



A Question of Life or Death
Treatment Access for Children Living With HIV in Kenya

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Human Rights Watch
350 Fifth Avenue, 34th floor
New York, NY 10118-3299 USA
Tel: +1 212 290 4700, Fax: +1 212 736 1300
hrwnyc@hrw.org

Poststraße 4-5
10178 Berlin, Germany
Tel: +49 30 2593 06-10, Fax: +49 30 2593 0629
berlin@hrw.org

Avenue des Gaulois, 7
1040 Brussels, Belgium
Tel: + 32 (2) 732 2009, Fax: + 32 (2) 732 0471
hrwbe@hrw.org

64-66 Rue de Lausanne
1202 Geneva, Switzerland
Tel: +41 22 738 0481, Fax: +41 22 738 1791
hrwgva@hrw.org

2-12 Pentonville Road, 2nd Floor
London N1 9HF, UK
Tel: +44 20 7713 1995, Fax: +44 20 7713 1800
hrwuk@hrw.org

27 Rue de Lisbonne
75008 Paris, France
Tel: +33 (1)43 59 55 35, Fax: +33 (1) 43 59 55 22
paris@hrw.org

1630 Connecticut Avenue, N.W., Suite 500
Washington, DC 20009 USA
Tel: +1 202 612 4321, Fax: +1 202 612 4333
hrwdc@hrw.org

Web Site Address: <http://www.hrw.org>



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Map of Kenya



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I. Summary

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.

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.

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.

II. Methodology

Field research for this report was carried out in July and August 2007 and August 2008 in Western province (Kakamega district), Nyanza province (Siaya and Bondo districts and Kisumu), Rift Valley province (Uasin Gishu district and Eldoret), Coast province (Mombasa), and Nairobi, including Kibera and Mathare slums.

We conducted 68 interviews with children, parents, and guardians. Twenty-five interviews were with children, of whom 18 were confirmed to be HIV-positive; 6 others were orphans whose status was not known, and 1 was an orphan who had tested HIV-negative. Of the children interviewed, 16 were girls and 9 were boys. Our interviews also included conversations with 29 HIV-positive mothers, 2 HIV-positive fathers, and 12 guardians of children living with HIV. Adults were in a better position to explain to us the obstacles to testing and treatment both for very small children and in some cases (for the reasons described below), for older children. In situations where children were too ill to be interviewed, we refrained from the interview. For those children who were not aware that they are HIV-positive, we limited our questions to issues that did not touch on the child's HIV status.

In addition, we carried out over 80 interviews with social workers, community health workers, counselors, nurses, clinical officers, doctors, administrative medical staff, and nongovernmental organizations (NGOs) working on health or child rights.¹ In the Kenyan government, we interviewed representatives of the Ministry of Health, the Ministry for Gender and Children Affairs, and the Ministry of State for Special Programs. We also interviewed academic experts and staff of international donors, UNICEF, and humanitarian agencies.

¹ We use the term community health worker broadly to mean all persons working in the community, with or without payment, as part of health facilities, agencies, or NGOs with health programs. This includes social workers, outreach workers, counselors, adherence counselors, and others whose main role is to provide information about health issues and accompany patients in the process of seeking health care.

Carrying out interviews on a sensitive issue such as HIV poses a number of methodological and ethical challenges, particularly with children.² Children who have experienced a parent's suffering and death may be particularly susceptible to re-traumatization and heightened stress when questioned by an unknown person.³ For each child interviewed, we explained our work in age-appropriate terms and sought their consent. We took great care to interview adults and children in a friendly and sensitive manner, and ensured that the interview took place in a private setting. Information about the HIV status of the adults and children interviewed was kept strictly confidential. In order to protect the identities of the children interviewed, we have replaced all their names in this report with pseudonyms. The names of the community health workers whom we interviewed have generally been withheld in the report.

In order to avoid false expectations of support or financial assistance,⁴ we made clear at the start of each interview that we were not able to provide direct individual support to those who spoke with us. Instead, when we encountered situations where people were in acute need of medical treatment or food, we tried to refer them to local NGOs or other actors who could assist them.

Interviews were carried out in English, Swahili, Kikuyu, and Dholuo. Where interpreting was necessary, it was usually provided by a person well known to the interviewee, such as a community health worker or social worker.

In this report, "child" refers to anyone under the age of 18, in accordance with the Convention on the Rights of the Child.⁵ However, when referring to HIV/AIDS statistics, we usually refer to children up to age fifteen, as all authoritative HIV/AIDS

² National Children's Bureau (London), "Guidelines For Research," April 2003, http://www.ncb.org.uk/dotpdf/open%20access%20-%20phase%201%20only/research_guidelines_200604.pdf (accessed September 24, 2008).

³ The National Child Traumatic Stress Network (Los Angeles, CA and Durham, NC), "Understanding Child Traumatic Stress," 2005, http://www.nctsn.org/nctsn_assets/pdfs/edu_materials/understanding_child_traumatic_stress_brochure_9-29-05.pdf (accessed September 24, 2008).

