

## Summary and Recommendations



# A QUESTION OF LIFE OR DEATH

Photographs by Benjamin Lowy

The photographs of children orphaned by AIDS in Kenya were taken in an orphanage and a school. Orphaned children in Kenya often face barriers to HIV testing and treatment.







Nearly 90 percent of HIV-positive children worldwide and roughly two-thirds of all HIV-positive people live in sub-Saharan Africa. The vast majority of the massive efforts to roll out antiretroviral drugs has concentrated on adults, not children. Children in Africa continue to die of AIDS at high rates. If untreated, AIDS kills 50 percent of children born with HIV before their second birthday.

Eastern and Southern Africa have been particularly affected and have the highest number of child deaths due to HIV of any region in the world. An estimated 5.3 million adults and children there need antiretroviral therapy, more than half of the total number of people in need of treatment worldwide.

Kenya has a generalized HIV/AIDS epidemic and is representative of many of the challenges Eastern and Southern Africa face in fighting the epidemic. Some 150,000 children in Kenya are infected with HIV, and 60,000 of them urgently need antiretroviral treatment (ART). About one-third of them—20,000 children—are currently getting the treatment, while the other 40,000 are without access and will soon die if they do not get the drugs. At present, adults with HIV are about twice as likely to receive ART as children. This report looks at obstacles to HIV treatment for children in Kenya, many of which are also relevant to understanding treatment access barriers for children in other parts of Eastern and Southern Africa.

In the past, children's access to AIDS treatment in Africa was hindered by the sheer absence of antiretroviral drugs or their enormous cost. Today, this has changed in many African countries, including in Kenya, and ART is now available for free. Accessing these drugs is a question of life or death for children. Yet, too many children are still not accessing treatment, for several reasons.

Human rights abuses against HIV-positive children or their HIV-positive mothers constitute one of the major treatment access barriers. HIV-positive mothers are frequently victims of abuse, including stigmatization, violence, and property rights violations, and unable to care for their children. AIDS orphans are most often in the care of other relatives, but can suffer neglect and abuse on the part of their caregivers. Their foster parents may shun and exclude them, physically abuse them, or refuse them food or medical care, even when the child is visibly sick. Some relatives abdicate responsibility by sending sick children to other family members; sometimes these children end up with no real caregiver. Occasionally, children who experience abuse run away and become street children, which seriously reduces their chances of receiving HIV



treatment, or they are taken in by complete strangers. Any HIV-positive child needs a great deal of medical, emotional, and practical support from a parent or caregiver, but many do not get it. The Kenyan government has a child protection policy and staff to implement it, but it has failed to intervene and protect children in the vast majority of abuse cases, contrary to Kenya's obligations under both national and international law.

Lack of accurate information about medical care for children is a critical problem. Many people are still unaware that effective and affordable medicine is available for HIV-positive children, and some people turn to traditional healers. Some caregivers

mistakenly believe that a healthy-looking child cannot have HIV, or stop a child's treatment when side effects become severe and they lack information about how to address them.

The stigma and guilt associated with the disease also remain barriers to testing and treatment. Many children are not taken for testing because their caregivers worry the children will not keep the results secret, bringing stigma on the family or revealing the HIV-positive status of adult members of the household. Other children, and even adolescents, are tested but then not told by their parents that they are HIV-positive.

Access to health care for children is also hampered by transport costs and health-related costs. Antiretroviral drugs are free, but caregivers still have to find the money for transportation to medical facilities that provide ART, which are often far away. For children over the age of five, caregivers also often have to pay for a CD4 cell count, a test that assesses the child's immune function, as well as for other medical tests and treatment of opportunistic infections.

In the context of rising food prices and food shortages, especially in East Africa, caregivers are often reluctant to give their children a drug that leads to pain, vomiting, or other side effects when taken with no food, little food, or the wrong type of food.

Interruption of antiretroviral treatment was a particular problem during the post-election violence that shook the country in early 2008. Among the many internally displaced persons (IDPs), about 21,000 were living with HIV. The government and donors recognized this issue quickly and largely managed to get adults and children back on treatment within a few weeks, even though they had not prepared for such a scenario. However, some patients stopped treatment due to lack of food. Access to healthcare and HIV services has not been so forthcoming in many so-called transit camps, where about 100,000 displaced people moved following the government return program and closure of larger IDP camps.

The Kenyan government's HIV policy, supported by international donors, has prioritized adults over children in the provision of HIV treatment. Up to now, many HIV services remain inaccessible for children and are not geared toward the specific needs of children. ART for children is rarely available in local health facilities, even when adults can get it there. This requires caregivers and children to travel longer distances to pediatric treatment sites, often in district hospitals. Health workers often lack the training to treat children, and tend to refer them to higher-level health facilities. There also are not enough community health workers, social workers, and counselors who can play a crucial role in convincing caregivers to test children and in ensuring that children living with HIV are treated.





A Kenyan cemetery. Some 40,000 children in Kenya are likely to die if they do not receive antiretroviral treatment.







