

Treatment, care and support for people living with **HIV**

5

Treatment and care for women and girls

Biology matters

HIV affects men and women in different ways, and women's immune systems may respond differently to the virus (Farzadegan et al., 1998). On top of the many HIV-related diseases and ailments suffered by both sexes, HIV-positive women have a higher incidence of cervical cancer than women without the virus. When women are on antiretroviral treatment, they may experience stronger side effects. Studies suggest female hormones may play a role, as may the fact that both sexes take the same size dose of drugs, even though the average woman weighs less than a man (Project Inform, 2001).

Despite these differences, when treated equally, the differences between men and women's survival rates disappear. Unfortunately, in most parts of the world, the social and economic power imbalances between men and women raise fears that women are being denied equitable and timely access to treatment options.

Targets and obstacles

In many countries, prevailing gender attitudes mean women and girls are the last priority for health care. Husbands and elders often decide whether to spend family resources on health care, or whether a woman can take time away from her household duties to visit a health centre. AIDS has further complicated this situation. When male and female family members are HIV-infected, and resources are limited, addressing male treatment needs often comes first.

To reflect the global distribution of HIV by sex, which is nearly 50–50, women should constitute at least half of the millions of people in low- and middle-income countries expected to gain access to antiretrovirals in coming years. To account for regional differences (such as in sub-Saharan Africa, where women account for 57% of HIV infections), countries need to set national treatment targets based on the epidemic's sexual distribution. Furthermore, communities need to overcome barriers to women being tested for HIV, including the risk of violence they may face if they are found to be HIV-positive.

Adolescent girls face strong obstacles to gaining access to treatment. In many countries, they are at the highest risk of HIV due to gender power imbalances, early marriages, sexual violence, and intergenerational sex. Yet, they have the least power to demand treatment. They also often face legal barriers such as age-of-consent laws. These laws are meant to protect young people, but they may also deny them the ability to make important life decisions (Center for Health and Gender Equity, 2004).

Ensuring gender-sensitive access to treatment

Recently, the Center for Health and Gender Equality proposed essential elements for gender-sensitive access to AIDS treatment (Center for Health and Gender Equality, 2004). These include ensuring that:

- **eligibility criteria reflect both biomedical and socioeconomic vulnerabilities**—Treatment eligibility should consider factors such as the inequality in social status of many women and girls, as well as CD4 cell counts.
- **eligibility criteria do not discriminate against women depending on their pregnancy status, nor focus on women only in relation to their pregnancy**—Non-pregnant women and adolescent girls should not be neglected during efforts to expand access to services that prevent mother-to-child transmission.
- **criteria and processes for expanding access to treatment are transparent and accountable to communities in question.**
- **drug adherence programmes are gender-sensitive**—A service's hours of operation and staffing need to consider a woman's work and domestic schedules or responsibilities, as well as her need for privacy and dignity when accessing care.
- **sound efforts are made to achieve quality of care and an end to bias within health-care systems**—In many places, health-care infrastructure and procedures need to be improved to provide safe, comprehensive and sustained treatment. At the same time, health-care providers must model gender-sensitive behaviour and not perpetuate gender bias, even if it is rampant in the wider community.

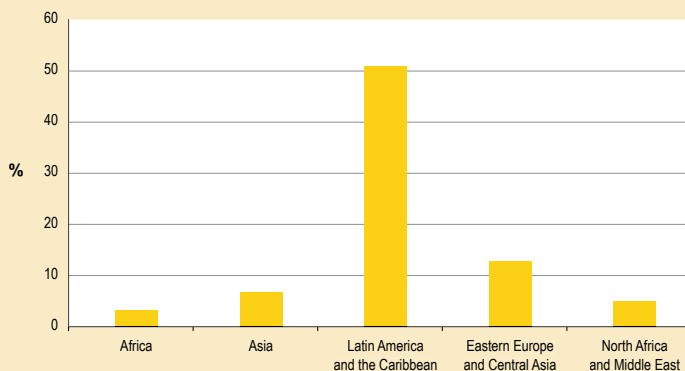
In Botswana and South Africa, treatment programmes raise hopes that gender equity can be achieved. Both have observed that women outnumber men in gaining access to scaled-up treatment services. Various reasons may exist for this. Both programmes have strong roots in efforts to prevent mother-to-child transmission of HIV that do not target men. Also, it may be that general experiences with antenatal, maternity and child-related public health care make women more comfortable with accessing AIDS-related health services. It is still unclear whether the experiences of these programmes can be replicated in other acutely affected countries, especially those where public-health infrastructure is less developed and where women face greater obstacles in gaining access to general health care (Fleischman, 2004).

Treatment, care and support for people living with HIV

The global community is at a crossroads in expanding access to HIV treatment and care. Never before have the opportunities been so great: unprecedented political will in countries; unprecedented financial resources to fund treatment, care and support; and unprecedented affordability of medicines and diagnostics.

Antiretroviral therapy coverage for adults, end 2003

400 000 people on treatment: 7% coverage



Source: UNAIDS/WHO, 2004

Figure 33

Despite these extraordinarily positive conditions, access to antiretroviral treatment and other HIV-related disease care remains abysmally low. Five to six million people in low- and middle-income countries need antiretroviral treatment immediately. However, the World Health Organization (WHO) estimated that only 400 000 people at the end of 2003 had access to it. This means that nine out of ten people who urgently need HIV treatment are not being reached.

Scaling up treatment and care

Nevertheless, the global movement to scale up access to HIV treatment has made critical gains during the past several years. In endorsing

the 2001 Declaration of Commitment on HIV/AIDS, all UN member states pledged to progressively provide the highest attainable standard of treatment for HIV-related disease, including antiretroviral therapy. Most countries with national AIDS plans have incorporated antiretroviral treatment into them and have set specific antiretroviral treatment coverage targets. Meanwhile, UNAIDS and other partners have developed tools to measure progress and promote accountability in achieving this goal, and are actively monitoring and evaluating the situation in countries.

Globally, governments, the UN system, bilateral donors, the Global Fund to Fight AIDS, Tuberculosis and Malaria and civil society are increasingly focusing on treatment and care as part of their commitment to scaling up the global HIV response. For example, the World Bank's Multi-country AIDS Programme, which amounts to US\$ 1 billion for Africa and US\$ 155 million for the Caribbean, is allowing governments and other beneficiaries to use World Bank funds flexibly for HIV treatment, including for procuring medicines, strengthening health system infrastructures and training.

In May 2004, the Bank agreed to allocate US\$ 60 million through a new Treatment Acceleration Programme to scale up treatment in three pilot countries: Burkina Faso, Ghana

Progress update on the global response to the AIDS epidemic, 2004

Less than one in ten people who need antiretroviral therapy receive it

- An estimated five to six million people in low- and middle-income countries will die in the next two years if they do not receive antiretroviral treatment. As of December 2003, only an estimated 400 000 people in these regions were obtaining it.
- On average, 80% of responding countries reported having a policy in place to ensure or improve access to HIV-related drugs. However, in reality, it is estimated that access to antiretroviral treatment is below 10% in every region except the Americas.
- Several South American countries have universal coverage for antiretroviral therapy, including Argentina, Brazil, Chile, Cuba, Mexico and Uruguay. Several others cover about two-thirds of people in need, including Barbados, Colombia, Costa Rica and Paraguay.
- In sub-Saharan Africa, an estimated 4.3 million people need AIDS home-based care, but only about 12% receive it. In South-East Asia, coverage drops to 2%.
- In South America and Eastern Europe, most patients receive at least the essential package of care services recommended by WHO and UNAIDS. In Africa and Asia, only one-third of people receive at least the essential package.

Source: *Progress Report on the Global Response to the HIV/AIDS Epidemic*, UNAIDS, 2003; *Coverage of selected services for HIV/AIDS prevention and care in low- and middle-income countries in 2003*, UNAIDS/USAID/WHO/CDC and the Policy Project, 2004.

and Mozambique. Meanwhile, the Global Fund to Fight AIDS, Tuberculosis and Malaria's HIV-related grant monies mean that 700 000 people will be able to gain access to antiretroviral treatment (Global Fund to Fight AIDS, Tuberculosis and Malaria, 2003). About 80% of the Fund's HIV/AIDS and integrated HIV/Tuberculosis approved proposals include provisions for strengthening antiretroviral programmes and procuring HIV medicines.

Bilateral donors are increasingly open to supporting care and treatment if they are part of comprehensive AIDS plans linked to broader national development plans. The United States of America has launched the *President's Emergency Plan for AIDS Relief* which includes the goal of reaching two million people with HIV treatment in priority countries in Africa and the Caribbean. France and seven other countries have initiated a 'twinning' project called Ensemble pour une solidarité thérapeutique hospitalière en réseau to help support antiretroviral programmes in several low- and middle-income countries.

Low- and middle-income countries are also increasingly allocating funds from national budgets and debt relief to support treatment services. For example, in 2003–2004 Cameroon allocated over US\$ 30 million in debt relief under the Highly Indebted Poor Countries Initiative to support AIDS programmes—most of the money went to care activities. Meanwhile, South Africa's national AIDS care plan is based largely on domestic financing.

