MODELS FOR LIFE
Advancing antiretroviral therapy
in sub-Saharan Africa

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The chapters in this volume are based on papers and panel discussions from an international conference entitled “Models for Life: What can we learn about ARV distribution from field experiences in low-income countries?”, held in September 2004 in Copenhagen, Denmark, and a satellite seminar “The Power of the Pill: Challenges of ARVs in East Africa” the same month in Uppsala, Sweden.

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LIST OF ABBREVIATIONS ................................................................................................. 4

ACKNOWLEDGEMENTS ........................................................................................................ 5

INTRODUCTION ...................................................................................................................... 7

ACCESS TO ANTIRETROVIRAL THERAPY ........................................................................ 9

Chairperson:
  Catrine Christiansen, Researcher, Nordic Africa Institute

Panellists:
  Cissy Kityo Mutuluza, MD, Deputy Director, Joint Clinical Research Centre:
  Ugandan Cost Recovery Model for Countrywide Provision of Antiretroviral Drugs:
  JCRC Experience
  Stine Haakonson, PhD Candidate, Department of Globalisation and Governance Research,
  Danish Institute for International Studies: Governance of ARV access in Uganda
  Lotte Meinert, PhD, Department of Anthropology and Ethnography, University of Aarhus:
  ARV models in Uganda

Discussants:
  Birgit Lundbak, Programme coordinator, Save the Children Denmark
  Lisa Ann Richey, PhD, Department of Geography and International Development Studies,
  Roskilde University

PROVIDING ARVs: HOLISTIC APPROACHES AND SCALING UP .................................. 20

Chairperson:
  Lisa Ann Richey, PhD, Department of Geography and International Development Studies,
  Roskilde University

Panellists:
  Rose Ochen, ARV coordinator, Reach Out Mbuya, Uganda
  Cathrine Wohlert, MD, and Alexandra Kruse, MD, Médecins Sans Frontières, Denmark

Discussants:
  Tilde Narp, HIV/AIDS Programme Delegate, Danish Red Cross Zimbabwe
  Hanne Mogensen, PhD, Department of Anthropology, University of Copenhagen

ARVs AND PUBLIC HEALTH SERVICES ........................................................................... 26

Chairperson:
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LESSONS LEARNED FOR THE NGO COMMUNITY .............................................................. 31
<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
</tr>
</thead>
<tbody>
<tr>
<td>AIDS</td>
<td>Acquired immunodeficiency syndrome</td>
</tr>
<tr>
<td>ARV</td>
<td>Antiretroviral</td>
</tr>
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<td>HIV</td>
<td>Human immunodeficiency virus</td>
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<tr>
<td>JCRU</td>
<td>Joint Clinical Research Centre (Uganda)</td>
</tr>
<tr>
<td>MSF</td>
<td>Médecins Sans Frontières</td>
</tr>
<tr>
<td>NGO</td>
<td>Non-governmental organization</td>
</tr>
<tr>
<td>PEPFAR</td>
<td>(US) President’s Emergency Plan for AIDS Relief</td>
</tr>
<tr>
<td>PMTCT</td>
<td>Prevention of mother-to-child transmission</td>
</tr>
<tr>
<td>TRIPS</td>
<td>Agreement on Trade-Related Aspects of Intellectual Property Rights</td>
</tr>
<tr>
<td>UNAIDS</td>
<td>Joint United Nations Programme on HIV/AIDS</td>
</tr>
<tr>
<td>VCCT</td>
<td>Voluntary confidential counselling and testing</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
</tr>
<tr>
<td>WTO</td>
<td>World Trade Organization</td>
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<tr>
<td>3 by 5 Initiative</td>
<td>WHO/UNAIDS goal to treat 3 million people living with HIV/AIDS by 2005</td>
</tr>
</tbody>
</table>
“Models for Life: Advancing antiretroviral therapy in sub-Saharan Africa” is based on two conferences that were held in Copenhagen and Uppsala, on 7–8 September 2004. The events brought together more than 70 key actors in the field of HIV/AIDS and antiretroviral (ARV) therapy from Denmark, Sweden and Uganda. The conferences were unique in that each panel and the subsequent discussion brought together researchers, donors and representatives from non-governmental organizations (NGOs), in order to link theory, operations research and practice. Background papers were presented and, in turn, a dialogue between researchers and practitioners was facilitated, with the goal of reaching concrete recommendations for non-governmental organizations. By sharing viewpoints on the same issues, conference participants were able to better grasp why antiretroviral drugs are so important right now, but at the same time often so difficult to provide to those who need them.

We would like to thank the Working Group on Children and Young People of the Danish NGO Network on AIDS and Development (Aidsnet) and Aidsnet’s staff for coordinating the conference and this publication as well as the Nordic Africa Institute and the Department of Geography and International Development Studies at Roskilde University for financial and technical support.

This working paper would not have been possible were it not for the excellent papers presented at the conference and the subsequent discussions. We would like to especially thank the following for their participation in the conference and their permission to publish material presented in this publication: Ib Bygbjerg, Bjarne B. Christensen, Stefan Hanson, Stine Jessen Haakonson, Betty Kyaddondo, Cissy Kityo Mutuluza, Lotte Meinert, Rose Ochen, Alexandra Kruse, Birgit Lundbak, Hanne Mogensen, Tilde Narp, Lisa Ann Richey, Susan Reynolds Whyte and Catherine Wohlert.

About this paper
This working paper reflects the presentations and discussions from both conferences that are most relevant for NGOs and researchers. It covers a wide range of the issues that were brought up at the conferences, but focuses on the following three main topics:

- Access to antiretroviral therapy
- Holistic approaches to providing antiretroviral therapy, prevention and support
- Antiretroviral therapy and public health services.

Each section begins by introducing the main issues to be addressed as well as giving information on the presenters, the discussants and the chairpersons. The different presentations are then put into perspective by summarising the main questions from the participants and the other panellists. This is followed by a short list of key works from the literature that were referred to by the panellists or provided by the organisers as essential background information. The final section concludes with a list of take-home messages for NGOs.

This working paper is based on the presentations that were given in September 2004 but as the field of analysis is rapidly changing, this paper has also been updated with more recent figures and findings in order to provide as much up-to-date knowledge as possible. It was prepared by an Aidsnet team including Jeffrey Victor Lazarus, Catrine Christiansen, Lisa Ann Richey and Lise Rosendal Østergaard, and was approved by the panellists.

Bjarne B. Christensen
Chairperson
Aidsnet Steering Committee
Copenhagen, May 2005
Estimated number of people receiving ARV therapy and percentage coverage in 20 countries with the highest unmet need, June 2005*

* Unmet need is expressed as the total number of people aged 0-49 in need of antiretroviral treatment in 2005 minus the estimated number of people on treatment in June 2005.

Introduction

Globalization has brought access to medical breakthroughs to the forefront of political debates addressing inequality and inequity between countries. In high-income countries, antiretroviral (ARV) therapy has become widely available, yet only approximately 8% of the 28.5 million people living with HIV/AIDS in sub-Saharan Africa benefit from this therapy. Today, efforts to scale up ARV drug distribution in low-income countries are proliferating. Yet as ARVs become more widely available, new issues arise. How can equitable access be ensured? Will the focus on treatment undermine prevention efforts? What broader care and support do people receiving ARV therapy need? What will the influx of resources for ARV therapy mean for public health services? These were some of the key issues raised at the XV International AIDS Conference held in Bangkok, in July 2004. While the theme of that conference was “Access for All,” the presentations revealed that access to ARV medicines is only the norm for a tiny minority in low-income countries (see WHO map, previous page) and even many middle-income countries, and that selection and exclusion mechanisms will only intensify as national and non-governmental organisation-based programmes develop.

A number of Danish non-governmental organisations (NGOs) are in the process of initiating ARV distribution within the framework of their HIV/AIDS prevention and care programmes in sub-Saharan Africa. To support these initiatives, a workshop entitled “Models for life: What can we learn about ARV distribution from field experiences in low-income countries?” was held in Copenhagen by the Danish NGO Network on AIDS and Development (Aidset) and the Nordic Africa Institute in collaboration with the Departments of Geography and International Development Studies, Roskilde University. It brought together researchers, donors and NGO practitioners from Denmark and Uganda. A satellite workshop “The Power of the Pill: Challenges of ARVs in East Africa” also took place, in Uppsala, Sweden, under the sponsorship of the Nordic Africa Institute. This workshop linked Danish and Swedish researchers and practitioners with Ugandan colleagues working on issues related to the provision of ARV therapy. The Copenhagen workshop was a part of the ongoing discussion within Aidset on evidence and better practices for NGO support to individuals and communities affected by HIV/AIDS in low-income countries.

It is only recently that the issue of ARV therapy has moved from being a question of why treatment is necessary to one of when and how to provide treatment in low-income settings. Until 2002, the global debate on HIV focused almost exclusively on preventing the spread of the virus. With prevalence rates escalating as HIV became endemic among the general population of numerous sub-Saharan African countries, the response, often based on arguments of cost-effectiveness, was that prevention made the most sense. After all, ARV drugs were far too expensive to be afforded by the countries where they were most needed. Furthermore, the health systems in poor countries did not have the technical or human resources capacity to provide ARV therapy or monitor their use. This was compounded by fears of the development of drug resistance resulting from non-compliance with treatment regimes.

However, a renewed interpretation of access to ARV therapy as an important human rights issue came after the international AIDS conference in Barcelona (2002). This radical change resulted from a coalition of NGOs from around the world, groups of HIV-positive activists, United Nations agencies and some governments. Both the Millennium Development Goals and the WHO/UNAIDS “treat three million by 2005 initiative” led to priority being given to the right of an individual to receive ARV drugs. It also led to a subsequent concern about the high prices and pharmaceutical companies’ rights to protect patents for life-saving drugs. This international trend was in fact an elaboration of the decision taken in 1996 by the Brazilian Ministry of Health, which guaranteed free and universal access to antiretroviral treatment for people living with HIV/AIDS.

ARV therapy represents a window of hope, and it has changed the nature of health interventions. It has brought forth the question of access – not only to ARVs, but also to health care in general. Many people lack access to treatment of opportunistic infections and reproductive health services, to basic information on prevention, and to methods such as
male and female condoms: all of which are key elements in limiting the further spread of HIV.