⁴ Erick O. Nyambetha, "Ethical dilemmas of social science research on AIDS and orphanhood in Western Kenya," *Social Science & Medicine*, vol. 10, 2008, pp. 1-9.

⁵ Convention on the Rights of the Child (CRC), adopted November 20, 1989, G.A. Res. 44/25, annex, 44 U.N. GAOR Supp. (No 49) at 167, U.N. Doc. A/44/49 (1989), entered into force September 2, 1990, art. 1.

statistics by the UN classify children over the age of fifteen as adults. This makes it more difficult to get complete data on children up to age eighteen, and is also problematic in that it might lead policymakers to treat adolescents between the ages of fifteen and eighteen as adults when designing policies.

III. Background

HIV/AIDS Treatment for Children

Mother-to-child transmission is the main cause of HIV infections in children. Infection can take place during pregnancy, labor, and delivery, and in 20 to 40 percent of infection cases through breastfeeding.⁶ Programs for the prevention of mother-to-child-transmission (PMTCT) greatly reduce infection among newborns: One dose of Nevirapine is given to the woman during labor, and one dose is given to the baby within 72 hours of birth.⁷

If untreated, one in two children born with HIV will die before their second birthday as their bodies succumb to opportunistic infections such as pneumonia, tuberculosis (TB), or diarrhea.⁸ In particular, a certain type of pneumonia has been identified as the leading cause of death in infants with HIV.⁹

Antibody tests, which are used to diagnose HIV in adults, are ineffective in children below the age of 18 months because children can carry their mother's antibodies until this time. Polymerase chain reaction (PCR) testing allows for testing of children under 18 months but requires expensive laboratory equipment and specially trained staff. PCR testing is not widely available in Kenya, although dry blood spot testing has been introduced in the past two years (see Chapter VI, below).¹⁰

⁶ The German HIV Peer Review Group, "Prevention of Mother-to-Child-Transmission of HIV in Kenya, Tanzania and Uganda," November 2007, http://www.charite.de/tropenmedizin/docs/PMTCT_long.pdf (accessed September 16, 2008).

⁷ PMTCT services also consist of HIV counseling and testing, obstetric practices to avoid transmission during delivery (if the mother gives birth in a health facility), and advice in feeding practices and family planning. Ministry of Health, "Interventions to prevent mother-to-child transmission," website of the ministry at <http://www.health.go.ke/>, under Health Programmes, page on HIV/AIDS in Kenya, subheading "Interventions for preventing the spread of HIV," (accessed August 22, 2008); USAID/Horizons, "Strengthening PMTCT Programs. Studies explore strategies to promote adherence and follow-up care," June 2007, <http://www.popcouncil.org/pdfs/horizons/hrptjuno7.pdf> (accessed September 16, 2008), p. 6.

⁸ Marie-Louise Newell et al., "Mortality of infected and uninfected infants born to HIV-infected mothers in Africa: A pooled analysis," *Lancet*, vol. 364, October 2004, pp. 1236–1243.

⁹ This type of pneumonia is called PCP, or *Pneumocystis jiroveci* pneumonia. World Health Organization, "New WHO Guidelines on Co-Trimoxazole Prophylaxis for HIV-related Infections among Children, Adolescents and Adults," http://www.who.int/hiv/toronto2006/FS_Cotrimoxazoleprophylaxis081006.pdf (accessed October 13, 2008).

¹⁰ Avert, "Children, HIV and AIDS," September 5, 2008, <http://www.avert.org/children.htm> (accessed October 6, 2008), section "Children infected with HIV."

Treatment of HIV and of opportunistic diseases—infections that the immune system is unable to prevent due to HIV—in children is also somewhat different from adults. Antiretroviral treatment should be given to all HIV-positive infants, and as needed to other children based on a CD4 cell count and a clinical assessment.¹¹ A number of different combinations can work effectively in children. A common combination in Kenya is Lamivudine (3TC), Nevirapine, and Stavudine (d4T).¹² Treating HIV in children is more complex than treating HIV in adults. For example, the dosage has to be calculated based on the child's weight or body surface area, and changed frequently as the child grows. Side effects can also be different than in adults.¹³

Many children who test HIV-positive must be given the antibiotic cotrimoxazole to prevent opportunistic infections and hence early death. Cotrimoxazole is inexpensive and reduces mortality of small children by about 43 percent.¹⁴

Until recently, the absence of pediatric formulations of drugs has been an obstacle in the treatment of children. Pharmaceutical companies have placed little interest into researching drugs that would primarily be consumed by children in developing countries. Those that were developed were late in coming and were much more expensive than adult antiretroviral drugs. Pediatric antiretroviral formulations have become more widely available in Kenya since late 2006, when the Clinton Foundation negotiated price reductions in pediatric drug formulations made by two Indian pharmaceutical companies.¹⁵ For small children who cannot easily swallow pills, liquid formulations (syrups) have been developed. For older children, there are single pills with a lower dosage than the adult formulation. Most recently, a fixed

¹¹ WHO, *Antiretroviral Therapy for HIV Infection in Infants and Children: Towards Universal Access. Recommendations for a public health approach* (Geneva: WHO, 2006), <http://www.who.int/hiv/pub/guidelines/pediatrico20907.pdf> (accessed October 6, 2008); Avert, "HIV treatment in children," <http://www.avert.org/hiv-children.htm> (accessed October 13, 2008).