The private sector

Private sector efforts are also increasing. Advocacy to set up prevention and treatment programmes in the workplace has been mainly led by businesses themselves. Under the leadership of Ambassador Richard Holbrooke, the Global Business Coalition on HIV/AIDS has grown to include 145 major business corporations. Many of these companies and other large and small enterprises are establishing HIV treatment programming for their employees as called for by the International Labour Organization (ILO). These companies include Anglo American (see box on page 103),

Anglo American and AngloGold—providing antiretroviral treatment to miners in Southern Africa

Over the past 16 years Anglo American has implemented a comprehensive response to HIV and AIDS including non-discrimination, prevention, testing and care. From mid-2002 through 2003, the company initiated an antiretroviral treatment programme, one of the largest global employer-based HIV treatment initiatives, with over 1100 employees receiving treatment by January 2004. To accelerate providing comprehensive HIV services in government primary care clinics located in their communities, Anglo American is extending HIV services beyond the workplace through partnerships with 'loveLife' and other community-based organizations.

In November 2002, AngloGold, a large gold mining company, also recognized that human and economic factors justify investing in HIV workplace programmes, and extended its programme for HIV-positive employees to include antiretroviral treatment. Treatment activists and commentators in South Africa have applauded these initiatives. However, they stress it is also important to provide treatment to other HIV-positive family members in order to avoid inequity in treatment access within families and to ensure women and children can obtain treatment for HIV-related disease.

DaimlerChrysler (automobiles), Eskom (utilities), Lafarge (cement), Royal Dutch/Shell (petroleum) and Heineken (beer). Tata Steel in India and ChevronTexaco in Nigeria are also expanding treatment services within their companies and wider communities.

In March 2004, the Accelerating Access Initiative (a public-private partnership of six research-based pharmaceutical companies and the UN) reported that the quantities of antiretroviral medicines from these companies supplied to Africa doubled in the last six months of 2003.

Falling antiretroviral prices

In recent years, the prices of antiretroviral medicine have fallen dramatically; a major development that has helped to make wider treatment access possible. In 2000, the price of a first-line WHO-recommended combina-

tion antiretroviral regimen to treat one patient for one year was between US\$ 10 000 and US\$ 12 000 on world markets. Several factors converged to help bring down prices—including advocacy by people living with HIV and by world leaders. By early 2002, generic competition and the practice of differential pricing by pharmaceutical companies had contributed to dramatic price reductions, particularly for low-income countries. The price for certain generic combinations dropped to US\$ 300 per person per year.

The William J Clinton Presidential Foundation has played a critical catalytic role in planning in individual countries and in engaging generic drug manufacturers from India and South Africa in moves to lower prices. By the end of 2003, it announced that it had negotiated antiretroviral prices as low as US\$ 140 per

Equitable access to affordable medicines—the power of advocacy

“People no longer accept that the sick and dying, simply because they are poor, should be denied drugs which have transformed the lives of others who are better off.”

—Kofi Annan, Secretary-General of the United Nations

Prices (US\$/year) of a first-line antiretroviral regimen in Uganda: 1998–2003

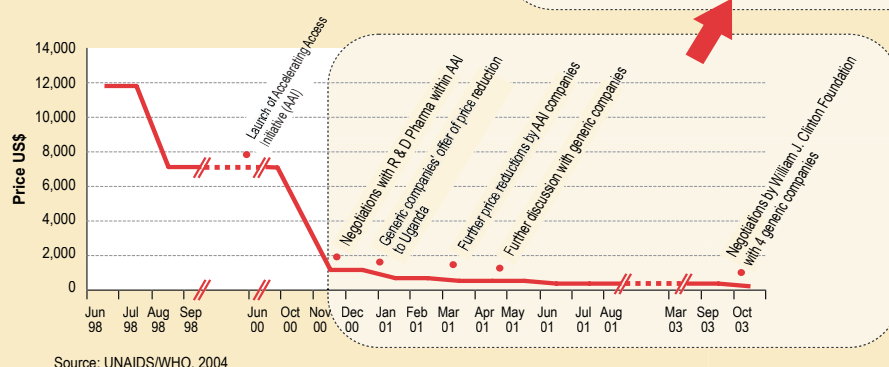


Figure 34

person per year (less than US\$ 0.50 per day) under certain conditions. These preferential prices for generics are available for WHO-recommended, first-line regimens in countries in which the Foundation is working in Africa and the Caribbean.

Recently, the Clinton Foundation has offered the same prices for antiretroviral procurement to the United Nations Children's Fund (UNICEF) and to World Bank and Global Fund beneficiaries. These are important advances, but antiretroviral prices remain extremely high in a number of middle-income countries, including Russia, Serbia and other Central and Eastern European countries. The price offered by pharmaceutical companies for WHO-recommended, second-line regimens is also high, exceeding US\$ 1000 per person per year—even in low-income countries.

Meanwhile, cooperation continues to increase between countries with antiretroviral medicine manufacturing capacity and countries wishing to set up local production facilities. Brazil, India, Thailand and several large African countries recently signed cooperation

agreements. Then, at a January 2004 WHO meeting, they and other low- and middle-income countries agreed to cooperate with European and North American industrialized countries. Together, they will jointly promote and undertake antiretroviral production technology transfer to low- and middle-income countries interested and able to create local production capacity.

In sub-Saharan Africa, many more countries say they intend to set up their own production facilities. These include Ethiopia, Kenya, Mozambique, Nigeria, Tanzania, Uganda and Zambia. South Africa already launched its first antiretroviral drug in August 2003. All have plans to start manufacturing generics sometime during 2004–2005 (Dummett, 2003).

Treatment and prevention: mutually reinforcing

Some people oppose scaling up treatment with prevention-versus-treatment 'cost-effectiveness' arguments. But cost-effectiveness analyses comparing HIV prevention and treatment provide a simplistic and outdated view that prevention should be funded to the exclusion of treatment,

merely because prevention programmes may be cheaper.

In July 2003, the World Bank concluded that most studies underestimate the long-term impact of the epidemic, and that AIDS can cause far greater long-term damage to national economies than previously assumed. The Government of Brazil has estimated that antiretroviral treatment has resulted in savings of about US\$ 2.2 billion in hospital care that would have otherwise been required by people living with HIV. The government says antiretroviral treatment has contributed to a 50% fall in mortality rates, a 60–80% decrease in morbidity rates and a 70% reduction in hospitalizations among HIV-positive people.

Cost-effectiveness analyses pitting prevention against treatment ignore the mutually reinforcing synergy of integrating these interventions. Ultimately, there is no arbitrary threshold at which treatment can be valued. No nation hit by an expensive security breach would refrain

from correcting it on the grounds that it would be cheaper to prevent future breaches. It would deal with the breach *and* take preventive measures. So it should be with AIDS.

Widespread access to antiretroviral treatment could bring millions of people into health-care settings, providing new opportunities for health-care workers to deliver and reinforce HIV prevention messages and interventions. Doctors, nurses and community health workers should be trained to integrate risk reduction promotion into antiretroviral adherence support. Simultaneous and aggressive expansion of both HIV prevention and AIDS treatment in a truly comprehensive approach can halt and begin to reverse the epidemic.

Antiretroviral medicines in resource-limited settings

With unprecedented opportunities now in place for scaling up treatment, it is almost universally agreed that antiretroviral medicines can

5

The link between prevention and care

The belated focus on AIDS treatment is highlighting the synergies between many aspects of prevention and treatment. For example, the fact that antiretroviral drugs are becoming more available means that more people are seeking voluntary counselling and testing and finding out their HIV status. Both treatment and prevention are needed simultaneously for a successful response.

- In South Africa, a health survey conducted after the start of Médecins Sans Frontières' antiretroviral programme in Khayelitsha found that, of eight sites reviewed, the Khayelitsha township had the highest level of condom use, willingness to join AIDS clubs, and willingness to be tested for HIV (WHO, 2003b).
- In Masaka, Uganda, a voluntary counselling and testing unit that had closed its doors for lack of clients was rehabilitated in 2002 at the same time an antiretroviral programme began on the same hospital premises. Attendance soared. By February 2003, a total of 5060 clients had received voluntary counselling and testing—a 17-fold increase on 2000 (Mpiima et al., 2003).
- In the first year of the HIV Equity Initiative, an antiretroviral programme run by Partners for Health in Cange, Haiti, demand for voluntary counselling and testing increased more than threefold (WHO, 2003a).
- A survey of 700 HIV positive people in Côte D'Ivoire in 2000 indicated that those with access to antiretroviral treatment were more likely to use condoms during sex than those without access (Moatti et al., 2003).