We hope that this working paper will contribute to efforts to effectively and equitably scale up treatment in low-income countries by:

• Sharing new and proven research-based and NGO-based knowledge on ARV provision in low-income countries;

• Facilitating a further dialogue between researchers, donors, sub-Saharan African NGO representatives and key Danish NGO staff on the complexity of ARV provision in resource-poor settings; and

• Providing concrete recommendations for Danish and other Nordic NGOs.

Box 1. Why antiretroviral therapy?
- Antiretroviral therapy prolongs lives, making HIV/AIDS a chronic disease, not a death sentence. Affluent countries have seen a 70% decline in HIV/AIDS deaths;
- It has the potential to help calm fears and change attitudes towards HIV because HIV can be turned into a chronic instead of a fatal disease;
- As part of a prevention plan, it can significantly reduce HIV transmission;
- Once very costly, it has become much more affordable;
- It can reduce overall health-care costs by preventing opportunistic infections and restore quality of life.

Source: <www.who.int/3by5/about/en/>
Access to Antiretroviral Therapy

Why do people seek and obtain treatment for health problems or, in the case of HIV/AIDS in low-income countries, why do they often not seek treatment, or not receive it when they do seek it?

This chapter looks at the concrete example of how Uganda was able to expand access to antiretroviral (ARV) therapy and the national and international players who affected this decision and helped implement it. This macro level is fraught with questions of how international trade and development aid influence the availability of antiretroviral drugs.

There is a further focus in this section on access mechanisms in the social sphere – at the local level, specifically family dilemmas and the problem of exclusion. Here, the question is what the different mechanisms are that people use to access antiretroviral therapy and how they are linked to the decisions of global actors.

While there is a diversity of ways in which ARV therapy can be accessed, this chapter primarily addresses the case of Uganda’s Joint Clinical Research Centre (JCRC), which is based on a cost-recovery model, i.e. patients do not receive treatment entirely free of charge. In the early 1990s, Uganda had one of the highest reported HIV prevalence rates in the world. Many people were infected and had already progressed to AIDS, while others died without treatment at a time when therapy was available in the developed world. The JCRC, in a joint venture with the ministries of health and defence and Makerere University, pioneered the use of ARV drugs in 1991 in both Uganda and sub-Saharan Africa. Starting in 1993, drugs were stocked at the JCRC as they became available on the international market, but only a tiny minority of patients could afford to pay for them. By 1996, when triple combination therapy became available, a handful of wealthy patients started accessing highly active antiretroviral treatment (HAART) through the JCRC and the cumulative number accessing therapy has risen over the years to over 20,000 patients, thanks to the recent reduction in the cost of the drugs.

Many – especially from abroad – criticised the focus on promoting lifelong treatment in a setting with a weak health system, fearing high costs, poor distribution and storage facilities, a lack of adherence to the treatment regime and ultimately widespread drug resistance. While the response to HIV/AIDS in Uganda has created a unique situation, the efforts of the JCRC to provide ARVs and then to scale up toward national distribution provide a lesson for combating the HIV/AIDS pandemic in resource-poor settings.

In addition to the cost-recovery model, this chapter also addresses other channels of access to ARV therapy such as research and donor-funded projects and their implications for the affected population.

I. Access to antiretroviral therapy in Uganda

There are many explanations for the limited provision of ARV therapy in low-income countries, especially in sub-Saharan Africa, where there are 28.5 million people living with HIV, of whom some 4 million need treatment. Explanations include that taking the drugs correctly and consistently is complicated, drug resistance will emerge due to non-adherence, the individuals are too poor to buy drugs, the available resources should be used for prevention, ARV therapy is too costly for the health-care system and therefore unsustainable, and that countries lack the infrastructure for distribution – in addition to funding competition from other treatable diseases like tuberculosis and malaria. Several of these constraints to HIV/AIDS care can, however, be addressed.

The major constraint for the widespread use of ARVs in low-income countries has been the high cost of the drugs and monitoring tests. Over the last few years, the cost of ARV drugs has fallen and new funding opportunities have emerged, including the Global Fund to Fight AIDS, Tuberculosis and Ma-
Models for life

laria, some health insurance, employer sponsorship and NGOs like Médecins Sans Frontières and the François-Xavier Bagnoud Foundation. Some pharmaceutical companies like Boerlinger Ingelheim have donated nevirapine and other drugs for use in programmes to prevent mother-to-child transmission.

In addition to the cost of the drugs, another constraint in the use of ARVs in sub-Saharan Africa has been the sophisticated and expensive monitoring through laboratory tests including viral load and CD4 counts. As the cost of ARVs comes down, the cost of these tests remains high and sometimes exceeds the cost of the lowest triple combination ARV therapy. The high costs are in part because manufacturers of these reagents do not have competitors in the form of generic manufacturers and continue to charge high prices.

The poor state of logistics for reagent and drug procurement, storage, distribution, and monitoring of adherence and side-effects further complicates the situation.

Another constraint is the lack of capacity: both infrastructure and human. This is being addressed by an increasing partnership between resource rich and poor countries to train health-care providers in low-income countries and to define cost-effective and user-friendly laboratory monitoring tests. Examples of such partnerships include Harvard AIDS Institute which is working closely with the governments in Botswana and Haiti in an effort to train key health-care providers in the use of ARVs. The newly launched “Academic Alliance for AIDS Care and Prevention in Africa”, led by a group of Ugandan physicians from Makerere University and the Infectious Diseases Society of America with HIV/AIDS care experts from North America, to be based in Kampala, Uganda, will provide training in ARV use and be a nucleus in the region for wider access to ARVs in collaboration with local institutions and ministries of health.

These reasons and others had previously resulted in a reluctance to introduce widespread treatment for HIV/AIDS in Africa. However, many people have died as a result of these claims, and in Uganda the decision was made, at the highest political levels, to do something about the soaring HIV epidemic and the many people suffering with AIDS.

There are an estimated 1.1 million people infected with HIV in Uganda, of whom some 114,000 are

Box 2. When to start ARV therapy

The decision on when an HIV-positive patient should initiate ARV therapy is essentially one to be taken by a doctor – where there is a doctor. This decision can be made based on laboratory results where you count the CD4 cells. CD4 cells are a type of lymphocyte that co-ordinate the immune system’s response to certain micro-organisms such as viruses. HIV can infect and kill CD4 cells. Where there is no doctor or no laboratories, ARV therapy may be recommended based on the presence of a specific AIDS condition such as thrush, rapid weight loss or the onset of a sudden illness.

Wherever possible, WHO encourages countries to use CD4 cell counts in their ARV treatment programmes and to consider the use of simple, low cost CD4 methodologies that are currently available to enable the wider use of CD4 cell counts in their programmes. However, in cases where CD4 counts cannot be assessed, the presence of a total lymphocyte count below 1200/mm$^3$ may be used as a substitute indication for treatment in the presence of symptomatic HIV disease (i.e. WHO stages II or III).

While the total lymphocyte count correlates relatively poorly with CD4 count, in combination with clinical staging it is a useful marker of prognosis and survival. Treatment should be started:

- **If CD4 testing available:**
  - WHO Stage IV disease irrespective of CD4 cell count
  - WHO Stage I, II or III with a CD4 cell count below 200/mm$^3$,

- **If CD4 testing unavailable:**
  - WHO Stage IV disease irrespective of total lymphocyte count
  - WHO Stage II or III disease with a total lymphocyte count below 1200/mm$^3$.

It should be noted that children pose a special problem since it is difficult to diagnose HIV in children under the age of 18 months without expensive, specialised tests. At present, WHO is trying to develop a so-called “presumptive diagnosis” of HIV in children so that children can qualify for treatment without “definite confirmation”.


Access to Antiretroviral Therapy
currently in need of antiretroviral therapy according to figures released by WHO in December 2004. In a country plagued by civil war, with a weak health system and a population unable to afford expensive treatments, the challenge has been how to expand access to treatment for those in need. At the end of 2004, it was estimated that 35,000 people received ARVs, which represents a 40% coverage.

In the 1990s, the Joint Clinical Research Centre (JCRC) in Kampala, realised that in order to scale up the provision of treatment, they would need a cost-recovery programme. Currently, the JCRC provides 60% of the ARV drugs distributed in Uganda, and most people pay for them out of their own pocket – contrary to popular belief. In 2000, the JCRC started importing generic drugs and in 2001 they succeeded in expanding ARV distribution from the capital, Kampala, to rural districts. One way to facilitate the provision of ARVs has been for the JCRC to take on research projects, which in addition to funding, provide the opportunity for the training and capacity building of their staff as well as a learning opportunity for visiting groups from other countries.

In the eyes of the JCRC, Uganda was in a state of emergency, and it was decided that a poor health system infrastructure should not prevent them from providing treatment to people in need. Fewer physical resources are needed to test for HIV and provide ARV therapy than for many other health problems and the JCRC sought to maximize the existing infrastructure, while striving for the lowest cost, e.g. small treatment centres. Improvisation became the name of the game, and treatment was the goal. The spirit of innovation, prompted by the increasing death toll, is exemplified by the case in which a tent was set up to provide free testing for an extra 1,000 people, when it was said no buildings were available for local screening.

With this general expansion, the issue of laboratory testing for HIV was raised. The JCRC responded by setting up networks between clinics within the country for specimen transfer to laboratories. The few laboratories in the country could do the tests and send back the results to the clinics. In the long term, the scarcity of laboratories, while a constraint with regard to time and logistics, was seen as contributing to ensuring the quality of the laboratories themselves, as their expertise was built up.

The next goal for the JCRC is to scale up the provision of ARV therapy to cover the entire country. Eighty per cent of the population live in rural areas and many patients have to spend scarce resources on travelling to the clinics, which are still primarily based in Kampala. Therefore, capacity must be developed where the people who need services live. The JCRC is in a position to lead this effort as they collaborate closely with the Ministry of Health, which supports their capacity building efforts. For example, in some clinics with no healthcare workers trained to work with ARVs, the JCRC staff provide hands-on training for the local staff, instead of taking over ARV drug distribution.