¹² Clinton Foundation dosing wheel, provided by the Clinton Foundation to Human Rights Watch in August 2008; Human Rights Watch telephone interview with James Kamau, Kenya Treatment Access Movement (KETAM), October 13, 2008.

¹³ American Academy of Pediatrics, "Increasing Antiretroviral Drug Access for Children With HIV Infection," 2007, <http://aappolicy.aappublications.org/cgi/reprint/pediatrics;119/4/838.pdf> (accessed October 13, 2008).

¹⁴ Newell et al., "Mortality of infected and uninfected infants." Cotrimoxazole costs about US\$0.04 per pediatric tablet, and a child needs a maximum of two per day, according to the Ministry of Health. See "Summary Report October 2007," *MMePA (Monitoring Medicine Prices and Availability) Quarterly*, p. 2. This regular publication is produced by the Ministry of Health in conjunction with international NGOs and agencies, including Health Action International (HAI).

¹⁵ Avert, "HIV Treatment and Children: The Problems," <http://www.avert.org/children-hiv.htm> (accessed October 19, 2008).

dose combination pill has been developed for children, six years later than the one for adults.¹⁶

In high-income countries, HIV is very rare in children, partly due to the success of PMTCT programs. For those children who have contracted the virus, ART has turned HIV into a manageable chronic disease with significant numbers of children in good health who go on to live with the infection into adulthood. However, in Africa, HIV still kills children at alarming rates.

The Epidemic in Eastern and Southern Africa

HIV/AIDS is a crisis of unprecedented magnitude across Africa. An estimated 22.5 million people in Sub-Saharan Africa are living with HIV¹⁷—roughly two-thirds of the world's HIV-positive people. Around 1.8 million children in Sub-Saharan Africa are HIV-positive, nearly 90 percent of the children living with HIV worldwide.¹⁸ More than 12 million children have been orphaned by AIDS in Africa.¹⁹

Eastern and Southern Africa have been particularly affected by HIV. An estimated 5.3 million people are in need of antiretroviral therapy there, more than half of the total number of people in need of treatment worldwide.²⁰ In Eastern and Southern Africa, HIV is also the leading cause of death in children under the age of five: The top 10 countries with the highest number of child deaths due to HIV are all in Eastern and Southern Africa.²¹

¹⁶ Human Rights Watch interview with Prof. Olago, head of the National AIDS Council (NACC), Nairobi, August 10, 2008; Medecins Sans Frontieres (MSF), "Affordability, Availability and Adaptability of AIDS Drugs in Developing Countries: An Ongoing Challenge," August 1, 2008, <http://www.doctorswithoutborders.org/events/symposiums/2008/aids/news/?id=2877> (accessed October 13, 2008).

¹⁷ UNAIDS/WHO, "AIDS epidemic update 2007," December 2007, http://data.unaids.org/pub/EPISlides/2007/2007_epiupdate_en.pdf (accessed October 6, 2008), p.4.

¹⁸ UNAIDS, *2008 Report on the Global HIV Epidemic* (Geneva: UNAIDS, 2008), http://data.unaids.org/pub/GlobalReport/2008/jc1510_2008_global_report_pp29_62_en.pdf (accessed October 6, 2008), p. 33.

¹⁹ Avert, "Sub Saharan Africa HIV & AIDS Statistics," September 29, 2008, <http://www.avert.org/subaadults.htm> (accessed October 6, 2008).

²⁰ WHO, UNAIDS, UNICEF, *Towards Universal Access: Scaling up priority HIV/AIDS interventions in the health sector - Progress Report 2008*, http://www.who.int/hiv/pub/towards_universal_access_report_2008.pdf (accessed October 6, 2008), p. 16.

²¹ UNICEF, "HIV attributable deaths in children aged under 5 in ESAR," August 2008, unpublished statistics, on file with Human Rights Watch.