Another treatment obstacle is that children are not routinely offered HIV testing during visits to health facilities, but instead are usually only tested for HIV when they show AIDS-related symptoms—for some, too late to save their lives. To test a child, parents or guardians must agree and participate, but this does not always happen. A policy to routinely offer testing for infants has been recently put in place but still needs to be implemented.

It is indicative of the current lack of attention to pediatric HIV that the country's major HIV/AIDS survey, the Kenya AIDS Indicator Survey, published in July 2008, excludes data about children under age 15 entirely.

Meanwhile, there are new infections every day. While Kenya has made progress in expanding programs for the prevention of mother-to-child-transmission (PMTCT), about 40 percent of pregnant women still give birth without going through these programs, some of them to HIV-positive infants.

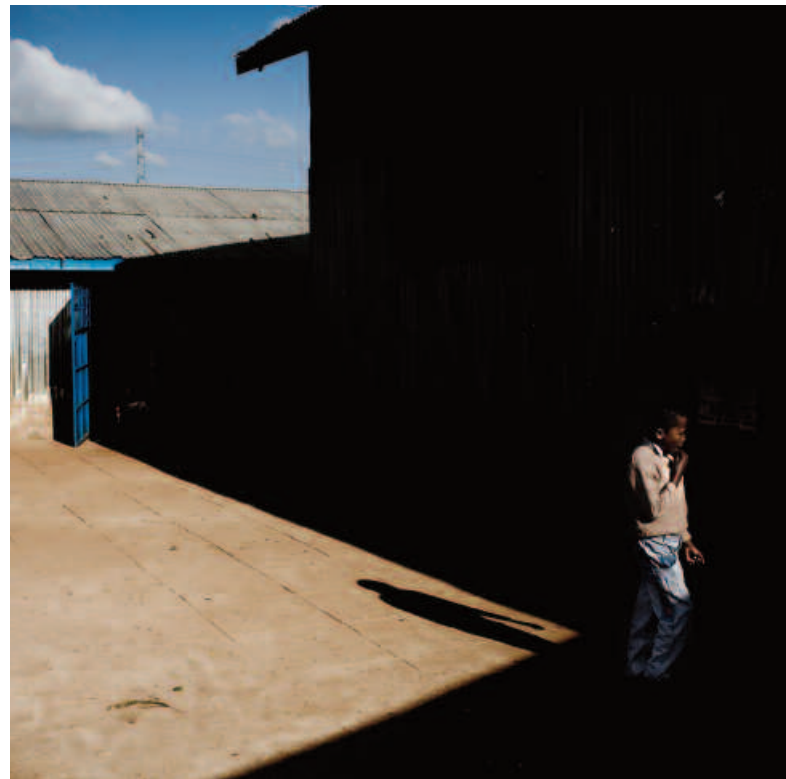
Under international law, the Kenyan government is obliged to progressively realize children's right to health. In particular, the government has to take measures to reduce child mortality. The government also has a duty to progressively realize the right to an adequate standard of living, including adequate food. Furthermore, it is obliged to protect children from all forms of violence, injury or abuse, neglect or negligent treatment. While the government has gone a long way toward realizing the right to health, it has failed to prioritize the dramatic problem of HIV-related child mortality, nor has it succeeded in protecting children against abuse, thus violating its obligations under international law.

The Kenyan government should, as a priority, initiate and implement policies that help HIV-positive children access treatment. Child-friendly health policies should include an information campaign about pediatric HIV; the integration of pediatric testing and treatment into regular child health care, including in lower-level health facilities; easing restrictions around parental consent for child testing; strengthening the role of community health workers, social workers and counselors; and increasing capacities in the areas of pediatric HIV and child psychology.

Stigma and abuse against HIV-positive children or their mothers should be addressed through awareness-raising campaigns, as well as through protection measures for women and children. In particular, the current child protection system needs to be strengthened, especially with respect to orphans; and access to justice for child victims needs to be improved.

There also needs to be a special effort to improve food security of people living with HIV, and their communities.

Kenya's fight against HIV is largely donor-funded: the United States alone contributed about US\$368 million in 2007, more than the government's own allocation of funds for HIV programs. Donors should support measures to increase treatment access for children in Kenya. When doing so, they should seek to strengthen the health system as a whole, in order to achieve lasting improvements.



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# KEY RECOMMENDATIONS

- **Develop child-focused health policies, in order to make child testing and treatment easily available at local-level health facilities, with staff trained in pediatric HIV and child psychology. Publicize information about available pediatric HIV services.**
- **Strengthen the role of community health workers, social workers, and counselors who often help children get tested and treated. Ease regulations requiring parental consent for tests. Develop a policy on disclosure of HIV-status to children.**
- **Take measures to improve food security in vulnerable communities, as lack of food constitutes a major treatment access barrier.**
- **Strengthen existing child protection mechanisms with a view to improving protection against abuse and neglect, in particular of orphans. Ensure that cases of disinheritance, child neglect, and abuse are investigated and prosecuted in accordance with international legal standards.**
- **Take measures to fight stigma and discrimination, for example through the creation of HIV support groups and through an awareness-raising campaign about the rights of people living with HIV.**

Detailed recommendations are given at the end of this report.