Expanding access to treatment quickly
At present, the JCRC has 16 operational ARV therapy centres in Uganda. By the end of 2005, this number should reach a minimum of 24 (see Figure 1). In addition to the work of the JCRC, many NGOs have also started working within the country, which means coverage could be even higher.

Uganda intends to provide drugs for at least 60,000 people by the end of 2005, as part of the target set with WHO and UNAIDS, discussed below. The policy for increasing access is to find the cheapest possible drugs, which means continued negotiations with generic drug manufacturers. The cheapest triple combination is now about US $25 per month, as compared to US $800 in 1996. And

Figure 1. Scale up: At least 24 operational centres by the end of 2005
this price is expected to continue falling. By importing lower-cost generic drugs, the number of infected people who were able to afford treatment began to increase. In addition, combined fixed doses have led to improved adherence. But while affordable drugs are necessary, it is also necessary to have free drugs for the poorest segments of the population, which in turn means developing criteria to identify them and services to ensure compliance.

Officially, the Ministry of Health of Uganda employs WHO classifications (see Box 2) to determine who is in need of treatment for HIV/AIDS. However, only few people can pay for this. Laboratory tests are still expensive although the price for some tests has fallen over time, as it has for treatment. The JCRC try to cut expenses at their clinics by using clinical indicators, and are engaged in a study on other strategies that will decrease costs and thus increase access to drugs.

With money from the Global Fund, drugs became available free of charge in the public sector in mid-2004. In addition, there are several initiatives to improve access to treatment, including employer-treatment sponsorships, health insurance for employees, subsidies from pharmaceutical companies and NGO sponsorship programmes.

Lessons learned

The JCRC has had a number of successes in expanding access to ARV therapy, in line with the principles set out in Box 1. This was done in large part by bringing down the price of drugs by using generic drugs and negotiating with pharmaceutical companies, as well as using innovative strategies to set up testing and ARV provision centres and train staff. The next step is to build further on this progress and to see what can be learned by and from other sub-Saharan African countries as well as NGO partners. The following are some of the key lessons learned to date by JCRC:

- The cost-recovery programme has been essential in the provision of drugs, carrying out operational and other research, and reaching rural districts. In effect, the JCRC has become able to provide treatment to those who can afford it – in spite of a weak overall health-care system;
- The way forward is access to treatment for all through partnerships with: pharmaceutical companies (to reduce prices), the private sector (e.g. insurance companies and employers), the public sector (e.g. the Ministry of Health, local government authorities and the police), bilateral and multilateral donors (e.g. Danida, Sida, USAID, WHO and the World Bank) and NGOs (national and international);
- Special initiatives to treat health workers are needed, including that they be encouraged to be tested for HIV. This should be done in combination with initiatives to improve safety procedures at the hospitals;
- Treatment can also improve prevention. Opportunistic infections are a major problem and often more expensive to treat than providing HIV-positive individuals with ARV therapy. By properly treating HIV, these infections are prevented, which is clearly more cost-effective and

Box 3. The Global Fund to Fight AIDS, Tuberculosis and Malaria

The Global Fund was created to increase resources to fight three of the world’s most devastating diseases, and to direct those resources to areas of greatest need. Its principles, from governance to grant-making, are:

- Operate as a financial instrument, not an implementing entity;
- Make available and leverage additional financial resources;
- Support programmes that reflect national ownership;
- Operate in a balanced manner in terms of different regions, diseases and interventions;
- Pursue an integrated and balanced approach to prevention and treatment;
- Evaluate proposals through independent review processes;
- Establish a simplified, rapid and innovative grant-making process and operate transparently, with accountability.

Donors have been generous in their promises to the Global Fund and the amounts promised are large. However it must be remembered that these funds are expected to cover three major diseases, and not just HIV/AIDS alone. In 2004, 56% was spent on HIV/AIDS whereas 31% was spent on malaria and 13% on tuberculosis. Furthermore, actual pledges and even real disbursements and use of the funds still lag far behind the real need.

Source: <www.theglobalfund.org>
more ethical towards the patient in a long-term perspective;
• The provision of treatment and the establishment of more testing centres also means that more patients are now going to voluntary consultations at JCRC – a healthy development not just for HIV/AIDS prevention but also for improved sexual and reproductive health.

II. Global governance of trade and aid to AIDS treatment

Whether ARVs are available or not in low-income countries is not only a question of health sector decisions but also of global politics. To understand this, one must take account of different levels of governance when examining treatment for HIV/AIDS, such as (i) drug prices at the global level; (ii) ARV therapy programmes at the global level; and (iii) ARV therapy access and costs at the national level. The often uneasy relationship between these three areas makes it difficult for countries to govern access to ARV therapy. This section looks at some of the international actors and how they relate to these issues.

Acknowledging this broad range of actors is important for understanding the ways in which they each influence access to ARVs. The rapid increase in donor funding for HIV/AIDS, for example, stems not just from the need in sub-Saharan Africa, but from the successes in reducing the spread and providing treatment in other places, such as Brazil. The many actors (e.g. the Global Fund, PEPFAR, WHO – see boxes 3−5) all have their own agendas, and these are not always fully in sync with each other or with local needs.

Nevertheless, in spite of the many donors and new funding, ARV coverage in poor countries remains very low: between 270,000 and 350,000 people are estimated to receive ARVs out of 4 million people who need it in Africa – only 8% coverage. The Latin America and Caribbean region, on the other hand, has 65% coverage largely reflecting the commitment of Brazil to universal treatment. And while a few low-income countries have limited the spread of the epidemic, most have not. There is therefore no reason to believe that the dramatic need for ARV therapy will disappear soon. The number of HIV-positive individuals, many of whom currently need treatment, will continue to increase in the foreseeable future.

Box 4. What is PEPFAR?

In 2003, US President Bush announced the launch of the President’s Emergency Plan for AIDS Relief (PEPFAR) a five-year, US $15 billion initiative to turn the tide in combating the global HIV/AIDS pandemic. This commitment of resources will help the most afflicted countries in Africa and the Caribbean.

This virtually triples the US commitment to international AIDS assistance. Specifically, PEPFAR sets out to:
• Prevent 7 million new infections (60% of the projected new infections in the target countries);
• Treat 2 million HIV-infected people;
• Care for 10 million HIV-infected individuals and AIDS orphans.

Implementation of PEPFAR will be based on a “network model” being employed in countries such as Uganda. This involves a layered network of central medical centres that support satellite centres and mobile units, with varying levels of medical expertise as treatment moves from urban to rural communities. The model will employ uniform prevention, care and treatment protocols and prepared medication packs for ease of drug administration. It will build directly on existing clinics, sites and programmes. However, PEPFAR funds can only be used to purchase brand-name ARVs in treatment programmes, and not generic drugs. In addition, its prevention strategies focus on abstinence, “faithfulness” and testing rather than condom promotion.

See the Centers for Disease Control and Prevention for details <http://www.cdc.gov/od/pgo/funding/AA006.htm>.

Trade and AIDS

The World Trade Organization (WTO) has an important impact on access to ARVs in member countries, especially in those countries without a large pharmaceutical industry to supply their home market. The gospel of the World Trade Organization (WTO) is that trade increases economic growth, and members must comply with trade agreements, also on pharmaceuticals, e.g. the Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS Agreement). This has been an on-
going issue of contention because patents normally maintain high prices. Not surprisingly, pharmaceutical companies investing in research and development of new medicines welcomed the TRIPS Agreement. These companies received increased support for investing in research and the ability to export worldwide without the fear that other companies would copy their products. Consumers are paying higher prices because of the monopoly status of patented products. This is the trade-off in intellectual property rights, giving incentives for research and paying by granting monopoly for a specific time (Mansfield 1986). This argument holds when the customers have money to buy the product, but in the case of ARVs in the poorest countries it is clear that most patients cannot be expected to be able to afford to pay for their drugs. Therefore, NGOs argue, the companies do not lose customers by letting them access copied products, as there is hardly any purchasing power in that market.

Underlying TRIPS is an inherent conflict between the private property rights of inventors of new medicines on the one hand, and human rights and the rights of states to protect people’s health on the other (Joseph 2003). The TRIPS Agreement did not intend to prevent developing countries’ access to essential medicines. However, the result has been restricted access to medicines for AIDS because AIDS is a relatively new disease and ARVs are new products still working under patents without alternatives (as there are for malaria and tuberculosis). In short, while advocates argue that the sick die as a result, the pharmaceutical companies counter that their high revenues must be maintained in order to ensure further research and development.

While the patent obstacle to ARV access has been formally resolved in the WTO, this has not yet led to increased access to ARVs in developing countries. The Doha World Trade Organization ministerial declaration (2001) allowed poor countries to buy generic pharmaceuticals and to bypass certain laws to gain access to medicine (see <www.wto.org for details>). Part of this declaration calls for the implementation and interpretation of the TRIPS agreement, “…in a manner supportive of public health, by promoting both access to existing medicines and research and development into new medicines…”. This is perceived as a major victory for low-income countries, but is still opposed by many pharmaceutical companies, who are reluctant to step in where governments have failed. It is worth noting that although the least developed countries have the possibility of compulsory licensing of life-prolonging medicine, they do not use it – only Mozambique and Zambia have done so to date. Many countries fear that issuing a compulsory licence for AIDS medicines will lead to an unfavourable trade status with their donor countries where the pharmaceutical companies are powerful political interests.

Uganda and donors

Uganda is a good example for looking at ARV therapy, as outlined above, due to its relative political stability, donor governance (having followed donor recommendations) and recognition of AIDS as a major problem as early as 1986. The successes in Uganda have in effect led to the country becoming a donor magnet. Although the country has been advocating for free trade and economic growth, Uganda continues to be dependent on development aid, especially for its HIV/AIDS programmes. As with most development aid, HIV/AIDS funding is often time-limited and there is no continuity between disparate projects. The projects end and, if not planned to ensure sustainability, leave the target group unable to continue its work. At the same time, the influx of large amounts of aid for AIDS has led to the proliferation of new projects without adequate coordination and communication between them.

