 per client remains in place. Also, despite claims that treatment is available across the country, many treatment centres report having few or no drugs to distribute.

Equally problematic is the fact that all relevant tests require a fee from the patient. An HIV test in most public institutions costs between US$1 and US$2; only pregnant women and children younger than five are screened for free. On average, many biological tests (for liver and kidney function, for example), now cost US$42 per person, less than half of what was charged in the recent past but still beyond the reach of all but the very rich.

These fees are a barrier because it is difficult for PLWHA to avoid them. People qualify for treatment based on results from CD4 tests, viral load analysis, and various other tests, including those measuring the health and function of the liver and kidneys. Individuals can receive these tests at health centres as well as from mobile screening teams that visit schools, markets, and other public places on special occasions. Confirmation tests are carried out only in approved centres.

The tests alone are not the only financial burden on most Cameroonians. Many people cannot afford transit costs to accredited treatment centres and thus have little or no opportunity to access ART.

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RECOMMENDATIONS

The following steps are necessary to improve access to ART for all who need it in Cameroon.

The government should:

- provide all pre-treatment tests free of charge;
- establish more treatment centres; and
- eliminate registration fees.

Health providers should:

- provide better information on drug side effects;
- offer more extensive information on the importance of proper nutrition and how it can be obtained in a resource-poor environment; and
- increase the availability of counselling services.

NGOs should:

- create more support groups; and
- establish mechanisms to effectively monitor and evaluate government and health providers' structures, policies, and services.

MALAYSIA

By Edward Low

As of December 2006, there were some 90,000 PLWHA in Malaysia and, according to the National HIV/AIDS Treatment Registry, the number of people receiving ART had increased to approximately 5,000. According to a WHO report on progress towards universal access, the number of people in need of treatment in Malaysia will reach 12,000 by the year 2010. The Ministry of Health estimates that it currently costs between US$4 million and US$7 million to provide ART per year.

The Ministry of Health provides first-line ART free of charge only at selected government hospitals. However, not all of those facilities have proved willing and able to participate in the initiative, and others have yet to enrol enough patients to meet their targets.

The following are the most important barriers to effective scale-up of treatment access:

- *Discrepancies in distribution by ethnic groups*. Although ethnic Chinese comprise only about one-quarter of the population, many more ethnic Chinese (71%) than Malays (16%) are on ART. One likely reason is that more Malay PLHIV are IDUs and therefore less likely to start on ART because of financial constraints and poor family support. Also, the Chinese community in general tends to have greater purchasing power than other ethnic groups. This is important because patients must buy at least one or two of the three ARVs in the first-line regimen, with the government subsidizing the rest.
- *Halting ART*. The most common reasons for stopping ART have been financial constraints, poor adherence, and loss to follow up.
- *Lack of Kaletra*. The government does not provide Kaletra for second-line therapy due to its relatively high cost.

Selected recommendations to boost treatment access

The Ministry of Health claims that it had abided by WHO's "3 by 5" initiative, but no plan was produced indicating that it had accepted or followed through on the treatment targets. Among the areas not addressed are programs for peer counselling and adherence support.

Although Malaysia aims to put 12,000 people on ART by the end of 2010, the training of physicians and medical staff and the upgrading of laboratory support are likely to fall short of what is needed.

The Ministry of Health should issue a compulsory license for efavirenz and Kaletra and/or import cheaper drugs to increase the number of people on treatment and achieve its treatment target.

MOROCCO

By Othman Mellouk

It is estimated that between 20,000 and 30,000 Moroccans were living with HIV by the end of 2006[1], of whom 3,100 were in need of treatment. The Moroccan national treatment program began near the end of 1998, when approximately one hundred persons were enrolled. In September 2003, with the support of the Global Fund, universal access to treatment was guaranteed for all Moroccans with HIV. Currently, though, only 1,585 adults and 68 children are receiving ART in the eight treatment centres in the country; 45% of adults on treatment are women (women represent 38% of the reported AIDS cases). About 7% of those treated are covered by the private sector and/or medical insurance, while the rest are equally supported by the Moroccan Ministry of Heath and the Global Fund. The goal of the Ministry of Health is to reach 65% of the estimated number of people in need of treatment by 2007 and 75% by 2010 (3,250 adults and 135 children). Lab tests are free, although there is limited availability. Viral load tests are only performed at one site, and despite recent efforts to make CD4 testing available in some cities, PLWH still must travel in order to have these tests. The major weakness of the Moroccan HIV program is limited access to drugs for the prevention and treatment of OIs. Except for a few drugs like cotrimoxazole provided by the government, treatments for OI are mostly the responsibility of patients and generally provided for by a local NGO (ALCS).

Morocco has national guidelines for treatment that are updated in accordance with WHO guidelines. Both 1st line and 2nd line treatments are available, but prices for ARVs remain very expensive in comparison with other lower-middle income countries. The MINISTRY OF HEALTH and treatment activists are working on a strategy for price reductions in order to guarantee the sustainability of the treatment program. One of the major challenges is how to allow more generic competition subsequent to the enforcement of TRIPS in 2005, as Moroccan intellectual property law doesn't include all the flexibilities allowed by WTO (ex. parallel import is not permitted). The recent conclusion of a free trade agreement with the US that includes additional patent protections that go beyond TRIPS provisions will probably have a negative impact on the prices of ARVs and OI drugs.

RECOMMENDATIONS

- The Ministry of Health should accelerate the process of decentralization of lab tests to all the cities where treatment centres exist.
- OI drugs budget remains underestimated and should be increased rapidly.
- There is an urgent need to develop a strategy for price reduction of ARVs and OI drugs, which are still very high in comparison with similar countries.
- Treatment activists request the revision of the patent law in order to include safeguards to protect access to medicines and facilitate the use of generic drugs.
- The "side letter" exchanged between Morocco and the US after the FTA should be used to protect public health and access to medicines by allowing more generic competition.

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[1] 2,169 cases of AIDS have been reported by the end of 2006, 62% are men and 38% are women.