Providing antiretroviral treatment in Thailand

In Thailand, lower drug prices have contributed to a fivefold increase in the number of HIV-positive patients receiving antiretroviral treatment; from about 2500 cases in November 2002 to more than 15 000 cases by November 2003. The 2004 target is 50 000 people. The Thai government's antiretroviral treatment programme now offers free treatment to HIV-positive patients, and uses the locally produced combination drug GPOvir (d4T, 3TC and nevirapine) as the standard first-line treatment regimen. Using GPOvir has reduced the monthly cost for one patient's treatment from about US\$ 300 to US\$ 29. All 92 of the provincial hospitals under the Public Health Ministry are capable of providing antiretroviral treatment, and this capacity is to be rolled out to other hospitals in the near future.

be delivered safely and effectively in resource-limited settings. Beginning with the UNAIDS Drug Access Initiative in 1997 in Abidjan and Kampala, and then from Africa to Asia to the Caribbean, one after another, small-scale pilot projects have demonstrated programme effectiveness and safety.

Civil society has long been at the forefront of delivering HIV treatment. The Catholic Church reports that it delivers 26% of health care globally, and other faith-based groups are increasingly active in providing HIV care. Nongovernmental organizations (NGOs) have been treatment pioneers. They include Haiti's Zanmi Lasante (Partners in Health), San Egidio in Mozambique, and international campaigners such as Médecins sans Frontières (see box on page 107). They have stimulated the energies and commitment of the international community, and have taught valuable lessons.

Many countries, including those with high HIV prevalence or with emerging epidemics in large populations, have already been mobilizing in response to the HIV treatment gap. Several countries in Latin America and the Caribbean now offer universal coverage for antiretroviral treatment, including Argentina, Barbados, Chile, Costa Rica, Cuba, Mexico and Uruguay. Bahamas and Guyana are advancing towards universal access. Brazil is engaged in

a South-South cooperation programme with Bolivia and Paraguay to achieve universal access in those countries. Other countries that have made substantial progress include Botswana and Senegal. However, Brazil remains the only country with a large population to achieve universal access to AIDS treatment.

In Asia, as of November 2003, the national AIDS programmes in only two countries—India and Thailand—offered both first- and second-line treatment regimens. Only three others—Indonesia, Nepal and Sri Lanka—provided at least one first-line treatment regimen. The challenge now is to show that nationwide treatment programmes can be made available to millions of people in other low- and middle-income countries.

For development planners, the AIDS epidemic is a global public health emergency. Life expectancy of people with HIV is plummeting and the epidemic of infection is rapidly transforming into one of disease and death. Therefore, emergency approaches are needed to counteract the gradual approach to development that is often traditional to the health sector. At the same time, it is critical that expanded antiretroviral treatment coverage does not signal a return to disease-specific approaches to health care, but rather systematically builds and strengthens health systems across the board.

Médecins sans Frontières: pioneering HIV treatment in low- and middle-income countries

Since the early 1990s, Médecins sans Frontières has been caring for people living with HIV in low- and middle-income countries. Its first antiretroviral treatment programmes began in 2001. As of April 2004, approximately 13 000 people were on treatment in 42 of its projects in 19 countries in Africa, Asia and Latin America. The organization has been scaling up its programmes rapidly: from 1500 people in 10 countries in mid-2002, to a projected 25 000 in 25 countries by the end of 2004. At the same time, Médecins sans Frontières is sharing lessons learned through its diverse treatment experience. These lessons include:

- 'one pill twice a day'—adhering to treatment needs to be made as easy as possible; 80% of the organization's patients are on a WHO-recommended, triple fixed-dose combination.
- 'decentralize and adapt'—Médecins sans Frontières operates in areas with limited infrastructure and personnel. So, it uses mobile treatment clinics, delegates basic patient care to nurses and community health workers, and often begins treatment on the basis of a positive HIV test and clinical assessment by trained staff.
- 'available to the poorest'—cost should never be a barrier to treatment, and treatment will therefore have to be free for most people in the poorest countries.
- 'price matters'—the lower the price of medicines, the higher the number of patients who can be treated.
- 'involve the community'—community engagement helps to raise treatment and prevention adherence, and to break down the taboo surrounding HIV.

Voluntary counselling and testing, HIV prevention and treatment programmes, and sexual and reproductive health services need to be effectively integrated and form part and parcel of primary health services. An excellent example of prevention-treatment integration is provided by mother-to-child transmission prevention programmes that also include antiretroviral treatment for mothers who need it, both during and after pregnancy.

At the XIVth International Conference on HIV/AIDS in Barcelona, Spain in 2002, key participants set a global target of expanding antiretroviral treatment to three million people in low- and middle-income countries by the end of 2005. UNAIDS Secretariat, WHO and other partners concluded that this target was feasible if sufficient funds were raised and other measures taken. These 3 million people are among those who will die within two years if they do not receive antiretroviral treatment now.

Shortly after the Barcelona conference, additional steps were taken by the international community to mobilize around this target. This included establishing a global partnership of organizations working for expanded treatment access: the International HIV Treatment Access Coalition. The coalition grew to more than 120 members, but proved to be unsustainable as a vehicle for coordinating international community support.

The '3 by 5' Initiative

In September 2003, a crucial development occurred at the second UN General Assembly Special Session on HIV/AIDS. The Director-General of the World Health Organization and the Executive Director of UNAIDS declared the lack of treatment in low- and middle-income countries a global public health emergency and launched the '3 by 5' Initiative. They appealed to the global community to bridge the treatment gap, calling it one of the greatest human rights and public health crises of our times.

On World AIDS Day 2003, WHO took another important step, the announcement of its '3 by 5' Initiative. In the '3 by 5' context, WHO and UNAIDS have urged partners, including NGOs and the private sector, to join in mobilizing support to governments for scaling up treatment programmes in countries.

This '3 by 5' Initiative is an interim target, part of a global movement to mobilize support for vastly expanded—and ultimately universal—treatment access. Since its launch, many countries have announced, reconfirmed, or stepped up their commitments to bringing HIV treatment to their people who need it. To date, some 40 countries have formally said they wish to participate in the Initiative. With support from UNAIDS, WHO is seeking resources to expand the technical support that it can offer to countries in scaling up treatment programmes. As of June 2004, the governments of Canada, Sweden and the United Kingdom together with allocations from the UNAIDS Unified Budget and Workplan had provided important financial support for WHO to carry out its '3 by 5' strategy.

The strategy

The WHO strategy, *Treating 3 million by 2005—Making it happen*, includes a clear commitment by WHO to act in an urgent manner; involve people living with HIV in a central role; work in partnerships; safeguard equity and human rights; ensure sustainability for lifelong care; and make certain the Initiative is complementary with existing services. '3 by 5' will enshrine country ownership—the overriding feature of the 'Three Ones' approach initiated by UNAIDS (see 'National Responses' chapter). WHO's strategic framework contains 14 key elements which fall into five 'pillars': global leadership, strong partnership and advocacy; urgent, sustained country support; simplified, standard-

ized tools for delivering antiretroviral therapy; effective, reliable supply of medicines and diagnostics; and rapidly identifying and reapplying new knowledge and successes.

Global leadership, strong partnership and advocacy

The most vital work of '3 by 5' is happening in countries and communities. But global leadership and alliances among international participants help create the conditions for success. Partnership is essential to making the Initiative work. The target of '3 by 5' and the longer-term goal of universal access far outstretch the capacities of any single organization. Innovative collaborative mechanisms are now being built that link national governments, international organizations, the private sector, civil society groups and communities.

A fundamental principle of '3 by 5' is that people living with HIV need to play a central role in designing, implementing and monitoring antiretroviral treatment programmes. Involving infected people in treatment-related activities contributes to reducing stigma and to making programmes more effective (Farmer et al., 2001). But stigma continues to be an obstacle to recruiting people living with HIV to work in antiretroviral programmes. Therefore, massive and creative efforts to combat stigma are required to create the supportive environment necessary for people living with HIV to play their full role in treatment scale up.

At the global and multilateral level, key partners supporting action in countries include international associations of treatment activists and treatment providers; WHO and other UNAIDS Cosponsors including the World Bank's Multi-country AIDS Programme; and the Global Fund to Fight AIDS, Tuberculosis and Malaria. To scale up country antiretroviral

Lack of health workers: a key impediment to antiretroviral programme success

The number of health workers available, including health administrators and training staff, is critical to country capacity to deliver services. Often health personnel have received no in-service training or even basic information about HIV and AIDS. According to a recent report, China has fewer than 200 doctors with any specialist skills in diagnosing and treating AIDS opportunistic infections.

In countries hard-hit by AIDS, research suggests that lack of health-worker capacity is a serious problem for all programmes, but particularly for those that plan to distribute antiretrovirals widely. For example, in Tanzania, the size of the health workforce must triple in order to deliver priority interventions to most of the population by 2015. In Chad, it must quadruple. In Botswana, health officials say that achieving universal coverage of antiretroviral treatment alone would require doubling the current nurse workforce, tripling the number of physicians and quintupling the number of pharmacists.