The case of Kenya

Kenya has a generalized HIV epidemic—that is, an epidemic that affects all segments of society. The country faces many of the same challenges in fighting HIV as other countries in the region. Over 1.5 million people have died of AIDS in Kenya.²² In 2008 there were an estimated 1.6 to 1.9 million people living with HIV in the country, about 7.4 percent of the adult population.²³ This is a significant increase from the prevalence of about 5 percent in 2006.²⁴ The impact of HIV on the country has been disastrous. HIV/AIDS has contributed to a downturn in the economy and increased poverty, and has led to the breakdown of community and family structures.²⁵

The situation regarding children is also indicative of the challenges in the sub-region. HIV is a leading cause of death in children in Kenya: according to UNICEF, 15 percent of all child deaths are attributable to HIV.²⁶ Around 20,000 infants were infected through their mothers in 2006.²⁷ While this was the most common mode of transmission, children have also become infected through sex,²⁸ and more rarely

²² WHO, “Kenya: Summary country profile for HIV/AIDS scale-up,” December 2005, http://www.who.int/hiv/HIVCP_KEN.pdf (accessed October 6, 2008), p. 1. On the spread of AIDS in Kenya, see John Iliffe, *The African AIDS Epidemic. A History* (Oxford: James Currey, 2006), pp. 27-29.

²³ Ministry of Health, “Kenya AIDS Indicator Survey, preliminary report,” July 2007, http://www.aidskenya.org/public_site/webroot/cache/article/file/KAIS__Preliminary_Report.pdf (accessed October 6, 2008). This prevalence rate is for ages 15-49. According to UNAIDS the prevalence is between 7.1 and 8.3 percent. UNAIDS/WHO, “Epidemiological Fact Sheet on HIV and AIDS, Kenya,” July 2008, http://www.who.int/globalatlas/predefinedReports/EFS2008/full/EFS2008_KE.pdf (accessed October 6, 2008).

²⁴ UNAIDS/WHO, “AIDS epidemic update 2007,” pp. 11-14, 18. The Kenya AIDS Indicator Survey is the first population-based survey of the HIV epidemic in Kenya since the 2003 Kenya Demographic and Health Survey. It is possible that earlier surveys were inaccurate. “Kenya: Shocking Rise in HIV Prevalence,” *allafrica.com*, July 29, 2008, <http://allafrica.com/stories/200807290187.html> (accessed October 27, 2008).

²⁵ Human Rights Watch, *In the Shadow of Death: HIV/AIDS and Children’s Rights in Kenya*, vol. 13, no.5(A), June 2001, <http://www.hrw.org/reports/2001/kenya/>.

²⁶ UNICEF, “HIV attributable deaths in children aged under 5 in ESAR,” August 2008.

²⁷ National AIDS Control Council, *UNGASS 2008: United Nations General Assembly Special Session on HIV and AIDS, Country Report - Kenya*, 2008, http://data.unaids.org/pub/Report/2008/kenya_2008_country_progress_report_en.pdf (accessed October 6, 2008), p. 12.

²⁸ According to the 2006 UNGASS report, 14 percent of women and 29 percent of men had sex before the age of 15. National AIDS Control, *UNGASS 2006: United Nations General Assembly Special Session on HIV and AIDS, Country Report - Kenya*, 2006, http://data.unaids.org/pub/Report/2006/2006_country_progress_report_kenya_en.pdf (accessed October 15, 2008), p. 25. According to a study in Nyanza province, the average age at first sex is 12 among boys and 13 among girls. Population Council/Constella Futures, “Situation Analysis of the Sexual and Reproductive Health and HIV Risks and Prevention Needs of Older Orphaned and Vulnerable Children in Nyanza Province, Kenya,” March 2007, http://www.popcouncil.org/pdfs/Kenya_OVC_report.pdf (accessed November 10, 2008).

through drug use²⁹ and unsafe circumcision.³⁰ Treatment coverage of adults is almost double that of children: according to government figures, about 54 percent of adults (177,000 persons) who need treatment receive it,³¹ compared with only 27 to 30 percent of children (20,000).³²

Despite this, and the recent increase in HIV prevalence, Kenya is seen as a relative success and a leader of strong HIV policies within the region. The country has been hailed for reducing the prevalence of HIV due to changes in sexual behavior among young people. In its recent HIV/AIDS “Epidemic Update,” UNAIDS named Kenya as one of the countries in which “prevention efforts are having an impact.”³³

The Global Fight against HIV/AIDS

In the past decade, the international community has made concerted efforts to stem the HIV epidemic. In 2001, UN member states adopted the Millennium Development Goals (MDGs), which set ambitious targets in the area of health. Goal 4 aims to reduce the under-five child mortality rate by two-thirds between 1990 and 2015. Goal 6 aims to halt and begin to reverse the spread of HIV by 2015, and to achieve, by 2010, universal access to treatment for HIV/AIDS for all those who need it.³⁴ In 2003 the World Health Organization (WHO) initiated a program to get three million people in developing countries on ART by the end of 2005.³⁵ The Global Fund to Fight

²⁹ “Deadly Cocktail: HIV and Drug Use,” *PlusNews*, November 2007, <http://www.plusnews.org/InDepthMain.aspx?ReportId=75625&InDepthId=67> (accessed October 15, 2008).

³⁰ D. Brewer, “Male and Female Circumcision Associated with Prevalent HIV Infection in Virgins and Adolescents in Kenya, Lesotho and Tanzania,” *AEP*, vol.17, no.3, March 2007, pp. 217-226. More recently it has been recognized that medically performed male circumcision reduces the risk of HIV transmission.