There have been many HIV/AIDS programmes in Uganda since 1986, and since 1990 a multilay-

**Box 5. The 3 by 5 Initiative**

On World AIDS Day 2003, WHO and UNAIDS released a plan to provide antiretroviral therapy to three million people living with AIDS in developing countries and those in transition (e.g. the former Soviet Union) by the end of 2005. There is a five-pillar strategy to do this:

- Develop global leadership, alliances and advocacy;
- Provide technical, sustained country support;
- Simplify standardized tools and assure quality of the drugs;
- Create an effective, reliable supply of medicines and diagnostics;
- Rapidly identify and reapply new knowledge and best practices.

See www.who.int/3by5/en/ for details.
Access to Antiretroviral Therapy

...strategy based on donor funding has been in place. Governance can be seen as the overlapping (or individual) actions of local, national and international actors as they all exercise political, economic and administrative authority in governing AIDS treatment and prevention in Uganda. In most low-income countries the government is not capable or prepared to run the scale-up in ARV therapy due to a lack of infrastructure and limited financial resources. Therefore, the national governments here are not directly engaged in agenda-setting. Rather, if seen from an overall perspective, treatment of AIDS stems from models of global governance.

Until 2004, relatively few of the funds were allocated to treatment in Uganda, but this share was still large when compared to other African countries. Also, the proportion of funds for treatment is now rapidly growing as providing ARV therapy becomes more central in the donors’ agenda. In effect, access to ARV therapy has become a high priority in the Ugandan government in part because global AIDS funding to the country is rapidly increasing. The Global Fund (see Box 3) has given US $200 million in aid while PEPFAR has to date provided US $95 million, and has pledged a further $500 million over the next five years. By the end of 2004, WHO had also given $6 million. Most of this money is aimed at treatment. However, as mentioned above, there are many barriers to this funding reaching the people in need: poor infrastructure and health system capabilities, donor demands and politics, sustainability of funding and trade governance. Regarding the latter, the JCRC uses a provisional import permit to acquire generic drugs from the Indian pharmaceuticals company Cipla, as the import of ARVs into Uganda today is illegal, and the country does not produce generic products nationally. Uganda has not issued a compulsory license and is unlikely to do so in the future. According to President Museveni, donors will be discouraged from giving aid to the country if trade in branded drugs decreases. Simultaneously, more external funding could mean that transnational companies gain an additional argument to demand that their patents be respected. In short, international considerations and conditions can effectively limit the room for manoeuvre of national governments and leave local providers without medicines.

Governance and political stability

While international aid conditions may shape the national government’s room for manoeuvre, the influx of funds may also allow governments to use their national resources for other things. For example, the northern parts of Uganda have been at war during the last two decades and Uganda has consistently intervened in the regional power struggles around the ongoing war in neighbouring Congo. More than one and a half million displaced people are currently living in camps. The money that the government has earmarked for the war could have been spent on preventing and treating HIV/AIDS and other human development initiatives. Instead, donor money is being used for this, which is a good example of how external funding indirectly influences national governance: donors fill in the spending gap when governments choose to prioritise other issues. At the same time, the conflict increases the spread of HIV/AIDS as soldiers and opposition forces move between districts, internal migration increases and rape in the conflict areas goes unchecked. While Museveni’s government is best-known in international circles for its AIDS successes, its political failures will also have an impact on the country’s continuing battles with AIDS and poverty.

III. Social change at the local level

While the above sections focus on the national level, this section treats the local level, providing a background to the work being carried out by the JCRC and NGOs. It is difficult to gain an overview of the availability and distribution of ARV drugs over time, even in one country, in part due to a black market where medicines are purchased without being registered in any national statistics and in part due to weak coordination at the national level that also leads to poor collection of national data on medicine use. It is important to remember that there is a lack of nationally representative data on Uganda because it is not possible to collect data in a war situation. Without fully knowing the long-term perspective, NGOs have to act with what information they currently have on hand, however limited that might be. Research in itself takes time and so does the process of establishing functional working relationships between NGOs and researchers where both parties learn how to understand each other’s “language”, needs and space for manoeuvre. Many
NGOs, driven as they most often are by an action oriented imperative, feel an urgent need to act while the problems are most dramatic and the funds to address them are available. As a result, projects are starting to employ what sometimes are referred to as “good enough practices” based on experiences elsewhere, instead of using best practices based on results from local, applied research or documented best practices from other NGOs and actors.

By studying local phenomena, such as sexual networks, over a period of time, one can often better comprehend complex and rapidly changing situations, e.g. a change in HIV incidence. One kind of research can, for example, help improve practice, while another can feed into advocacy. One current example of applied research is the Tororo Community Health (TORCH) project in Uganda, which is relevant in many ways for NGOs in and outside of the country. TORCH involves collaboration between the Child Health and Development Centre, Makerere University in Uganda, the Institute of Anthropology, University of Copenhagen, and the Departments of Social Medicine and of Social Anthropology at Aarhus University in Denmark. One study within this broad research programme is aimed at gaining an overview of ARV access channels in Uganda and describing dilemmas of restricted access for families and health personnel. Four ARV access channels have been identified:

- Research projects and donor-funded projects: they are free of charge for patients who fulfil specific criteria but are exclusive and selective;
- Authorized public health centres: they tend to have an urban bias and require user fees;
- Private clinics and pharmacists: they also have a strong urban bias; and
- Private contacts in the country or abroad: they have a strong elite bias where the patient uses family, friends or “connections” abroad to obtain access to the drugs.

Research projects and donor-funded projects

The growing numbers of research and donor-initiated projects provide free treatment, but this treatment is exclusive in that it is limited to specific geographic areas, target groups and inclusion criteria. For example, prevention of mother-to-child transmission programmes target the baby. This raises many ethical issues: what happens to the mother after the child is born? Or why is one family excluded from this intervention while others are treated? The difficulty a household has in comprehending why treatment is not readily available for all of the household members in need is seldom addressed in-depth by onsite project staff, who tend to focus on the chosen patient alone instead of taking into consideration the wider social and family-based network of the patient.

Families face dilemmas

Although access to ARV therapy is increasing in part due to research and donor-funded projects, the reality is that most families in Uganda have to pay for the medicine they need. In a situation of scarce resources, this additional burden often means cutting support elsewhere, e.g. education or other long term investments. This situation is further aggravated if several family members are HIV positive and in need of treatment and the heads of household have to make especially difficult decisions as to who should receive medical treatment and who should not.

When patients can just barely manage to purchase the drugs, be they from local pharmacies or public health-care centres, the medical consequences of adherence problems can be fatal. Consider the situation in which a family member died because she stopped taking ARVs after six months, due to the burden the cost put on her family. Treatment is expensive, and to obtain medicine requires a major expedition for families living in rural settings, who often have to travel to larger towns or cities.

In addition, apart from being able to afford the medicine, as pointed out above, one also needs to pay for the laboratory tests – this often makes it impossible to maintain regular treatment. As a result, it is still unaffordable for the vast majority of the population, especially the poor. For the middle class it means changing their priorities by, for example, selling land or moving their children to a less expensive school.

Implications for children and young people

The focus of ARV provision interventions is usually on the patient and not the entire family, which can be problematic. Children will often have questions regarding disclosure (status of their parents), stigma and other worries. In the 1990s, the focus of much attention was on “AIDS orphans”. This new social
Box 6. Strained kinship relationships and the shared vulnerability of Samia widows and orphans in Uganda

One example of how vulnerability can occur as a result of denial, stigmatisation and discrimination is to be found in the story of Emma, a 20-year-old Ugandan girl whose father died of AIDS in 1997.

Emma’s parents had been on such bad terms that in 1994, her mother left home and ultimately managed to set up a small business. Soon afterwards, she took her children, only to return a year later to care for her then dying husband. When he died, the in-laws chased their daughter-in-law and grandchildren off the land, refusing any compensation or future assistance. According to the father-in-law, Emma’s mother had “gone outside” the marital relationship and introduced AIDS to the family, which had claimed her husband’s life. Blaming her for killing the husband, they did not want to live with a “murderer” or her children.

This example shows how arguments on AIDS, morality and guilt between family members might be more fatal than the disease itself. This is especially the case in societies where women and youngsters are not automatically guaranteed the right to inheritance of land and property. Among the Samia people in Uganda the word ‘Abalekwa’ refers to “the people who have lost” or “the people left behind”. This local term traditionally includes widows/widowers and their offspring. The linkage between the parent and children reveals interdependence as well as a recognition that children always belong to somebody – a family, a piece of land and a clan. Most people know a child through relations with the mother or father, and it is because of their relations with the parent(s) that they will (or will not) care for the children. A child is never ‘just’ an orphan but rather ‘my sister’s child’, for example (Christiansen 2004).

Children’s needs for treatment are often neglected

Children and young people are systematically being neglected in all of the efforts to accelerate access to ARV therapy in sub-Saharan Africa. This has many reasons. Firstly, children are often marginalised in the social networks within their own families and households. Secondly, a rights-based approach to children and youth has been weak in project work as well as in research. Finally, it is often, wrongly, assumed that ARV therapy does not work in children. According to WHO (2005), children under 15 are estimated to account for one-sixth of all HIV/AIDS deaths globally, but only for a much smaller proportion of all ARV therapy. There is clearly an important gap in under-15’s access to life-prolonging treatment.

ARV therapy programmes are opening new opportunities in supporting children and families with HIV/AIDS in a holistic way including psycho-social support and other counselling to the family as some of the efforts seek to provide comprehensive support. It is important to see medicine and other care measures as interlinked and advocacy in this emerging field is a key area where NGOs can play a leading role. However, it is the experience of NGOs such as Save the Children that the needs of children and young people are being neglected in the fight for ensuring access to ARV therapy. Advocacy in favour of the rights of children and young people is weak and so is the category that was quickly integrated into NGO jargon raised many ethical and sustainability questions as the consequence was that equally vulnerable children did not “qualify” for the same attention as children that were orphaned due to AIDS. With treatment it is possible to lessen the problem of orphans, as parents who are fortunate enough to access the drugs can live longer, which consequently reduces the number of orphans in society. Instead of using the category of “AIDS orphans” it might be better to speak of the vulnerability of different categories of children and even more important to explore the different social situations where children are made vulnerable because they do not receive appropriate care, resources or recognition.