Unfortunately, in countries most affected by AIDS, health staff vacancy rates are extremely high. In 1998, Ghana had a vacancy rate of 43% for physicians in public facilities; in Malawi it was 36%. In 1998, Lesotho reported its public sector nurse vacancy rate was 48%, Malawi's was 50% in 2001. Another problem is that health workers are not evenly distributed in a country. In Tanzania, the nurse-per-100 000 population ratio in urbanized Dar es Salaam is 160, but in the rest of Tanzania there are districts with a ratio of fewer than 6 nurses per 100 000. Of course, this problem is not confined to countries with high HIV prevalence. In Nicaragua, approximately 50% of the country's health workers are concentrated in the capital city, Managua, where only 20% of the population lives.

Migration is a key reason that health workforces are shrinking in low-income countries. Better wages and benefits, career opportunities and active recruitment attract health workers with internationally-accepted degrees to industrialized countries. In Zambia, more than 600 doctors have been trained since independence, but only 50 remain in the country. More than 50% of physicians trained in Ghana during the 1980s practise abroad. The UN has estimated that 56% of all migrating physicians flow from low- and middle-income to industrialized countries, while only 11% flow in the opposite direction. The imbalance is even greater for nurses. Finally, far greater efforts must be made to improve working conditions and incentives for health and social service workers in rural areas.

treatment access, these partners are linking with key bilateral initiatives, including the United States *President's Emergency Plan for AIDS Relief*, the European Union and the United Kingdom's Call to Action on AIDS led by its Department for International Development, as well as efforts by other donors and the private sector.

Strengthening country capacity

When countries align their national AIDS treatment goals to the '3 by 5' Initiative, many request collaboration with WHO and its partners. During early 2004, special WHO missions worked with countries, international partners,

health authorities and stakeholders to support national plan development and funding request preparation, and other activities to scale up anti-retroviral treatment implementation.

For example, in conjunction with '3 by 5', Zambia raised its 2005 treatment target from 10 000 to 100 000. Kenya announced a similar increase. But achieving these ambitious targets requires overcoming major implementation obstacles. The challenges are enormous: the health services of many countries have been badly undermined by inadequate investment over decades, and by the burden of AIDS itself (UNAIDS, 2003a). Virtually everywhere, the number of available health sector personnel

is too low to meet the needs (see 'National Responses' chapter).

If obstacles are not addressed systematically, expanding antiretroviral treatment on a massive scale will remain merely an aspiration; it could also drain staff away from elsewhere in the health-care system. On the other hand, '3 by 5' can play a catalytic role in drawing new personnel into health work. Key actions to increase staff include: intensified recruitment and training of new and existing staff; improving conditions of employment in the public sector; reassessing job specifications and tasks; and addressing 'brain drain' from poor countries, including providing incentives for attracting nationals home from abroad. Another possible solution is recruiting national and international volunteers to address urgent service delivery gaps.

One way to bridge the health staff gap is to actively train and involve community members. Successful pioneering antiretroviral programmes based in communities in Haiti, South Africa, Uganda and elsewhere have shown that community health workers can take on significant responsibilities in counselling, psychosocial support to patients and their families, adherence support, nutritional support, home care and palliative care and monitoring patients for drug toxicity and clinical failure. To be successful, community members require good training and ongoing support, as well as clear mechanisms for communicating and collaborating with other members of the health-care team.

Simplified, standardized tools

Reducing complexity is a major factor in accelerating the roll-out of treatment in areas with weak health-care systems and severe shortages of trained health professionals. The streamlined guidelines of '3 by 5' have cut the number of

recommended first-line treatment regimens from 35 to four. Regimens are simple and pills are fewer, and the four combinations cover a variety of circumstances including co-infection with tuberculosis, and pregnancy.

Twice-a-day regimens also help patients adhere to treatment, resulting in more people remaining healthier, regimens working longer, and opportunities for drug-resistant viruses to be reduced. Just as rapid HIV tests need to be a key feature of voluntary counselling and testing roll-out (see 'Prevention' chapter), so must laboratory testing and diagnostic tools to monitor the health of people on treatment be simplified and made more readily available to the poorest populations. In the interim, the fact that sophisticated monitoring tests such as viral load tests are not currently available in resource-poor settings is not cause to delay scaling up.

Effective, reliable supply of medicines and diagnostics

Maintaining a reliable, affordable supply of quality medicines and diagnostics is one of the greatest challenges countries face in scaling up. UNICEF, the Dutch NGO International Dispensary Association and others are already experienced in procuring antiretrovirals for low-income countries. To provide expanded country support, WHO is creating the AIDS Medicines and Diagnostics Service to be undertaken jointly with UNAIDS, UNICEF, the World Bank and other UN partners. It will serve as an information clearinghouse to help countries gain access to quality antiretroviral medicines and diagnostic tools at the best prices, including through providing information on forecasting need and demand, prices, sources, patents, customs and regulatory matters. The Service will also provide information on quality through its links with WHO's quality assessment programme—the

The commitment to equity must be more than window-dressing

How can we ensure that we make fair decisions about where to locate services and which patients to serve first? In the face of limited resources, ensuring that access to antiretroviral treatment is truly fair and equitable involves making the right choices: how and where to spend the money to set up services, and who gets priority for treatment among those within reach of facilities. There is no single formula for making such choices, but selecting people fairly requires an equitable deliberative process involving various levels of decision-making in society. The *process* of decision-making should be guided by the following key principles and be:

- *inclusive*—to involve a wide range of participants representing all interest groups;
- *impartial*—to avoid conflicts of interest;
- *transparent*—to ensure that the criteria set and rationales for treatment eligibility are open to scrutiny;
- *public*—to satisfy people's basic need to know the grounds for decisions that fundamentally affect their well-being;
- *relevant*—to ensure stakeholders can agree that priorities are based on appropriate and pertinent situational factors;
- *revisable*—to allow for changing decisions in light of new evidence; and
- *accountable*—to maximize fairness, appropriate individuals or institutions need to be responsible to communities for the principles and procedures they implement.

Prequalification Project—in collaboration with UNICEF, the UNAIDS Secretariat and with support from the World Bank.

Providing antiretrovirals in an equitable manner: who gets what and when

In many resource-limited settings, universal access to HIV-related disease treatment cannot be achieved immediately. Indeed, the interim target of expanding antiretroviral treatment access to 3 million people by 2005 is an admission that all people in need today will not be reached. Until resources and programmes are available for all people who need them, ensuring equity of access to services—fair distribution of treatment—will be a key challenge for governments and health-care providers.

Some governmental authorities and health services managers may be reluctant to make decisions about who should be served first and may not foresee the ethical implications of where

to site services. In the absence of an explicit structured approach to the ethical roll-out of HIV-related treatment, eligibility may be determined without reference to ethical standards and procedures. When not all people in need can be served, distributing HIV treatment services needs to be guided by principles of equity and human rights such as freedom from discrimination, as well as agreed-upon procedures.

Given the urgency of the situation, antiretroviral treatment will inevitably be delivered initially from those facilities that already have the basic requirements. To ensure this does not simply perpetuate and deepen existing inequalities in health-care delivery, substantial resources need to be directed simultaneously at building the infrastructure to serve people who are considered 'hard to reach' or whose needs have been neglected up to now, including women, young people and the poor.

In many countries, ensuring equitable access for women and girls will require changing

attitudes, removing structural impediments to treatment such as discriminatory laws and regulations and monitoring practices for accountability. The same holds true for people whose behaviour is widely stigmatized—injecting drug users, sex workers and men who have sex with men. Specific proactive measures are needed to ensure that gender inequities and barriers to care for vulnerable groups are addressed, and ultimately eliminated. Treating children with antiretrovirals also requires special planning (see box on page 117).

Antiretroviral treatment: part of a comprehensive package

The effect of antiretrovirals on individual lives is often near-miraculous. They are not a permanent cure, but by reducing viral load, they can extend the lives of people living with HIV by years, hopefully until a cure for AIDS is found. But antiretroviral therapy must be part of an integrated package of interventions that includes prevention, care and support activities, all of which complement and reinforce each other (see 'Prevention' chapter).

People on these drugs may still need treatment for opportunistic infections from time to time and treatment for pain that may be a side effect of the drugs they are taking. Some will need

substitution maintenance therapy for opiate dependency and many will continue to need psychosocial support in coping with an illness with serious implications for behaviour and lifestyle. They also need sexual and reproductive health services.

Antiretroviral prevention of mother-to-child transmission should avoid compromising future treatment options for women and use dual and triple combinations rather than single dose nevirapine wherever possible (WHO, 2004). Moreover, it must be remembered that even if '3 by 5' achieves all its targets, millions of HIV positive people with advanced immune deficiency will not have access to antiretrovirals for some time to come.

Services for people living with HIV-related disease need to be coordinated to create a 'continuum' of care—i.e. a system of care that meets the multiple and changing needs of infected individuals and their families, and that extends from the home and the community, to the clinic or hospital and back again. Services should be delivered at times and places that are convenient for HIV-positive people and their carers, and in a manner that is culturally sensitive. In addition, there should be efficient and effective referral mechanisms between the different services and levels of care.