³¹ Dr. I. Mohamed, head of National AIDS and STD Control Programme (NAS COP), “2007 Kenya AIDS Indicator Survey Preliminary Results,” July 29, 2008, http://www.aidskenya.org/public_site/webroot/cache/article/file/Final_KAIS_Release_Presentation.pdf (accessed September 25, 2008).

³² Human Rights Watch interviews with Dr. Lyndon Marani, ART program manager, NAS COP, Ministry of Health, Nairobi, August 13, 2008; and Gerald Macharia, country director of the Clinton Foundation, Nairobi, August 20, 2008.

³³ UNAIDS/WHO, “AIDS epidemic update 2007,” pp. 11-14, 18.

³⁴ United Nations, “End Poverty. Millennium Development Goals 2015,” <http://www.un.org/millenniumgoals/> (accessed October 13, 2008). In the 2001 UNGASS Declaration of Commitment on HIV/AIDS, world leaders further spelt out their commitments to fighting HIV. United Nations General Assembly Special Session on HIV/AIDS, “Declaration of Commitment on HIV/AIDS,” June 25-27, 2001, http://data.unaids.org/publications/irc-pubo3/aidsdeclaration_en.pdf (accessed October 13, 2008).

³⁵ This report uses the term antiretroviral treatment (ART). In Kenya, many refer to ARV or ARVs meaning the drugs and the treatment. In quoting from interviews we have left this term as it was used by the interviewees.

AIDS, Tuberculosis and Malaria prioritized treatment access in Africa and started concerted efforts to place the drugs within reach of the ordinary population. This was partly due to pressure from activists and people living with HIV, who demanded access to the drugs in poor countries, and who helped change international rules to allow distribution of generic drugs in those countries.³⁶ While this has been an enormous step forward, many medicines, in particular those that are still relatively new, are still too expensive for use in poor countries. Patent protection has increased in developing countries, and this pushes prices up.³⁷

On the regional level, the African Union (AU) has committed itself to fighting HIV/AIDS on the continent. In particular, the May 2006 Abuja Call for Accelerated Action Towards Universal Access to HIV and AIDS, Tuberculosis and Malaria Services in Africa reiterates the importance of access to treatment.³⁸

However, the global roll-out of antiretroviral drugs has largely focused on adults. It was only in 2005 that a coalition of international actors came together to call for increased attention to treatment of children. Under the leadership of UNICEF, the “Unite for Children Unite Against AIDS” initiative was launched. The campaign aims to provide either antiretroviral treatment or cotrimoxazole (an antibiotic), or both, to 80 percent of children in need by 2010.³⁹

Fighting HIV/AIDS in Kenya

In 1999 the Kenyan government declared HIV/AIDS a national disaster and a public health emergency. At that point, the national prevalence rate was about 14 percent among adults; Nyanza province in western Kenya had a prevalence rate of about 29 percent.⁴⁰ Shortly after, the National Aids Control Council (NACC) was established as

³⁶ Avert, “Providing drug treatment for millions,” <http://www.avert.org/drugtreatment.htm> (accessed September 26, 2007).

³⁷ Avert, “AIDS, drug prices and generic drugs,” <http://www.avert.org/generic.htm> (accessed October 19, 2008); MSF, “Campaign for Access to Essential Medicines,” <http://www.accessmed-msf.org/about-us/> (accessed October 19, 2008).

³⁸ African Union, “Abuja Call for Accelerated Action Towards Universal Access to HIV and AIDS, Tuberculosis and Malaria Services in Africa,” Special Summit of the African Union on HIV and AIDS, Tuberculosis and Malaria, Abuja, Nigeria, May 2-4, 2006, http://www.africa-union.org/root/au/conferences/past/2006/may/summit/doc/en/ABUJA_CALL.pdf (accessed October 13, 2008).

³⁹ UNICEF/UNAIDS, *Children: The Missing Face of AIDS. A Call For Action* (New York: UNICEF, 2005), http://www.uniteforchildren.org/knowmore/files/U77HIV_letter.pdf (accessed October 13, 2008).

⁴⁰ Human Rights Watch, *In the Shadow of Death*, pp. 10-13.

part of the Office of the President to provide a stronger response to HIV/AIDS.⁴¹ In May 2003 the government of President Mwai Kibaki proclaimed a “total war on AIDS,” and the following year started providing antiretroviral drugs in public hospitals, but to a limited number of patients.⁴² Generic drugs were initially imported from Brazil and are now coming mostly from India.⁴³

Current HIV/AIDS policies are defined in the Kenya National HIV/AIDS Strategic Plan 2005-2010 by the NACC. The Plan emphasizes the need to target vulnerable groups, including orphans and vulnerable children, and to focus on women and youth. The Strategic Plan refers directly to the MDGs and defines specific targets for 2010 such as: lowering the prevalence rate to 5.5 percent; reaching at least 50 percent of infected pregnant women with PMTCT treatment; reaching at least 75 percent of patients in need of ART; reaching all patients with affordable opportunistic infection drugs; and informing 75 percent of people living with HIV about their treatment and their rights.⁴⁴

In order to implement policies and provide guidance to health workers and others involved in HIV/AIDS-related work, the government has also developed guidelines on a variety of issues, including testing,⁴⁵ antiretroviral drug therapy,⁴⁶ nutrition and HIV/AIDS,⁴⁷ and many other topics.