It is also important not to forget the children who are affected but not infected. Children do not want to be defined as “an AIDS orphan” but rather as “the child of somebody” be it a specific lineage, a clan or through belonging to a place. However, the label “orphans” often attracts more donor funding. Additional research on the implications for children living in affected families as well as a better assessment of the child’s vulnerability, especially in relationship to the available resources of other people within their social network and their willingness to take care of orphaned children is crucial. Researchers can help NGOs by making this kind of knowledge available and comprehensible.
Models for life

monitoring and evaluation of projects that seek to increase the access of children and youth to ARV therapy. We therefore have limited surveillance data on the HIV status of children and their responses to ARV therapy. Furthermore, children have specific needs in relation to HIV infection as listed in Box 7. It must, however, not be forgotten that poverty, e.g. the inability to give your child more than one meal a day or to provide him or her with medicine, is an overall obstacle that in itself makes it difficult for parents to respond to the needs of children.

IV. Discussion points

Overall, the panellists presented two distinct discourses: one Ugandan and the other international, which have different political implications. Their conclusions also open up a number of new questions, as discussed below.

Policy implications: The disconnect between practice and policy

Uganda as a case teaches us lessons on the global nature of ARVs. When triple-therapy became available in the West, it was also available in Kampala. Thus there is a connection. But we can also see a certain disconnect as availability was extremely limited due to costs, priorities and the weak health-care infrastructure.

It is important to think about whether we perceive HIV/AIDS as an emergency situation or a long-term development problem. This has serious implications for what the government can do. Is there an impetus for improved infrastructure, emergency relief and cost-recovery or rather a long-term need for structural changes to address the underlying causes that make communities and individuals vulnerable to HIV infection?

The Ministry of Health in Uganda stated in June 2004 that all who need HIV/AIDS treatment will get it, while other authorities said that it was not possible at the time due to the poor state of the health system. Uganda’s president has been very successful in mobilising support to combat HIV/AIDS nationally and internationally, but now there are calls for more pluralistic efforts. In spite of increasing access to ARV therapy, Uganda’s health system is deteriorating and has not shown similar achievements in improving e.g. maternal health. Thus while President Museveni can now take the credit for saving lives (with donor money), what about the sustainability of the efforts?

More effort should go into ARVs

No one is advocating for less effort, but more accountability is needed. There is much disconnect with what is actually happening on the ground, like the black market for medicines and ministries that are not fully taking the lead in much needed coordination efforts. Applied research and well documented sharing of experiences from projects could help address this situation. It also raises the issue of health-care personnel. Well-funded programmes recruit the best qualified people, people looking for opportunities. Some are leaving the country as a result, while others are moving from the public to the private sector, including NGOs.

Both practitioners and researchers recognise that access to ARVs changes the framework for AIDS

Box 7. Ensuring that children benefit from increased access to ARVs

The challenge:
- Disease progression in children is not properly understood;
- There are inadequate testing/health-care facilities for children;
- There is a lack of antiretroviral treatments suitable for children;
- The needs of HIV-positive children are not prioritised by their families and/or communities;
- Families cannot afford to obtain care, support and treatment for HIV-positive children.

What children living with HIV/AIDS need:
- Support for their family (e.g. advice on caring for them, psychosocial support and advice on how to disclose the child’s status);
- Rehabilitation for those who are severely malnourished or traumatised, with longer-term nutrition and livelihood strategies;
- Medical care;
- Counselling;
- Adherence support;
- Psychosocial support and spiritual care;
- Physiotherapy;
- Occupational therapy;
- Education;
- Support groups.

Source: Adapted from “Beyond the Targets: Ensuring children benefit from expanded access to HIV/AIDS treatment”, International Save the Children Alliance <http://www.savethechildren.net/sitesearch.php#res>
prevention, treatment and care and forces NGOs working with HIV/AIDS to try and integrate this new opportunity into their programmes. HIV/AIDS is rooted in poverty, violence and gender imbalances and it is well known that this cannot be dealt with by treatment alone. Treatment can, for example, reinforce inequity if only provided to the urban population or the wealthiest strata of society. Yet, the benefits of ARV therapy extend beyond the health system.

Earlier, HIV/AIDS was seen as more of a health issue than a development issue, and some feel that the focus seems to be retreating to this again, with the current focus on scaling up ARV therapy. However, the emphasis on treatment is because it was neglected or impossible to provide in the past. It is important to note that the new initiatives presented above, for example, provide funds for both treating and preventing HIV/AIDS that require strengthening the overall health system, making HIV/AIDS just as much a development as a health issue.

Resources
Ena J. and Pasquau F., “Once-a-day highly active antiretroviral therapy: A systematic review”, Clinical Infectious Disease, 2003 May 1; 36(9):1186–90.
While the previous chapter addressed the how and why of providing ARV therapy, this chapter delves further into the accompanying activities needed to ensure the full treatment of those receiving medicine. This is an often overlooked aspect of scaling up ARV therapy.

Concretely, this chapter looks at the experiences of a holistic approach to ARV drug distribution. One of the fastest attempts to scale up the provision of antiretroviral therapy in low-income countries took place on the outskirts of Kampala, the capital of Uganda, in the community of Mbuya, in 2004. Dubbed “Reach Out Mbuya”, as a part of this project more than 1000 HIV positive people living in the area were offered ARV therapy and invited to become project clients, which entitles them to food, educational opportunities and other kinds of care in addition to medicine.

The Reach Out project is presented as a model for other communities in Uganda, but also for any country where health care is not a right or not provided free of charge or at affordable prices. To ensure adherence to ARV medicine, and thus minimise the risk of developing resistance, it is important to reduce the stigma associated with being HIV positive. Too many individuals, communities and governments have not yet recognised that sick people must be treated, and that part of that treatment includes helping them with other aspects of their life, like school and work. The holistic approach can be applied in any treatment setting, provided the will and resources are there to do it.

Next, the chapter looks at issues of scaling up. What the example below shows is that this demands many resources, and while there have been some successes in Haiti, Uganda and among the NGO projects of Médecins Sans Frontières, there is still a long way to go, especially if the aim is to scale up ARV therapy in accordance with the need.

I. Reach Out: A unique Ugandan initiative

The Reach Out HIV/AIDS Initiative was started in May 2001 to support people living with HIV/AIDS in Mbuya Parish, on the outskirts of Kampala. Initially, there were just 14 clients. At the end of March 2005, there were 1639 active clients enrolled. This is an estimated 5.5% of the adult population in Mbuya Parish. The total number of active clients enrolled in the ARV programme was 605, or 36.9% of all clients.

But the goal of Reach Out Mbuya is much more than providing ARV therapy to those in need. The objectives are to provide free medical care coupled with social, spiritual and emotional support to poor people living with HIV/AIDS in the Catholic parish of Mbuya. The driving idea is that this is a holistic model of care, which includes community education and psychological care. For example, school fees are provided to those in need because as a result of being sick, many clients are not able to raise enough money to send their children to school. Reach Out recognises that this is one of the daily problems, in addition to needing medicine, which impedes patients’ recovery.

“Godfrey had a very low CD4 count. He received ARV medication and was admitted to a hospital. It was a process starting him on ARVs. His family had a very negative attitude towards the drugs. It was explained to them that they had nothing to lose. Now he is doing very well and his future plan is to get married. There are many cases like this one. Stigma is decreasing because the community sees that there is hope with ARV.”

Rose Ochen, Uganda,
Conference presentation, September 2004

The Reach Out programme started as pastoral work linked to the Catholic Church, but to supplement home visits for the increasing number of people living with HIV, a small clinic was opened and staff outside the Church were trained as counsellors. It is in effect a community-based programme that recognises that everyone in the parish is either infected or affected by HIV/AIDS. Some 200 volunteers, of
whom 78% are also clients (i.e. they are HIV positive, but may only be receiving treatment for opportunistic infections), work in the programme.

The activities in the medical programme include voluntary confidential counselling and testing, continuing medical care, tuberculosis and ARV adherence education, home visits, a prevention of mother-to-child transmission programme and a food programme. One early achievement is that the Reach Out programme is now officially accepted as a tuberculosis treatment centre by the government. This opens new channels for government support to Reach Out.

The clinic runs from Monday to Friday and is staffed by nurses, who are supervised by a doctor. Some 110–150 clients visit Reach Out each day, free of charge, thanks to its many volunteers and hundreds of individual donors, in addition to local and international organizations. On average, each client is seen twice a month at the clinic or at home. There were 605 clients on ARV therapy by the end of March 2004. This group is broken down into three different categories: 79 in a JCRC study initiated in July 2003 (for more on the JCRC see the previous chapter); 63 on generic drugs bought by private individuals arranged by Reach Out started in November 2003 and since February 2005 also on generic drugs provided by the Ministry of Health/Global Fund; and 463 on PEPFAR-funded drugs, started March 2004.

Voluntary counselling and testing is conducted twice a week, reaching 250 people per month, of which 63% are women. Fifty-two per cent of these have tested HIV positive.

As part of its holistic approach, Reach Out recognises that food is important to clinical care. In collaboration with the World Food Programme, 900 clients receive select foodstuffs (e.g. corn, soya blend and vegetable oil), with priority being given to tuberculosis patients and HIV positive individuals receiving ARV therapy. Food is distributed once a month in family-sized containers.

Social support

Social support is an important aspect of holistic care. Microfinance loans, in this case for the amount of US $50–125 at 10% interest, to be paid within five months, have been found to be an important part of getting HIV-positive people back on their feet. The overall payback rate is 80% and it is sufficient to maintain the programme and the loans help decrease financial stress.

Vocational training was initially started as an income-generating programme in 2002 with a tailoring workshop called Roses of Mbuya. As people are surviving longer, due to ARV therapy, the programme is becoming an important part of Reach Out’s activities. It shows that if people are given the possibility to live they may also be able to provide for themselves.

More than 390 children are supported in school, i.e. their fees and other costs are paid for, through individual sponsorships. This is an important step in ensuring their future quality of life – as well as for the infected parents, who at least can see their children go to school. As of March 2005, Reach Out had 15 children on ARV therapy. Other important activities in this sphere include:

- Community outreach (community mobilization and education on HIV/AIDS in schools and local communities);
- School drop-outs being brought together in performance groups;
- Adult literacy classes to improve self-esteem;
- Treatment literacy classes to ensure that clients know how to take their drugs and recognize possible side-effects;
- Preventing mother to child transmission of HIV: a community supervisor supports the pregnant women and provides antenatal care and counselling.