Cuba: a comprehensive care success story

Cuba offers a rare example of comprehensive care across the continuum. In the early 1990s Cuba's HIV policies were the focus of controversy and criticism when HIV-positive people were quarantined. Now, people diagnosed with HIV are given a thorough clinical and psychological assessment and then offered the choice of outpatient care provided by a hospital and their family physician, or inpatient care at an AIDS sanatorium. They receive special high-calorie food rations and take part in an eight-week course on all aspects of living with HIV, including the progression of disease and safer sex. Their immune systems and general health are monitored regularly and entered on an electronic database, and health problems are treated promptly. Antiretrovirals are part of the package; about 1500 people currently have access to treatment (WHO, 2003e).

Public-private partnership with strong government leadership—the Botswana model

Botswana has one of the highest HIV prevalence rates in the world—nearly 40% of the adult population is living with HIV. It was the first country in Southern Africa to actively move towards scaling up antiretroviral treatment. President Festus Mogae's strong political leadership (he used the word 'extinction' to describe the threat of AIDS to the Tswana people) was instrumental in mobilizing domestic and international support for treatment programmes. Since 2000, the Botswana national treatment initiative—now called *Masa* (or 'new dawn')—has been supported by the African Comprehensive HIV/AIDS Partnership. This strong, unique public-private partnership involves the Government of Botswana, the Bill and Melinda Gates Foundation, and the Merck Company Foundation. The Botswana-Gates-Merck partnership supports the comprehensive national response and enhances local capacity through the strengthening of health-care infrastructure and the transfer of managerial and technical skills for sustainable health-service delivery.

By early 2004 *Masa* was the largest government HIV treatment programme in Africa, despite Botswana having a small population of 1.7 million and the fact that HIV stigma slowed initial uptake. As of April 2004, more than 24 000 people were enrolled in the programme, with more than 14 000 patients on antiretroviral therapy. However, inadequate capacity to rapidly increase people's awareness of their HIV status is considered the major barrier to expanding access. So Botswana is instituting a routine offer of HIV testing in clinical settings and engaging traditional healers as a potential source of referrals. In terms of equitable access for women and girls, so far more women are receiving treatment than men, by a 3 to 2 ratio.

Comprehensive care approaches are standard in Botswana (see box above), Brazil and other countries that have achieved universal access or are moving rapidly towards it. However, on the whole, comprehensive HIV care remains the exception.

In Africa, WHO estimates that less than 30% of HIV-infected people with tuberculosis—the most important opportunistic infection—are receiving anti-tuberculosis drugs (WHO, 2003c). In 2001, only about 1% of people in need in Zambia and Malawi, and 2% in Uganda, were receiving tuberculosis prophylaxis with isoniazid

(Garbus and Marseille, 2003; Garbus, 2003a; Garbus, 2003b; Garbus, 2003c).

Food—an essential part of the response to AIDS

One of the key elements of comprehensive care is having enough to eat. This is the single most pressing preoccupation for many people with AIDS. Disease quickly impoverishes families and leaves many struggling to feed themselves adequately (see 'Impact' chapter). Therefore, relieving hunger is a high priority to help people cope with illness. But good nutrition

Essential medicines are hard to find in many poor countries

The majority of HIV-positive people in low- and middle-income countries do not have access even to relatively simple medications. Furthermore, some countries with high burdens of AIDS have poor and unequal access to essential drugs for *any* condition (World Bank, 2003). For example, in Haiti, Kenya, Malawi and India, coverage of essential medicines ranges from 0–49% across their populations. WHO reports that although access to essential medicines has doubled in the past 20 years, over one-third of the world's population still lacks such access and pays a heavy price in terms of poor health and high death rates. In the poorest parts of Africa and Asia, over 50% of the population lacks access to even the most basic essential medicines.

also has an important role to play in helping people with HIV stay healthy, in counteracting physical wasting due to HIV infection and in boosting energy levels. Moreover, many medicines, including some anti-tuberculosis drugs and antiretrovirals, cannot be taken on an empty stomach. Therefore, food support needs to be part of the comprehensive care package. This is important for the well-being of carers too: many say that one of the most stressful aspects of their job is visiting homes where there is no food and having nothing to offer (UNAIDS, 2000).

To help with food and nutrition issues, the World Food Programme (UNAIDS' ninth Cosponsor) is expanding its food assistance programmes to include HIV-positive people on treatment, as well as hard-hit communities. It is doing this in the context of AIDS treatment and HIV prevention programmes and is working with UNAIDS and other Cosponsors. The Programme has also helped to call attention to the problem of AIDS and food security in the most-affected countries.

Tuberculosis and HIV

In many countries where AIDS has hit hardest, tuberculosis is the leading cause of death in people living with HIV. The greatest impact of HIV on tuberculosis has been in sub-Saharan Africa, where up to 70% of tuberculosis patients are also infected with HIV. The virus is already increasing the incidence of tuberculosis in much of South-East Asia, Eastern Europe and Central Asia, especially where sub-groups of often marginalized people are at high risk of both diseases.

About one-third of the world's population carries latent tuberculosis infection (where *Mycobacterium tuberculosis* bacteria lie dormant in the body without causing disease). But, in the

absence of HIV, only about 5% of them will *ever* progress to active disease. Infection with HIV dramatically increases the probability that someone already harbouring latent tuberculosis will develop the active disease to 5–10% *annually*.

It is not expensive to treat tuberculosis. If the medication is taken properly, most cases will be completely cured. In 1991, the World Health Assembly set targets to be reached by 2005 of 85% cure rates and 70% case detection among infectious cases. WHO's recommended DOTS (directly observed treatment, short course), is a highly cost-effective strategy to reach these targets. It has proven feasible for scale up both in a range of low- and middle-income countries and in a variety of formal, informal and private health provider settings (Raviglione, 2003). In 2001, the Stop TB Partnership was formed to expand, adapt and improve strategies to control and eliminate tuberculosis. It develops advocacy, coordinates resource mobilization and monitors progress towards the goals.

In sub-Saharan Africa, the advent of the HIV epidemic has severely compromised the promise of tuberculosis control, with tuberculosis notification rates increasing at 6% per year (De Cock and Chaisson, 1999). In countries of the former Soviet Union, a dramatic rise in tuberculosis has occurred since the mid 1990s. Tuberculosis now constitutes a serious danger for the growing numbers of HIV-positive people in the region.

Tuberculosis and HIV programmes complement each other

In 1998, WHO recognized the need for tuberculosis (TB) and HIV programmes to work together in sub-Saharan Africa. So it began ProTEST projects for joint tuberculosis and HIV programming in Malawi, Zambia and South Africa (WHO, 2004a). Similar joint

intervention initiatives that build on collaboration between STOP TB and ProTEST have also been carried out in other parts of Africa and elsewhere (Family Health International, 2001; Piyaworawong et al., 2003). They show there are important benefits in coordinating key activities in tuberculosis and HIV programmes. For instance, in Malawi over a period of four years, an estimated 14 000 cases of HIV infection were avoided through ProTEST pilot projects.

WHO and the Stop TB Partnership's Global TB/HIV Working Group have members from both the HIV and tuberculosis communities. The Group has formulated an interim policy based on field experiences that provides guidance on which joint activities should be implemented (WHO, 2004b). The principle behind this policy of 'two diseases, one patient' encourages delivery of joint services at every tuberculosis or HIV and AIDS service outlet. First, collaboration between national tuberculosis and AIDS programmes needs to be established. Then, among people found to be HIV-positive, tuberculosis treatment or prevention can be provided at a relatively low cost and with high probability of success.

People with latent tuberculosis infection can be provided with isoniazid preventive therapy to prevent active tuberculosis disease, while those with active tuberculosis can be treated with six months of anti-tuberculosis medicines. Additionally, cotrimoxazole helps prevent HIV-related opportunistic infections, reducing the risk of death in people with both tuberculosis and HIV. In addition, intensifying tuberculosis case finding in HIV testing and counselling centres and in other HIV service outlets is essential. Currently, this is a huge missed opportunity to provide adequate care.

Effective HIV and tuberculosis collaboration needed

Antiretroviral treatment improves quality of life and survival among tuberculosis patients in the same way it does for other people living with HIV. In sub-Saharan Africa, tuberculosis patients with HIV infection form a large proportion of those eligible for antiretroviral treatment. The targets laid out in the 2001 UN Declaration of Commitment on HIV/AIDS, the '3 by 5' Initiative and the Millennium Development Goals for tuberculosis and HIV will be impossible to meet without effective collaboration between tuberculosis and HIV programmes in settings with high levels of both infections. Close collaboration is required to ensure community-level delivery of a comprehensive prevention, treatment, care and support package.

Tuberculosis control programmes face several challenges to achieving case finding and treatment goals; challenges that AIDS programmes have worked to overcome using innovative strategies. These include how to: address stigma, conduct outreach, engage with communities, involve patients and families in programme design and management, and undertake initiatives to deal with structural barriers to the prevention of tuberculosis such as poverty and social marginalization. Many of these challenges can be most effectively addressed if HIV and tuberculosis programmes work together in synergy.