⁴¹ NACC, “About Us,” http://www.nacc.or.ke/2007/default2.php?active_page_id=117 (accessed September 9, 2008). NACC is the government’s coordinating body on HIV/AIDS policies; it is now part of the Ministry of State for Special Programs. The National AIDS and STD Control Programme (NASCO) in the Ministry of Health is the key actor implementing governmental HIV/AIDS policies.

⁴² “Kenya: Feature – Help for HIV/AIDS patients,” *IRINnews*, <http://www.irinnews.org/report.aspx?reportid=43263> (accessed October 13, 2008); “New Kenyan President Declares ‘Total War On AIDS,’ Urges Religious Leaders To Support ‘ABC’ Prevention Model,” *Kaiser Daily HIV/AIDS Report*, May 21, 2003, http://www.kaisernetwork.org/daily_reports/rep_index.cfm?hint=1&DR_ID=17834 (accessed September 9, 2008).

⁴³ Human Rights Watch interviews with Protus Lumiti, manager, Nyumbani orphanage, Nairobi, August 7, 2007; and James Kamau, KETAM, October 13, 2008. See also the website of Ranbaxy, a manufacturer of generic drugs in India: <http://www.ranbaxy.com/socialresponsibility/AntiHIV.aspx> (accessed October 15, 2008).

⁴⁴ National AIDS Control Council, “Kenya National HIV/AIDS Strategic Plan 2005/6 – 2009/10. A Call to Action,” June 2005, www.nacc.or.ke/downloads/KNASP_2005-2010_Final_Report.doc (accessed November 11, 2008).

⁴⁵ NASCO, Ministry of Health, “National Guidelines for Voluntary Counseling and Testing,” 2001; NASCO, *Guidelines for HIV Testing in Clinical Settings* (Nairobi: Ministry of Health, 2004).

⁴⁶ NASCO, Ministry of Health, “Guidelines for antiretroviral drug therapy in Kenya,” third edition, 2005.

⁴⁷ NASCO, Ministry of Health, “Kenyan National Guidelines on Nutrition and HIV/AIDS,” 2006.

Following political conflict and post-election violence in late 2007 and early 2008, a new government was formed in April 2008 under President Kibaki and Prime Minister Raila Odinga. While the new government has not made any major changes to HIV/AIDS policies, its reorganization of ministries has created some confusion. The former Ministry of Health is now called Ministry of Public Health and Sanitation, and headed by Minister Beth Mugo. In addition, a new Ministry for Medical Services has been created, under Minister Peter Anyang' Nyong'o.⁴⁸ The division of labor between these two has remained unclear to observers.⁴⁹

Funding for health and HIV/AIDS

The overall health budget for the years 2007-2008 is 34 billion Kenyan shillings (KSh) (about US\$442 million).⁵⁰ This represents about 7 percent of total government expenditure,⁵¹ far below the government's commitment to allocate 15 percent of the government's budget to the health sector, in accordance with the Abuja Declaration of African governments.⁵²

Within health funding, a considerable amount of money goes to HIV/AIDS programs. At present, about KSh20 billion (approximately US\$260 million)—over 50 percent of Kenya's health budget—goes toward HIV/AIDS treatment and care.⁵³ HIV/AIDS services have often been funded through vertical programs that circumvent the

⁴⁸ "Speech by His Excellency Hon. Mwai Kibaki, C.G.H., M.P., President and Commander-In-Chief of the Armed Forces of the Republic of Kenya during the announcement of the Grand Coalition Government at State House, Nairobi," April 13, 2008, <http://www.statehousekenya.go.ke/speeches/kibaki/aprilo8/2008130401.htm> (accessed September 10, 2008).

⁴⁹ Human Rights Watch interview with representatives of Health Rights Advocacy Forum (HERAF), Nairobi, August 12, 2008.

⁵⁰ Hon. Amos Kimunya, E.G.H., M.P., Minister for Finance, "Budget Speech for the Fiscal Year 2007/2008," June 14, 2007, http://www.treasury.go.ke/downloads/budget_speech_2007.pdf (accessed November 11, 2008). Among those, about 20 billion KSh are budgeted for HIV/AIDS treatment and care. Human Rights Watch interview with Dr. Lyndon Marani, ART program manager, NASCOP, Ministry of Health, Nairobi, August 13, 2008.