Eligibility criteria for ARVs

Clients must be HIV positive, live in the Mbuya parish, be over the age of 12, have a CD4 count under 250 (because this is when it is most likely that an opportunistic infection will be acquired), have stayed three months on the programme with regular appointments and treatment compliance, and be willing to sign an agreement form (to ensure that they stay in the programme). If the CD4 count at enrolment is below 100, the three months with Reach Out is waived and clients are started as soon as possible. Priority is given to people with low CD4 counts.

Pre-ARV screening is carried out (e.g. TB screening, cryptococcal antigen (CrAg) testing (if the CD4 count is <100), and Hepatitis B) and
treatment preparedness in the form of pre-ARV education is a crucial element of the programme. All drugs are provided by a nurse as is follow-up, including home visits when necessary, to check for side-effects.

As a part of the holistic approach, members of the community are involved in various sorts of activities. CATTs (clients who have been on TB or ARV therapy) undergo a three-week training programme and are thereafter assigned clients. Their primary job is to monitor ARV and TB treatment, and provide support. In this way, CATTs are the link between clients and the clinic. All the CATTs have weekly meetings, where they are helped to work with and better understand the Reach Out Mbuya’s approach to living positively.

II. Reaching Farther Out: The Red Cross and MSF

Community-based care in Zimbabwe

The Zimbabwe Red Cross Society is implementing a community-based HIV and AIDS programme, which in the same way as the Reach Out programme works with a holistic approach to alleviate the human suffering caused by the AIDS pandemic in the country. The backbone of the programme is the home-based care projects implemented in 27 districts throughout Zimbabwe. The projects work as the hub of prevention activities targeting youth and the wider communities; palliative care, food and psychosocial support to AIDS patients and their families; and food, school fees and material and psychosocial support to orphans and other children made vulnerable by HIV and AIDS.

The Red Cross HIV and AIDS programme is a nationwide operation, which reaches more than 100,000 people, of whom 16,000 are home-based care clients potentially in need of ARV therapy. But the general availability of ARVs in Zimbabwe is very limited. In a population of 11.6 million, it is estimated that 1.8 million people are living with HIV/AIDS (i.e. 24.6% of the adult population), with an estimated 342,000 persons being in need of ARV therapy. In line with the WHO/UNAIDS 3 by 5 initiative, 171,000 should be on treatment by the end of 2005, but the latest statistics (March 2005) from Zimbabwe’s Ministry of Health and Child Welfare indicated that only 12,000 patients were currently receiving ARV therapy.

In 2004, the Red Cross took up the challenge of developing an ARV treatment model for rural settings, where distances to medical centres are long and the human resources in the public health sector scarce. The home-based care+ programme is a five year pilot programme that will enrol 1500 clients of the existing home-based care programme on ARV therapy. It relies on a nurse-led, doctor supervised ARV therapy model.

Nevertheless, in the Zimbabwean context, the treatment of an additional 1500 people is only a start. There is clearly a need to scale up by moving from piloting treatment programmes to comprehensive treatment, care and support activities, by building strong partnerships with both the public health delivery system and other organisations, e.g. providers of VCCT and prevention of mother-to-child transmission interventions.

Médecins Sans Frontières in South Africa

Whereas the Reach Out HIV/AIDS initiative in Uganda and the Red Cross programme in Zimbabwe are examples of small-scale ARV therapy programmes, Médecins Sans Frontières (MSF) was the first NGO to carry out a scale-up of ARV therapy at the international level. Almost 10% of all those receiving ARVs in low-income countries are a part of MSF projects. MSF has run HIV programmes since the early 1990s and as of May 2005, they provided free treatment to more than 25,000 people who are part of 50 different projects around the world. Patients on ARV therapy in MSF projects show a survival rate of 85% after 24 months follow-up.

There are some five million South Africans living with HIV/AIDS. One of MSF’s flagship projects is in the township of Khayelitsha, outside of Cape Town. There are more than 400,000 residents, of whom more than 50% are unemployed. Most of them live in makeshift housing. HIV/AIDS is endemic in this community, where one out of every four women attending antenatal care services is HIV positive.

The MSF project started in 1996 and focuses on the continuum of AIDS health care: counselling, support, prevention, treatment of opportunistic infection, mother-to-child care etc. Selection criteria for treating HIV/AIDS are a mix of clinical, biological and social criteria:
• The patient must be in stage 3 or 4 of AIDS (i.e. clinical AIDS, see Box 2, page 10);
• A CD4 count of less than 200;
• Patients must have attended HIV clinics for at least three months and been on time for the last four visits;
• Patients must meet certain social and adherence criteria including an evaluation of the home environment (e.g. family support) and willingness to disclose their status;
• The final selection is made by a community selection committee, anonymously and without MSF participation.

However, in order to scale up, and due to limited laboratory testing facilities, in some cases MSF removes the criterion of the CD4 count and focuses solely on the presence of a specific AIDS condition. There is also a clinician to present a client’s case to the local community selection committee in order to ensure objectivity when deciding on treatment – they do not know who the client is, only the factual details. Ultimately, some people are excluded by the selection committee.

Adherence

After an individual is selected, MSF requires that a number of conditions be met to encourage adherence to the treatment regime. Firstly, there are treatment assistants and lay counsellors, who also make home visits. Peer support is ensured in the form of monthly meetings, and information materials are provided to the patients. Ultimately, a simplified regime plays a major role in ensuring that the patients take their medicine.

In Khayelitsha self-reported adherence demonstrated that 90% of those receiving therapy took more than 95% of their medication. A main prevention outcome was that the number of people willing to undergo voluntary counselling and testing in Khayelitsha increased from 1000 HIV tests in 1998 to 12,000 tests in 2002. According to the Cadre Report of 2005, there was a 54% per cent condom prevalence rate among the population in Khayelitsha, versus 45% nationally (compared to 9 other townships). And 83% said they were willing to try a female condom, versus a national average of 59%. The project area also showed the highest levels in South Africa with regard to willingness to be tested for HIV (83%), already having been tested (45%) and interest in joining a so-called AIDS club (91%).

AIDS clubs are run on a volunteer basis and are set up for people living with HIV and those related to these individuals in order to help them find support and motivation for disclosing their status and seeking or staying on treatment.

Ultimately, there appeared to be strong civil society pressure in promoting HIV as a political issue (as a way to counter stigmatization), ARV therapy and education, hand in hand. It was argued that treatment helps keep families intact and financially stable in that heads of household and others who contribute to the family income stay alive and healthy enough to work.

MSF itself has been one of the leading advocates providing medical treatment for HIV/AIDS and is currently running a global campaign for access to essential medicines (see.accessmed.msf.org). However, many unresolved questions remain, for example:

• What is the impact of access to ARVs on sexual behaviour? Do those on ARVs change their behaviour and continue or return to riskier practices?
• Are MSF projects fully addressing equity issues just because the treatment is free within the time of the project life?
• Will treatment benefit prevention and can this be properly documented and reproduced in rural settings or townships that are even poorer than Khayelitsha, South Africa?
• Will resistance levels in low-income countries continue to be comparable with developed (high-income) settings?

III. Discussion points

NGOs need to ask themselves what their role is going to be with regard to ARV provision. Although NGOs for a long time, especially at the beginning of the epidemic, have played a leading role in the fight against HIV/AIDS in some countries, it is unlikely that they will continue to be the main actors to respond to the epidemic. One specific aspect NGOs need to address is that of how to apply a holistic approach and in partnership with others (local groups) – as one organization or within a network. NGOs have much to gain from establishing functional partnerships between NGOs specialised in AIDS work and NGOs devoted to reproductive and sexual
health or general development issues. At present, there is a lack of partners for this in some countries. In Zimbabwe, for example, in addition to the Red Cross, only MSF has a project, which in spite of being large, is restricted to certain urban areas. To supplement this lack of local partners, the Red Cross is trying to develop a rural-based model for the people who cannot come to the clinics.

At the same time, while a holistic approach is ideal, a rapid scale up is urgently required. In Zimbabwe alone, the Red Cross estimates that 3000 people a week die of AIDS. Ideally, ARV therapy should be integrated into public health sector structures. It should be a government responsibility, but that does not mean that the government can or will fulfill its task. And whether it is NGOs or the government that ultimately supply ARV therapy, how will sustainability be ensured? NGOs need to address the issue of dependency. For example, when a project like Reach Out does so much for the family, they should also encourage them to obtain some of the money for the drugs themselves, so that some additional value is attached and costs for the project are reduced.

Only a few years ago discussions focused on whether or not to promote ARV therapy in sub-Saharan Africa. Today, Reach Out, MSF and others have demonstrated that antiretroviral therapy can be provided in low-income countries and argued that it is unethical not to do so. Instead, the issue has become one of how best to ensure the necessary prerequisites for treatment as well as provide it. This includes community education and psychosocial support to the patients, adults as well as children and young people.

Here, it is important to remove any dichotomy between treatment and prevention. In many ways, ARV therapy has become synonymous with preventing HIV, as treatment works to both reduce the prevalence of opportunistic infections and to reduce HIV/AIDS transmission in at least two ways:

1. It reduces the viral load, making HIV-positive individuals less infectious;
2. It can help draw those who do not know their status to health-care facilities to get tested. This increases awareness about one’s status and with proper counselling, individuals should be better equipped to avoid transmission, regardless of whether or not they actually begin treatment.

However, we are still dealing with large problems and dilemmas concerning unequal access to treatment. The inclusion and exclusion criteria remain highly difficult to understand for many people, especially those needing but not receiving treatment. If a holistic approach is going to be employed, the social patterns of differentiation this (inclusion and exclusion) creates should be remembered. This implies that ARV therapy should not be provided to people living with HIV just because they think they need treatment. Clear inclusion and exclusion criteria, based in part on adherence, must be discussed with and explained to the community and, when agreed on, enforced. Other concerns include:

- Disclosure: Reach Out, for example, asks for consent from the client about whom to disclose their status to. They have documented that disclosure within the household makes success more likely by addressing stigma head on. At least one person in the family has to know. In addition, as with MSF, one has to be in the project for three months and remain in the area to receive ARV therapy. This stability, coupled with disclosure, is considered to be an important aspect of ensuring adherence.