AIDS medicines and the rules of global trade

The global trade in medicines is regulated by both national laws and regulations and international rules such as those in the World Trade Organization's Agreement on Trade-Related Aspects of Intellectual Property Rights—or

The Doha Declaration—the primacy of public health in international trade

The Doha Declaration on the TRIPS Agreement and Public Health was issued by the ministerial conference of the World Trade Organization in November 2001. It made it clear that public health and access to medicines for all are primary concerns in applying international trade rules. The Doha Declaration reaffirmed the flexibility that the TRIPS Agreement provides to countries in authorizing use of patented products—often called ‘compulsory licensing’—in the interests of public health. The Declaration also extended the transition period to 2016 for least-developed countries to issue patents in the pharmaceutical sector.

The World Trade Organization Ministers at the Doha conference acknowledged (in paragraph 6 of the Declaration) that countries with insufficient pharmaceutical manufacturing capacities could face difficulties in effectively using compulsory licensing under the TRIPS Agreement because of the limitation on exports under compulsory licensing.

On the eve of its Ministerial meeting in Cancun in September 2003, the Organization agreed to a case-by-case system for waiving the export limitation in TRIPS so that countries without manufacturing capacity of their own could find sources of generic medicines. However, by mid-2004 the waiver system has not been used by any country. It is essential that governments, and partners in civil society and the private sector, actively evaluate the flexibility that the TRIPS Agreement affords to promote access to affordable HIV medicines in their countries. Countries may need to amend their patent legislation in order to take advantage of flexibilities such as the 2016 transition period, and the paragraph 6 waivers.

5 TRIPS. The Agreement protects intellectual property rights including patents, which provide important incentives for creating new and better HIV medicines and, hopefully one day, an HIV vaccine. At the same time, the exclusive control provided by patents can hinder access to affordable medicines, so the Agreement contains a number of ‘safeguards’ or flexibilities which national authorities can use to promote more affordable access. The World Trade Organization’s Doha Declaration offered additional flexibility, as described in the box above.

In addition to offering lower prices to certain low- and middle-income country markets, some research-based companies have announced that they will not enforce patent rights for HIV medicines in some low- and middle-income countries. For instance, Roche, a major pharmaceutical company, produces saquinavir and nelfinavir used in WHO-recommended, second-line regimens. It has a written policy that it will not file or enforce existing patents on

HIV-related medicines in sub-Saharan Africa or in any least-developed countries elsewhere. Bristol-Myers Squibb, which produces d4T used in WHO-recommended first-line regimens, had earlier announced a similar policy of not letting its patents prevent access to affordable HIV treatment in sub-Saharan Africa.

A few countries have begun to take measures to use the TRIPS Agreement more effectively. In May 2004, Canada reformed its patent legislation to allow Canadian generics producers to export to countries eligible under the WTO Doha paragraph 6 implementation arrangement. Meanwhile, Malaysia and Mozambique announced they were issuing compulsory licences for some HIV antiretrovirals. However, challenges continue as some regional and bilateral trade agreements—such as those between the United States and Colombia and the United States and Chile, as well as the Central American Free Trade Agreement—contain provisions that overly protect patent rights, which, in those countries, offsets much of the flexibil-

ity provided to governments under the TRIPS Agreement.

Developments in combination therapy: simplifying for better adherence

Triple combination antiretroviral therapy has long been the standard for treating HIV infection. The pharmaceutical industry is contributing to simplifying treatment regimens through developing and manufacturing fixed-dose combination formulations. Fixed-dose combinations permit all three individual molecules to be taken in one tablet, capsule or, in the future, a solution which is of special importance to children.

Three fixed-dose combinations, one each from Indian generics producers Cipla and Ranbaxy, and one from GlaxoSmithKline, have been approved by the WHO pre-qualification quality assessment programme. The generic fixed-dose combinations provide a WHO recommended, first-line regimen. Patents for individual components are often held by different originator companies, and the research-based industry is exploring multi-company arrangements to

allow their products under patent to be combined or packaged together in blister packs.

Fixed-dose combination antiretrovirals offer a number of possible advantages. They can:

- increase patient adherence to treatment;
- delay the development of resistance;
- lower the total cost, including production, storage, transport, dispensing and other health system costs;
- reduce the risk of medication errors by prescribers, dispensers and patients themselves;
- simplify supply-system functioning and increase security; and
- facilitate patient counselling and education, and reduce waiting time for patients.

Based on its experience delivering antiretroviral treatment, Médecins sans Frontières strongly advocates fixed-dose combinations. Patients taking the most widely prescribed fixed-dose combination [d4T/3TC/Nevirapine(NVP)] are able to take one pill twice a day, in contrast with six pills a day if taken separately. Fixed-dose combinations can also be far

Romania's children with HIV—from tragedy to hope

Romania has the largest number of children living with HIV in Europe—more than 7500. It is believed that transfusion of unscreened blood and repeated contaminated medical injections between 1987 and 1991 led to more than 10 000 new born and young children becoming HIV-infected. In rising to meet this challenge, Romania was one of the first countries in Central and Eastern Europe to introduce antiretroviral treatment. The Romanian Government's strong commitment to improving access has included passing a special 2002 law guaranteeing HIV prevention and care, including publicly funded free treatment and a dietary supplement for all people who need it. Since 2001, a strong UN-facilitated public-private partnership has led to significant price reductions by six pharmaceutical companies involved in the Accelerating Access Initiative. Today, all those determined to be 'in need' according to international guidelines have access to HIV treatment in Romania. This covers some 5700 patients, including 4350 children. Romania is a special case; one in which treatment access for children sparked a campaign that led to achieving universal access to HIV treatment.

more affordable than the same combination procured as separate elements. Médecins sans Frontières says it pays US\$ 270 per patient, per year for the d4T/3TC/NVP combination, compared with US\$ 562 for separate products from originator companies (Médecins sans Frontières, 2004).

Antiretroviral treatment for children: a special challenge

Antiretroviral treatment for children presents special challenges. Few HIV medicines are produced in paediatric formulations, and those available as syrups have limitations. They have a short shelf-life, children sometimes object to the taste, carers may have difficulty measuring out the correct doses and they remain very expensive.

The indications that a child might benefit from antiretroviral treatment are different from those in adults, so different criteria for eligibility need to be set. However, the biggest challenges in treating children are not technical, but social and financial. Children are totally dependent on adults to identify their treatment needs, to take them to a clinic, and thereafter, to supervise them when they take their medicines and ensure they adhere to their regimens.

Children's treatment may be a low priority in a family with several HIV-positive members. Furthermore, many infected children have lost their mothers to AIDS, and it is often difficult to find a relative or guardian who will consistently supervise a child's treatment. A characteristic example, is the guardian of a small orphaned boy in Botswana who was supervising his treatment very reliably. Then the guardian died, leaving the child with other relatives who knew nothing of his treatment plan, and did not understand its requirements. When the boy seemed to get better, his relatives did not

see the need to take him to the clinic, and he dropped out of treatment (UNAIDS, 2003).

A successful approach to counter this has been achieved at the Mildmay International Jajja's Home in Uganda. It is a small-scale pioneer in treating children with AIDS. Each of the 85 children in the project has a 'care plan' worked out with parents or guardians, and only those with a supportive home environment are offered antiretroviral treatment (UNAIDS, 2003).

Across the board, greater investment is required to address the special needs of children, including the technical challenges of developing fixed-dose combination antiretroviral formulations for them. National laws need to ensure that children have access to HIV treatment as a human right. National policy-makers and programme managers need to pay far more attention to the special requirements of children in designing and implementing treatment programmes. Knowing when to involve a child in his or her own treatment is another major challenge, since in most cases health workers have only their personal judgement to go on. Everywhere there is a pressing need for national health-care policies and guidelines on treating children with HIV.

Care in the community

Almost universally, relatives and friends provide up to 90% of care for people with AIDS within the home of the sick person. Many community-based programmes, often with few links to public health services, have sprung up around the world to support their efforts. In Uganda, The AIDS Service Organisation (TASO) is the biggest provider of treatment and care services, and offers an increasing number of its more than 60 000 members a full package of services from psychosocial support and counselling, to

Morphine—essential medicine for AIDS care

Unfortunately, initiatives to deliver palliative care cover only a minute proportion of people who require them. In addition, morphine is not yet widely provided in home-care kits. In many countries, a major stumbling block is that morphine and other strong painkillers are often forbidden by law. Yet morphine is recommended on the WHO Model List of Essential Medicines; WHO has produced guidelines indicating that opiates, including oral morphine, are necessary to relieve suffering.

Regulations stipulating that physicians alone can prescribe them need review so that opiates can be widely administered by nurses and others working at the community level. Uganda and Tanzania are the only African countries in which oral morphine is generally available, and only Uganda specifically provides for palliative care in its national health plan (Ramsay, 2003). A WHO joint project with African countries shows that strong partnerships are needed between regulating authorities and health workers to overcome this 'opiophobia' (WHO, 2002).

medication for opportunistic infections and palliative care.

The huge contribution of community-based initiatives is widely recognized: home-based care is a part of almost all countries' health plans. However, despite some notable examples of good practice, progress in drawing them into the wider public health system has been extremely limited.