⁵¹ Ministry of Health, "Public Expenditure Review," 2007, and "Allocation Projections," 2008. This is a rise from 2006, when the government allocated 5.1 percent to health. Veloshnee Govender, Di McIntyre, and Rene Loewenson, "Progress towards the Abuja target for government spending on health care in East and Southern Africa," EQUINET Discussion Paper 60, April 2008, <http://www.tarsc.org/publications/documents/DIS60ofinABUJA.pdf> (accessed November 11, 2008), p. 13.

⁵² Organization of African Unity (OAU), "Abuja Declaration on HIV/AIDS, Tuberculosis and Other Related Infectious Diseases," African Summit on HIV/AIDS, Tuberculosis and Other related Infectious Diseases, Abuja, April 24-27, 2001, http://www.un.org/ga/aids/pdf/abuja_declaration.pdf (accessed October 19, 2008).

⁵³ Human Rights Watch interview with Dr. Lyndon Marani, ART program manager, NASCOP, Ministry of Health, Nairobi, August 13, 2008.

regular health system and create separate, HIV-specific structures. But for HIV goals to be met, broader health systems must also be strengthened.⁵⁴

Donors have funded much of Kenya's fight against HIV. In 2006, based on conservative estimates, about 34 percent of Kenya's HIV/AIDS-related funding came from external sources⁵⁵ (several analysts estimate the percentage of donor funding in HIV services to be significantly higher⁵⁶). The most important donor in Kenya for health is the United States, through the President's Emergency Plan for AIDS Relief (PEPFAR). During 2007 PEPFAR funding was over US\$368 million,⁵⁷ exceeding the government's own contributions toward HIV/AIDS of about US\$282 million in 2007.

Another important donor is the Global Fund to Fight AIDS, Tuberculosis and Malaria. It has approved HIV grants totaling nearly US\$130 million⁵⁸ and in November 2007 disbursed US\$70 million to Kenya. Before that, Kenya had failed to obtain approved Global Fund aid because of delays and mismanagement.⁵⁹ Corruption has also been a major problem within the NACC, whose first director had to step down as a result.⁶⁰

Other important donors include the United Kingdom, Japan, Germany, and several multilateral agencies, such as UNICEF, the World Bank, and the European Union

⁵⁴ Gorik Ooms et al., "The 'diagonal' approach to Global Fund financing: a cure for the broader malaise of health systems?" *Globalization and Health*, 2008, vol 4:6, <http://www.globalizationandhealth.com/content/4/1/6> (accessed November 11, 2008); Dongbao Yu et al., "Investment in HIV/AIDS programs: Does it help strengthen health systems in developing countries?" *Globalization and Health*, 2008, vol 4:8, <http://www.globalizationandhealth.com/content/4/1/8> (accessed November 11, 2008).

⁵⁵ Govender, McIntyre, and Loewenson, "Progress towards the Abuja target for government spending on health care in East and Southern Africa," p. 15.

⁵⁶ Human Rights Watch interview with James Kamau, KETAM, August 6, 2007; "Kenya's Dependency on Donor Funding Affecting Fight Against HIV/AIDS, NGO Consortium Head Says," *The Body: The Complete HIV/AIDS Resource*, <http://www.thebody.com/content/news/art44371.html> (accessed November 11, 2008); John Kamigwi et al., "Scaling Up the Response to HIV and AIDS in Kenya: Mainstreaming through the Government Budget Process," Constella Futures, March 2006, http://www.constellagroup.com/international-development/resources/cf_mtef.pdf (accessed October 15, 2008).

⁵⁷ United States President's Emergency Fund for AIDS Relief (PEPFAR), "Kenya FY 2007 Country Operational Plan (COP)," <http://www.pepfar.gov/about/82449.htm> (accessed September 15, 2008).

⁵⁸ Ibid.

⁵⁹ Kenya had failed to submit audited accounts for past grants or delayed grant reports. See Wairagala Wakabi, "Kenya's mixed HIV/AIDS response," *The Lancet*, vol. 369, issue 9555, January 6, 2007, pp. 17-18.

⁶⁰ Transparency International, *Global Corruption report 2006. Corruption and Health* (London/Ann Arbor: Pluto Press, 2006), pp. 112-115.

(EU).⁶¹ There are also two important private US donors, the Clinton Foundation—which almost exclusively funds pediatric HIV interventions—and the Bill and Melinda Gates Foundation.

⁶¹ USAID, “Kenya,” <http://www.usaid.gov/pubs/cbj2003/afr/ke/> (accessed September 15, 2008); Embassy of Japan in Kenya, “Japan’s ODA to Kenya,” <http://www.ke.emb-japan.go.jp/oda.htm> (accessed September 15, 2008).

IV. Barriers to Treatment for Children Living with HIV

Children living with HIV can face a range of treatment access barriers. HIV-positive mothers are victims of violence and property rights abuses, and unable to care for their children. Children, in particular orphans, are neglected and abused by their caregivers who prevent them from being tested or following treatment. Parents or caregivers lack accurate information about medical care for children, or avoid testing and treatment because of stigma and discrimination. Many families cannot afford transport to reach health centers, or enough food to avoid serious side effects from the drugs.