- Scaling up: the established follow-up programme at Reach Out means that scaling-up is not possible. If there is scale up, the follow-up is likely to suffer as home visits, education and ongoing counselling require substantial additional resources. In the case of MSF, it has been shown that treatment in resource-poor settings is possible, but to scale up will require a much larger, internationally funded initiative, in collaboration with local governments and the local population.

Nevertheless, much can be achieved with the right commitment and skills even in resource-poor settings. NGOs and others must consider how we can relate isolated successes to large-scale realities. Best or “better” practice projects have been presented but it must be remembered that they are parts of local realities. Will these pockets of access also lead to equal access on a national and international scale? And can duplicating mistakes be avoided? Strong coordination efforts are needed so that NGO efforts can be mapped.
Resources


While the previous chapters have looked at national and international policies on the global governance of ARV drugs as well as local and national NGO initiatives, in this section ARV therapy will be presented more in relationship to the individuals who are working with HIV/AIDS services, who are affected or infected themselves. This chapter considers whether the public health-care system facilitates prevention and treatment or favours one over the other, and whether the opportunity to receive treatment makes people more likely to test for their HIV status.

The role of the public health sector is clearly of paramount importance. As the response moves beyond prevention to include counselling, testing and treatment, it represents an enormous challenge to the health-care system and its staff. Counselling is one concrete example of a key under-addressed issue in this connection. How is it being undertaken and by whom? More than just providing information, counselling requires the active involvement of the client, which presupposes a certain level of understanding of the gravity of the situation on the part of those seeking help and the time for the counsellors to address these problems.

This leads to the issue of how health sector personnel perceive their role in a situation where there is often an unclear division of tasks between nurses and midwives on the one hand and doctors on the other. This is compounded where the existence of medicine to control the infection puts them into dilemmas in relation to patients who are unable to afford them.

I. The quest for a test

Whether the availability of ARV therapy influences an individual’s motivation to seek voluntary confidential counselling and testing (VCCT) has been raised as one of the most important questions since ARV therapy became more widely available in low-income countries. This is also of prime concern to the AIDS Information Centre (AIC) in Kampala. The AIC, set up in 1990, is an NGO with five (urban) branches in Uganda. The centre has tested more than 900,000 clients for HIV since 1990. The current prevalence rate among those tested is 20% (2004), which is higher than the estimate for the country as a whole. One reason for this may be that those most inclined to test are those most likely to test positive, while another hypothesis says that HIV rates are higher in urban areas.

Overall, there has been an increase in the number of people on ARVs as well as a sharp increase in attendance for VCCT as reported from the JCRC example above. However, this trend is not seen at the AIC branch where there is no nearby service for ARVs, suggesting that there is greater motivation to test where ARVs are available in the vicinity. Yet AIC staff did not think that advances with regard to AIDS treatment had had much impact on the majority of those infected. Therefore the TORCH project worked with AIC to investigate the possible ways in which the availability of ARV therapy is influencing people’s motivation to test for HIV/AIDS. Some 328 men and women were interviewed as part of a first study to look at this.

Asked about their reason for getting tested, almost half of the participants responded simply that they wanted to know their HIV status; 42% stated that they “feared for their health” or were “entering a new sexual relationship”. Less than 5% gave “wanting to get ARV treatment” as a reason for testing. Of those who chose not to get tested, fear of the certainty of being HIV positive and the likely ensuing stigma were reported as the main reasons. 73% of the respondents knew that HIV/AIDS is not curable, while 13% thought it was curable (mainly born-again Christians). Many of the respondents felt that even if they needed ARVs they would not be able to pay for them.

Whereas it can come as a surprise that the AIC clients’ reason for seeking VCCT did not seem to be founded in any aspiration for accessing ARVs, it should be noted that there was a strong selection bias in the AIC survey. AIC provides counselling...
and testing, but not ARVs. Those who consider themselves as treatment candidates and have the means to pay for the medicine would be more likely to test elsewhere, for example at the JCRC. What is needed is a comparative study with centres that provide ARVs to investigate whether or not the trends are different. One of these could be the JCRC, described above.

Herbal remedies

The respondents had mixed opinions on herbal treatment of AIDS: some believed it could cure HIV/AIDS, others that it could relieve symptoms and others that it had no effect. Understanding the role of the traditional or informal health care sector is thus an important step when advocating new biomedical treatment (i.e. ARVs) to the public in Uganda. One step would be for the government, NGOs and funding agencies to promote further research in herbal medicine and people’s use and understanding of it. Unfortunately, AIC has noted that people try to promote remedies that have not been tested sufficiently and that some of the herbal medicine has side-effects.

Next steps for VCCT

In spite of the reasons why people choose or do not choose VCCT services, VCCT does need to be expanded and sufficient human resources recruited to improve the quality of counselling and to effectively address the increasing demand for the services. Mass campaigns to educate people about the availability, advantages and side-effects of ARVs should be prioritised. Paediatric AIDS care issues, including counselling, care and support, must be addressed. An increased demand for VCCT along with the increasing demand for ARVs will have a direct bearing on the need for a consolidated and linked approach.

Figure 2. HIV Counselling and testing as an entry point for prevention, care and treatment of all people

Source: Adapted from the WHO online VCCT toolkit, <http://who.avkit.net/tc/en/content.jsp?d=tc.00>, Family Health International and UNAIDS
to prevention and behaviour change communication. This, therefore, requires a closing of the gap between solely providing prevention services or treatment services, as illustrated in Figure 2.

II. Health systems and ARV provision

In spite of the central role that NGOs have played in the fight against HIV/AIDS, they cannot and should not fully replace the government. What does the enormous influx of money, technical assistance and resources mean for one of the main providers of most health services to the poor – the public health system? A recent study (Whyte et al. 2004) looked at the prevention of mother-to-child infection programmes – the only HIV/AIDS-related programme at the national level attempting to scale up. The aim of this study was to take the perspectives of the government health workers on the frontline, as they are the people who are going to make the policy work or not. There are three principal areas of concern: access to resources, staff and workload, and the quality of counselling.

The Ugandan context

Uganda has been described extensively above, but here it is important to point out that the government policy is unique for its openness with regards to AIDS. Both the openness and the strong presidential leadership are attractive to external donors (see Richey and Haakonson 2004). The policy of multiplicity has meant that NGOs and bilateral and multilateral donors often intertwine with the government health system producing not a public-private mix, but a public-private-donor “mix-up”. Donors provide funds to NGOs and NGOs work partly through government staff and facilities. To know the health-care possibilities in a district one must know the acronyms of the NGOs, international donors and particular programmes. For the newcomer, this mix-up is a veritable jungle of resources, options and restrictions – a jungle that the local health workers must navigate while trying to deal with the influx of resources.

The NGO-influence on the public health-care system has entailed new social forms for interaction and access to social and financial resources, brought about by the new priorities in the health-care systems: seminars, workshops, and training sessions. The new emphasis on communication addressing behaviour change, sensitization and counselling activities leads to new skills and values. In addition, allowances, by which donors and NGOs can top up salaries, have become an even more important part of the public health-care salary system, with the new influx of donor funds.

Access to resources: Tororo District

In Tororo District of eastern Uganda prevention of mother-to-child transmission of HIV is offered at three health units and some outreach sites. Eight different donors support these activities, each with different possibilities and requirements. At one rural hospital, five donors are involved in this service.

The district health system is seriously understaffed and health workers are faced with numerous new tasks, such as pre-counselling, lab work, post-counselling, outreach and record keeping. No new staff are currently being appointed. There are no positions as counsellors, so counselling is carried out instead by nurses and midwives. The workload falls disproportionately on some staff members. And, ironically, successful publicity means more clients with the result that there is less time for proper counselling and a neglect of other regular duties.

There is a constant struggle to obtain resources for the health unit itself and for the staff members. There is a high staff interest in financial allowances, and different agencies have different policies for allowances. There is a clear awareness of who receives allowances and for what task as allowances constitute recognition and a much needed addition to salaries.

Staff and workload: The health workers perspective

While clearly a positive development, the increase in number of clients seeking VCCT is a major challenge for health workers. In a situation where no additional human resources or improved infrastructure are being made available, this increase can compromise the quality of normal services as well as new HIV-related services. Nurses, midwives and lab technicians must carry out their normal duties as well as new testing, counselling and outreach activities. As long as district health facilities are so understaffed, there is little interest in hiring staff designated only for HIV/AIDS activities. The need is for more health workers in all categories to provide the full range of health care. Understaffing and increased workload,
decreased morale, and burn-out among the staff are all unresolved problems at the public clinics.

The quality of counselling

The communication between health workers and patients is notoriously poor in many centres and regions. There are numerous examples of clients leaving a consultation without knowing their diagnosis or how to take the drugs prescribed for them. Here, Uganda is not unique. But the response to HIV/AIDS has brought new developments in health communication.

Before 1990, the term counselling was not used much in Uganda. Now it is a buzzword as counselling has become the key concept in communication about testing and living with HIV/AIDS. Perhaps it could be said that counselling is a new cultural phenomenon, part of a shift in the culture of health care in Uganda. NGOs have played an important role in this development. Originally, the organisation TASO introduced counselling and provided training in counselling. The focus of TASO was on psychosocial support with an emotional rather than spiritual focus. The notion of peer counselling is one of the contributions of TASO and other NGOs. Now, many different agencies train in counselling at different levels.

With the rapid expansion in VCCT/PMTCT, training cannot keep pace and some facilities use counsellors who have not yet been properly trained. There is a keen desire for training in counselling (it is a good career move) and a fast scale-up – many learn on the job and hope to get a certificate later.

Several issues require further discussion and study. Many people use the term “counselling” very generously, i.e. they label all communication counselling though it actually only applies to certain situations. Often, what is provided is sensitisation and not counselling. Calling this counselling suggests that health workers think of their patients as clients, whereas counselling implies a more egalitarian relationship. But health workers often report that hierarchies of age and status may be hard to overcome. It is difficult to counsel an older or “more important” person. Observations suggest that the professional status of a health worker can intimidate young, less-educated women. Research must address how counselling is understood by the main actors in the health-care systems and the clients themselves.