As described above, the '3 by 5' Initiative recognizes community-based care as the building block of treatment programmes. Communities must play a key role in treatment advocacy, information and literacy, as well as in providing treatment, and monitoring and supporting patients on antiretrovirals (WHO, 2003d). However, most community-based programmes work in isolation with precarious funding. They require support to enable them to take on and maintain the extra burden of antiretroviral treatment over the long term.

Governments need to ensure that they provide a supportive environment for carers, which means reviewing and reforming existing laws, such as those relating to female property and inheritance rights, as well as other policies and

guidelines that regulate their lives. It also means working on structural issues such as providing clean water and sanitation, shelter, education for girls, employment, old age pensions and other social security nets.

At the same time, individual carers need support so they will not succumb to fatigue and despair. They need information and training on what to expect of AIDS, how to care for a patient and access food support, and where to receive counselling for their own emotional needs. These 'informal' carers are a vital link in the chain. If they fail to cope, the whole system of community care begins to unravel. Systematic research needs to shed light on exactly who they are, what they do, and how they fit into the framework of community-based care. This information is a basic requirement for addressing their needs, strengthening their capacity and integrating them into the formal health-care system (Ogden and Esim, 2003).

Palliative care

One of the most neglected aspects of HIV care is palliative care, which is treatment to relieve pain and other distressing symptoms in people

who are incurably and often terminally ill. It is estimated that at least half of all people with HIV will suffer from severe pain in the course of their disease (WHO, 2002). This is a source of intense distress to carers, relatives and friends who must stand by helplessly witnessing this suffering. It is vital that people who need palliative care receive it.

Pain relief is an essential part of this care, yet morphine (see box on page 119) and other effective pain medications often cannot be obtained. Even if a person is on antiretroviral treatment, palliative care is needed because HIV can still cause considerable illness and death. For instance, in the United States, around 14 000 people died of AIDS in 2003. Besides pain control, palliative care for people with AIDS encompasses:

- treating other symptoms such as diarrhoea, nausea and vomiting, coughing and shortness of breath, fatigue, fever, skin problems and mental impairment;
- psychosocial support, including relieving depression, anxiety and spiritual pain; and
- support for families and carers, including practical assistance with nursing, respite care and counselling to help them work through their emotions and grief.

In Zimbabwe and neighbouring countries, Island Hospice provides training in palliative care to communities and institutions. In Kenya, the Nairobi Hospice was founded in 1990 and offers a wide variety of training courses and practical experience in palliative care for health professionals, non-health professionals and volunteers.

In Botswana, a hospice at Bamalete Lutheran Hospital in Ramotswa village offers outpatient clinical services, as well as day care to terminally ill patients who are given transport to and from

their homes. The hospice's respite care began in 2002, and is one of its most valued services (UNAIDS, 2003a). In addition, the Princess Diana Palliative Care Initiative, set up in 2000, is currently working in seven African countries. In 2001, WHO began a five-year joint initiative to set up national palliative care services for people with AIDS and cancer. It works through its Regional Office for Africa, health ministries and key partners in five African countries—Botswana, Ethiopia, Tanzania, Uganda and Zimbabwe.


Challenges of the 'Next Agenda'

Governments, civil society and their partners in countries face enormous challenges in bridging the treatment gap: the gap between aspiration and reality in scaling up antiretroviral treatment and comprehensive HIV care. Many questions still need to be answered. For example, how will it be decided who gets treated first when antiretroviral coverage is still limited? How can services best be provided to children? And how do governments strike a proper balance in service delivery for AIDS and other pressing health problems?

Final answers to most of these questions will be found at the national level, in accordance with local priorities and circumstances. These questions are difficult, controversial and often painful to resolve. But they must not be allowed to deplete global political will to dramatically expand HIV treatment throughout low- and middle-income countries.

The conditions for dramatically boosting access to HIV treatment have never before been so promising. There have been clear advances in high-level political commitment, international donor financing and affordability of medicines and other HIV-related commodities, as well as important progress in the work of civil society

and the private sector in designing and implementing HIV treatment programmes in countries and communities. The '3 by 5' Initiative will succeed only if governments and partners in low- and middle-income countries lead the way. Future challenges include:

- Strengthening capacity in hard-hit countries facing the growing human resource crisis. Efforts need to quickly ensure that doctors, nurses and community health workers, along with others have access to HIV treatment. Public sector incentives and working conditions need to be improved, training and education programmes expanded and fast-tracked, and measures taken to allow strong reliance on nurses, paramedics and community workers in scaling up care.
- Ensuring widespread knowledge of HIV status, since it is the gateway to HIV treatment and prevention. Opportunities for voluntary testing and counselling need to be expanded, and a routine offer of HIV testing should be made to all patients with symptoms consistent with HIV-related disease and to those seen in sexually transmitted infection clinics, antenatal clinics and other sites (see 'Prevention' chapter).
- Rolling out antiretroviral treatment programmes in an integrated manner that strengthens, rather than depletes, the larger health system, and which is consistent with a country's overall development agenda.
- Providing greater support for technology transfer and exports—from countries with antiretroviral manufacturing capacity to countries without it. The tenfold increase in antiretroviral access currently being planned requires all partners within the pharmaceutical industry—originators and generic manufacturers—to be part of the AIDS response to ensure that sufficient quantities of HIV medicines, and the active ingredients for the finished formulations, are available.
- Ensuring countries can take advantage of their rights to use trade agreement provisions to widen access to HIV medicines and technologies. This also means resisting stricter-than-necessary patent provisions in regional trade agreements in order to avoid undermining much of the flexibility provided in global trade agreements and declarations for low- and middle-income countries.
- Reducing HIV-related stigma through action by social and community leaders, advocates, health-workers and the public at large so that treatment can reach people in need. International, regional and country-based treatment preparedness groups need sustained support to promote greater knowledge of and demand for HIV treatment.
- Placing equity at the forefront of policies and programmes to ensure fair access and open and transparent procedures within treatment services. Barriers to treatment access for women, children and other groups such as sex workers, injecting drug users and men who have sex with men, must be effectively addressed if '3 by 5', and ultimately universal HIV treatment access, are to become a reality. 



Focus

AIDS and human rights: the need for protection

Safeguarding human rights is an essential part of responding effectively to the AIDS epidemic at individual, national and global levels. HIV strikes hardest where human rights are least protected, particularly among people and communities on the margins of society, including sex workers, injecting drug users and men who have sex with men. Conversely, safeguarding people's fundamental rights improves their ability to protect themselves and others at risk of HIV infection, helps reduce their vulnerability to HIV, and assists them in dealing with the epidemic's impacts.

In recent times, some have argued that human rights-based approaches to HIV prevention in efforts to scale up the AIDS response might have reduced the role of public health, which offers a more applied practical framework. However, experience has clearly shown that it is self-defeating to place public health and human rights in opposition. Public health strategies and human rights protection are mutually reinforcing. Their integration achieves the greatest effect in reducing HIV transmission and improving the quality of life of people living with HIV.

Rights-based achievements

Rights-based approaches to the AIDS epidemic have yielded results by:

- **Enhancing public health outcomes:** Protecting a person's right—particularly a person living with HIV—to achieve the highest attainable standard of physical and mental health has brought about increased confidence in health systems. In turn, this has led more people to seek and receive relevant information on HIV prevention, counselling and care.
- **Ensuring a participatory process** linking patients and care providers, which has improved the relevance and acceptability of public health strategies.
- **Fostering non-discriminatory programmes** that include marginalized groups more vulnerable to HIV infection. For example, the Stopping HIV/AIDS through Knowledge and Training Initiatives project in Bangladesh, and the Sonagachi project in Kolkata, India, have integrated the rights of people in sex work by ensuring that sex workers are part of planning, implementing and assessing all relevant AIDS programmes.
- **Scaling up the AIDS response** through empowering people to claim their rights to gain access to HIV prevention and care services. Several countries in Latin American, including Brazil, Costa Rica, El Salvador, Mexico, and Panama have entrenched this by providing free access to treatment and other related health services for many people living with HIV.
- **Enhancing the accountability of States** through people seeking redress for the negative consequences of health policies. Legal action based on human rights has been a vehicle to enforce people's right to gain access to health care, including antiretroviral treatment. For example, in South Africa, the Treatment Action Campaign won a court ruling that required the Government to supply the antiretroviral drug nevirapine to HIV-positive pregnant women at public health facilities, within a phased roll-out of a comprehensive national programme to prevent mother-to-child HIV transmission.

Progress at the national level

Despite challenges, there have recently been positive developments in addressing human rights issues at the national level. Through participatory processes, HIV-related human rights, particularly the principle of non-discrimination, have been integrated into programme tools such as national AIDS policies, strategies and legislative frameworks. For example, Cambodia adopted a law on HIV/AIDS in January 2003; the Parliament of Malawi adopted a rights-based policy on HIV/AIDS in January 2004; and similar policy and legal reforms have been announced in Belarus, India, Lesotho, Liberia, and the Russian Federation.