The content of sensitisation and counselling needs to be addressed. There is a lack of guidelines on counselling procedures for children. As more people go on to ARV regimens, it will be necessary to improve counselling about adherence and side-effects in order to minimize non-compliance that could lead to drug resistance.

The “C” of counselling in “VCCT” is also associated with condoms, which are a key point in prevention – counselling on safer sex. However, messages about condom use are controversial in some settings. Therefore, NGOs should be careful in picking project partners. The Catholic Church is one of the key players in health care globally, but for religious reasons does not openly recommend or provide condoms. So while they are an excellent partner in some circumstances, other partners need to be relied on for parts of the counselling services.

Furthermore, there seem to be problems with the “V” of voluntary. For example, in Botswana, one of the countries that have made the most efforts in sub-Saharan Africa to establish free access to ARV therapy in the framework of a public health-care system, there is a so-called opt-out policy with regard to counselling when getting tested for HIV. That means that the perspective is turned around and an HIV test is built into other routine checks. The patient therefore actively has to say that he or she does not want to take a test, when for instance being admitted into a hospital with a broken leg. Routine counselling and testing has also been introduced at the national hospital in Uganda. Such policies have ethical implications as poor people may not fully understand their options with regard to taking an HIV test. The ethical and practical problems of counselling very ill patients in hospital wards have yet to be fully worked through.

Researchers and NGOs need to work together with ministries of health and staff in the public health system to explore these problems and improve the quality of counselling.

Some conclusions and more questions

Some old problems are being exacerbated by the influx of resources for HIV/AIDS and new treatments are also presenting new dilemmas. For example:

- New tasks are assigned to understaffed public health facilities, falling disproportionately on
some staff and threatening to weaken the delivery of general services.

- While staff appreciate additional allowances to top up their salaries, these also contribute to unwillingness among staff to take on any new tasks without compensation and in some cases to neglect of “normal” work in favour of activities that provide allowances.
- Counselling is being mainstreamed as a part of public health care, but are quality issues being dominated by a thinly-spread approach?
- Counselling emphasises interpersonal communication, yet how is such dialogue possible when it takes place within the existing hierarchical health worker-patient relations?
- How does (HIV/AIDS) counselling fit in with wider cultural values about consulting and support?
- Should lay people be trained in counselling instead of focusing only on health workers?

And what does the focus on ARV therapy mean for other sectors of the health system? It can mean that resources, including staff, leave, leading to “brain drain”. Will we see better coordination in logistics systems? Will the efforts to build capacity for dealing with HIV/AIDS strengthen care for other health problems as well? In which ways is it becoming more effective? Or will new resources affect only very narrow, often vertical services? One encouraging example can be drawn from child immunization campaigns. When they were introduced they had a positive impact on the general health system and can be seen as examples of how a vertical programme can affect the horizontal health services.
Lessons Learned for the NGO Community

This paper has dealt with ARV therapy in relation to three major issues: access, holistic approaches and the public health sector.

The reason why this paper mainly refers to Uganda is that while each country in sub-Saharan Africa is unique, there are some common lessons and efforts that can benefit all of them from the Ugandan case. In spite of harsh conditions, Uganda has managed to have a large number of people living with HIV on ARV therapy. It has the second highest number of ARV patients in sub-Saharan Africa, after Botswana. The country has been able to attract increased funding to the area but is now facing the dilemma that as people are increasingly seeking to be tested, the concomitant costs of VCCT increase, as well as the costs for treatment, as more people become aware of their positive status.

In relation to access, the paper has touched upon the consequences of the present uneven access to ARV therapy for HIV-positive people and their families in a situation where resources are scarce.

One positive change is that in Uganda the business sector has become active in the area of treating HIV-positive individuals. Some employers are now contributing to the treatment of their employees because they do not want to lose workers. Some businesses have even made public announcements that this is their policy. But it raises ethical questions if the private companies are only interested in covering their skilled employees. Obviously, private companies cannot fill gaps that the public sector should address, especially not in countries where the majority of the workforce works in the informal sector. Most people in low-income countries must still rely on public health care, but private providers and NGOs are also part of the service provision constellation for the poor.

If NGOs can provide access to confidential counselling and testing that will attract people to the clinics, this should be encouraged. NGOs must also advocate for true integration of services, where relevant. There is a golden opportunity now for regenerating these activities. A major challenge will be how to get donors to give money to the general budget of clinics. One way to do this is to advocate for a basket of services to be covered, and not just ARV therapy.

However, NGOs working on the ground know better than anybody that the human suffering related to AIDS will not just be stopped by medicine alone but must be addressed through holistic approaches that include food, social support, information and reduced stigmatization, in addition to medicines. The work of Reach Out Mbuya has been a light in the darkness; we need to learn from local people how they have been successful in mobilising a community for all round support to people living with HIV/AIDS. Thus, medicines should be seen as only part of the continuum of care. To scale up, we need to provide broad spectrum care cheaper. To do this, we need some kind of compass to navigate through the jungle of the donor-public-private “mix-up”.

The relationship between treatment and prevention remains a major question for NGOs. Uganda has provided the example of successful prevention in Africa, yet we understand very little of what factors actually brought about success and in what ways. What impact will the swell of ARVs and information have on ongoing prevention efforts? Some Ugandans are aware of the existence of ARV therapy but are also aware that these drugs are probably unattainable for most of the population, in spite of the rapid scale-up of treatment. There is as yet no well documented direct link between the hope to get drugs and the increased interest in VCCT. Therefore, health-seeking behaviour with regard to HIV/AIDS, such as testing patterns, needs to be further researched with a focus on local context.

In relation to the public health sector, the district health teams have only a fair idea about what is going on, how many staff are actually active, and what they do. Nevertheless, district health teams are still the prime resources for understanding the local, economic and cultural dynamics of HIV transmission, AIDS care and health-seeking behaviour. They need
to be consulted in a meaningful way as they are the local experts. NGOs and government health workers would benefit from deeper collaboration between the public and private sector organisations working at the local level. But NGOs also need to consult other NGOs that have accumulated best practices that can be replicated elsewhere, such as from the work of Uganda’s TASO. It is important to have openness in policies, in failures as well as in successes, so NGOs can try out different approaches. It is therefore unethical not to report project failures as systematically as success stories because we need the full picture in order to improve interventions. NGOs can demonstrate their serious commitments in implementation in this field by reporting and sharing “worst practices”, “missed opportunities” and “imperfect interventions”, in addition to “best”, “better” and “good enough” practices.

One major risk in the scale-up of ARV therapy is that of health systems being developed in parallel to the government system and with regard to different developed aspects of comprehensive programmes. With regard to the actual treatment, most NGOs are trying to work through the government system. But, for example, to what extent is it possible to provide ARV therapy in programmes that can also provide the nutrition that is needed? Should programmes always be linked up with the public health system or can Uganda have an unlimited number of individual success stories?

It is worth emphasising that when people start taking ARVs, it is for life. More than 90,000 people in Uganda currently need treatment for HIV/AIDS and the number will continue to increase. The biggest concern in the country and across sub-Saharan Africa is not just counselling and testing, but how to sustain services for those who are already receiving ARV therapy, against a background of increasing numbers and uncertain financial resources. Even more affordable drugs are needed so that low-income countries are not entirely dependent on donor funds. The most sustainable solution is the unlikely scenario that those in need would be able to purchase the drugs themselves.

This issue of the cost-effectiveness of treating HIV/AIDS with ARV therapy is still to be studied. ARV therapy now has a central place on the agenda of most development donors, but what about comparing ARV therapy to measles vaccination – what are the cost-benefits and cost-effectiveness of the one versus the other? The often-hailed Haiti-model of Paul Farmer (“Haiti scaling-up in a resource limited setting”) will actually cost US $67 million for the next five years. Given the current funding situation, this would not realistically be possible to replicate in other settings. The focus on antiretroviral drugs may also detract attention from other forms of treatment and support. It is important to consider more effective treatment of tuberculosis and other opportunistic infections, and prophylactic use of micronutrients like vitamins and antibiotics like cotrimoxazole (Septrin).

The take-home messages for NGOs fall in many different areas, but the lessons that can be learned from Uganda include the following points of NGO intervention:

- **Contribute to public health development**: Access to ARV therapy as a project component is new to many NGOs and it requires considering broader public health issues, especially the relationship between prevention and care and principles of equity in access. To integrate an equitable approach to ARVs in the national health sector is a tremendous challenge that NGOs must assist the governments in meeting.
- **Emphasize and upgrade counselling**: NGOs need to look into the quality, the local perceptions and the use of counselling and peer education in relation to HIV/AIDS. The concept of counselling is not always well understood or well implemented.
- **Target approaches appropriately**: There is an urgent need for a refined understanding of the target groups of the different HIV/AIDS programmes, especially in relationship to children and young people. NGOs could, in collaboration with local or international researchers, undertake vulnerability assessments in order to explore the different vectors of vulnerability in local contexts.
- **Coordinate and communicate with government**: The collaboration between the public sector and NGOs (both international and local) must be strengthened, at the same time as duplication and competition between the public sector and NGOs must be avoided.
- **Coordinate and communicate with other NGOs**: National NGOs also need to improve the coordination of their activities and the sharing of available data and research results. Partner
NGOs must be better at encouraging a meaningful collaboration between NGOs that are located in the same geographical area.

- **Uphold human rights:** The rights perspective must be maintained. So-called “opt-out” approaches, where patients actively have to refuse HIV tests, should be contested. The human rights of HIV-positive people must not be violated in the name of expediency.

- **Nurture local capacity:** Brain drain, affecting the health system of entire countries, especially urban centres, is also taking its toll at the local level. Numerous sub-Saharan African countries face major staffing shortages in the health sector. NGOs should be mindful of their hiring practices and professional demands to ensure that their activities are contributing to the development of a local cadre of professionals who will remain rooted in their communities.

- **Act from evidence:** The use of applied research must be improved among NGOs and regular dialogue between local and international researchers and NGOs can facilitate that process. NGOs should also consult published research findings when planning their interventions.

### Resources