Meanwhile, supported by a Small Grants Facility established by the United Nations Educational, Scientific and Cultural Organization (UNESCO) and UNAIDS, young people in Malawi, Sri Lanka, Mozambique, Zambia and Bangladesh have developed and implemented programmes to address stigma and discrimination.

Rights and access to AIDS information and prevention

The right to seek, receive and impart information is a fundamental human right and is a *sine qua non* condition for ensuring effective HIV prevention and AIDS care. People have a right to know how to protect themselves from being infected with HIV. They also have the right to know their HIV status, and if they are infected, they have the right to know how to obtain treatment, care and support.

Adequate information, counselling and testing should be accessible to all those in need through rights-based, ethical and practical models of delivery. Globally, rights-based examples under way include: awareness campaigns targeting specific groups such as men who have sex with men, injecting drug users, medical profes-

sionals and prison populations (Guinea, Italy, Kuwait, Portugal); incorporating AIDS-related programmes into school curricula (Argentina, Cuba, Czech Republic, Mauritius, Saint Vincent); community development of education and prevention programmes (Lebanon, Thailand); and developing culturally specific education and prevention programmes for indigenous people, refugees, asylum-seekers and migrants (Canada, the Netherlands, Norway).

In March 2004, the UN Theme Groups on HIV/AIDS in Cambodia, Fiji, Nepal, and Thailand led national AIDS and Human Rights consultations. Furthermore, a meeting was held on AIDS and Human Rights in the Asia-Pacific region, sponsored by UNAIDS, the Office of the High Commissioner for Human Rights (OHCHR), the United Nations Children's Fund (UNICEF), the International Labour Organization (ILO), the United Nations Development Programme (UNDP), the United Nations Office on Drugs and Crime (UNODC) and the Policy Project. It was attended by representatives from 20 countries in the region, including government officials, national AIDS councils, lawyers, doctors, people living with HIV, injecting drug users, male and female sex workers, men who have sex with men, young people, mobile populations and ethnic minorities.

Recommendations from these consultations are contributing to advocacy activities, including the Asia-Pacific Leadership Forum. They are helping to improve training and guidance to increase the understanding of AIDS-related human rights issues in the region, and are assisting in identifying best practices.

In other regions, UNESCO and UNAIDS have provided support for young people's training sessions on human rights and AIDS. Sessions have been held in the Middle East and North

Africa (Beirut, Lebanon); in Francophone Africa (Yaoundé, Cameroon); and in Eastern Europe (Croatia). The training covered the knowledge, skills and attitudes needed to foster positive behaviour change. It also focused on the role of media and communications in rights-based messages, including how to dispel myths and fears that often create and reinforce AIDS-related stigma and discrimination. By the end of 2003, young people from over 60 countries had been trained.

AIDS mainstreamed into international human rights mechanisms

Increasingly, the UN and other organizations have focused on the principle that all people have the right to the highest attainable standard of physical and mental health. This has reinforced HIV-related human rights. In September 2002, the United Nations Commission on Human Rights appointed a Special Rapporteur on the Right to Health, who has paid close attention to AIDS-related issues. In June 2003, UNAIDS and the Office of the High Commissioner for Human Rights convened a meeting for Special Procedures on HIV/AIDS and Human Rights in order to develop a strategic approach to integrating AIDS-related issues into their respective mandates, and in so doing to strengthen AIDS-related human rights work at the country level.

AIDS issues have also been integrated into the work of other Special Rapporteurs, Independent Experts and Special Representatives on the situation of human rights in Cambodia, Haiti, Liberia, Myanmar, Somalia, Uganda and Yemen. In addition, Thematic Rapporteurs are monitoring AIDS-related rights. These include the Special Rapporteurs on violence against women, on housing and on the human rights of migrants.

The Special Rapporteur on the Sale of Children, Child Prostitution and Child Pornography has addressed the links between sexual exploitation of children and AIDS, and has identified practical steps governments can take to improve protection of children's rights in this regard. The Special Rapporteur Against Torture and Cruel, Inhuman or Degrading Treatment or Punishment has particularly focused on prisoners.

Resolutions on AIDS passed by the UN Commission on Human Rights, including the resolution relating to access to AIDS treatment, have catalysed political engagement and served to monitor AIDS-related rights.

In January 2003, the General Comment on HIV/AIDS and the Rights of the Child was issued by the UN Committee on the Rights of the Child, and was the first General Comment on the AIDS epidemic to be issued by a treaty-monitoring mechanism. The General Comment identifies good practices and specifically prohibits discrimination against children on the basis of real or perceived HIV status. It calls for countries to report on measures they have implemented to protect children from HIV.

The enduring challenge

Despite these gains, in various parts of the world grave AIDS-related human rights violations continue to occur with depressing regularity. Furthermore, serious gaps prevail between the time that governments pass laws and policies and when they actually implement them. Relatively few countries are on track to meet their human rights commitments.

Stigma and discrimination

AIDS-related stigma remains one of the greatest obstacles to people living with HIV being able to fulfil their human rights. Stigma is also a

major barrier to creating and implementing HIV programming. Stigma is a multi-layered process of devaluation that tends to reinforce negative connotations by associating HIV and AIDS with already-marginalized groups. Stigma lies at the root of discriminatory actions that exclude people who need AIDS-related services.

Discrimination is an infringement of human rights that often leads to people being subjected to various forms of abuse. For instance, the Asia-Pacific Network of People Living with HIV/AIDS carried out research among HIV-positive people in India, Indonesia, the Philippines and Thailand. The research found a wide and persistent range of discrimination against people living with or perceived to be living with HIV. This included discrimination by friends and employees in workplace and health-care settings, as well as exclusion from social functions and being denied benefits, privileges or services.

Similar research in four Nigerian states found discriminatory and unethical AIDS-related behaviour among doctors, nurses and midwives. Abuses included denial of care, breaches of confidentiality, and HIV testing without consent. One in ten care providers reported refusing to care for HIV-positive patients, and 10% reported refusing them admission to a hospital. Furthermore, 65% reported seeing other health-care workers refusing to care for an HIV or AIDS patient. Some 20% felt that many people living with HIV had behaved immorally and deserved to be infected.

These studies confirm that creating and enforcing anti-discrimination policies and legislation are necessary. But they need to be accompanied by other measures such as

in-service training and providing adequate resources for the health sector.

Denial of women's property and inheritance rights

About half of all people living with HIV are women; they face a variety of human rights concerns in the context of the epidemic. Two issues that need urgent action by governments are property and inheritance rights. When a woman's husband or father dies, other relatives may seize all property and evict orphans and widows. Women in this situation are sometimes stripped of their possessions and forced to engage in sex work or transactional sex in exchange for survival items such as food, protection and cash.

This gender inequality puts women at a much higher risk of HIV infection than men. It continues despite the fact that States are bound by the principles of the UN Charter, the Universal Declaration of Human Rights, the Convention on the Elimination of All Forms of Discrimination against Women and the Convention on the Rights of the Child.

Sexual exploitation of children

Sexual exploitation of children is a persistent flagrant violation of human rights. In the AIDS era, young girls have proven to be especially vulnerable to violence, or to being trafficked or coerced into sex work, since their youth and perceived virginity are associated with freedom from disease. Rates of HIV infection among sexually exploited children are unknown. But in 1999, country research in Asia found that 69% of sexually exploited children in Bangladesh and 70% of those in Viet Nam were infected with a sexually transmitted infection.

Ensuring a rights-based approach

As AIDS responses are scaled up worldwide, they need to be grounded in sound public health practice and they also need to respect, protect and fulfil human rights norms and standards. This is particularly important when it comes to HIV testing as a prerequisite for expanded access to treatment (see 'Prevention' chapter).

The concept that HIV testing must remain voluntary is at the heart of all HIV policies and programmes. Voluntary testing complies with human rights principles and ensures sustained public health benefits. The following mutually reinforcing key factors need to be addressed simultaneously:

1. Ensuring an ethical process for conducting the testing: this includes defining the purpose of the test and benefits to the individuals being tested and assuring there are links between the site where the test is conducted and relevant treatment, care and other services. Furthermore, testing needs to take place in an environment that guarantees confidentiality of all medical information.
2. Addressing the implications of a positive test result: people who test HIV-positive should not face discrimination and should have access to sustainable treatment.
3. Reducing AIDS-related stigma and discrimination at all levels, notably within health-care settings.
4. Ensuring a supportive legal and policy framework for scaling up the response, including safeguarding the human rights of people seeking AIDS-related services.
5. Ensuring that health-care infrastructure is adequate to address the above issues and that there is enough trained staff to meet the increased demand for testing, treatment and related services.

Source: UNAIDS Global Reference Group on HIV/AIDS and Human Rights

Reappearance of restrictive policies and laws

In recent years, a number of policies and laws have emerged that restrict the human rights of people living with HIV or AIDS, or those assumed to be infected.

Experience has confirmed that protecting people's human rights decreases their vulnerability to HIV and reduces the negative impacts of HIV and AIDS. Much progress has been achieved, but the world now needs to be vigilant to prevent backsliding toward practices that are not rights-based. 