Perceptions about HIV and Lack of Accurate Medical Information

Perceptions about HIV/AIDS and modern medicine

Perceptions of HIV/AIDS are closely tied to perceptions of body, health, sex, and sexual relations. As different ethnic groups in Kenya have different traditions, these perceptions are not uniform. In general, HIV is perceived not only as a disease, but also as an attack on traditions and morality. It is often seen as being associated with a wider process of societal decline.⁶² For example, among the Luo in western Kenya—the third largest ethnic group in Kenya, with about 3 million people—AIDS is often associated with “chira.” Chira is a physical condition that leads to symptoms similar to full-blown AIDS. It is considered the result of disordered social relations, and believed to befall people who have gone against the customs and traditions of the society.⁶³

Kenyan churches’ response to HIV/AIDS has added a religious dimension to the fear associated with the disease and sometimes deterred people from seeking medical treatment. Many churches have explained AIDS as a curse from God that is meant for sinners; people with AIDS were at first blamed for their illness and severely

⁶² Iliffe, *The African AIDS Epidemic*, p. 29.

⁶³ Ruth J. Prince and Paul Wenzel Geissler, *“The Land is Dying”: Contingency, Creativity and Conflict in Western Kenya*, (Oxford/New York: Berghahn, 2009) (forthcoming), pp. 263-307, 334-336.

stigmatized. Such beliefs are still very strong,⁶⁴ although the Anglican church has apologized for its stigmatization of people living with HIV, has become more constructively engaged in the care of people living with HIV over the years, and has made efforts to overcome this prejudicial attitude⁶⁵ (for more on stigma as an enduring barrier to HIV testing and treatment, see below). Some Christian movements believe in the power of prayer to heal, and sometimes instruct their followers not to seek medical treatment. For example, churches such as Legio Maria in western Kenya instruct members to reject modern medicine and to pray together for God to heal the person.⁶⁶ Other sects and churches do the same.⁶⁷

Many people living with HIV seek the help of traditional healers. Herbalists treat symptoms of opportunistic infections, in particular pain and body rashes, with herbs and potions.⁶⁸ Other traditional healers pray for healing or perform ceremonies to exorcize bad spirits. Traditional healers can play an important role in treating opportunistic diseases and educating people about HIV/AIDS prevention if they convey accurate information, but they have no treatment against AIDS itself, contrary to what many patients hope and some healers claim.⁶⁹

Lack of accurate medical information

The lack of accurate information on HIV/AIDS can contribute to discrimination against those living with HIV. For example, many people still believe the disease can be spread by sharing the same dishes or even by living near a person with HIV;

⁶⁴ "Catholic church says 'it's not right' to use condoms to fight AIDS," *Press Esc*, July 1, 2007, http://pressesc.com/01183307636_catholic_church (accessed September 1, 2008).

⁶⁵ Prince and Geissler, *"The Land is Dying,"* pp. 336-339; "Kenya church makes AIDS apology," *BBC News Online*, March 16, 2006, <http://news.bbc.co.uk/1/hi/world/africa/4814022.stm> (accessed September 20, 2007).

⁶⁶ Ruth J. Prince, "The Legio Maria Church in Western Kenya: Healing with the Holy Spirit and the Rejection of Medicines," dissertation, Department of Anthropology, University College London, 1999 (unpublished).

⁶⁷ Human Rights Watch interview with two community health workers, GROOTS Mothers Development Center, Mathare slum, Nairobi, August 7, 2007; Human Rights Watch interview with CHAK representative, Nairobi, August 20, 2008.

⁶⁸ J. Kusimba et al., "Traditional healers and the management of sexually transmitted diseases in Nairobi, Kenya," *International Journal of STD&AIDS*, vol. 14, 2003, pp. 197-201. On the role of herbal medicines and "chira" in Luo society, see Prince and Geissler, *"The Land is Dying,"* pp. 237-244.

⁶⁹ Joseph Amon, "Dangerous Medicines: Unproven AIDS cures and counterfeit antiretroviral drugs," *Globalization and Health*, vol. 4, <http://www.globalizationandhealth.com/content/4/1/5> (accessed October 6, 2008); "Kenya: The lure of dodgy herbal 'cures' for HIV," *PlusNews*, August 21, 2008, <http://www.plusnews.org/Report.aspx?ReportId=79915> (accessed October 27, 2008).

sometimes people are reluctant to take in AIDS orphans because of this.⁷⁰ The manager of Nyumbani orphanage for HIV-positive children explained,

Often, when other family members take in AIDS orphans, they really do not want to associate with that child. They are worried that they and their children could get infected.⁷¹

It is also not widely known that the virus might be present in a healthy-looking person. As a result, parents often fail to have their children tested soon enough, waiting until they show signs of a serious illness although even an apparently healthy child can be HIV-positive and need treatment.⁷² One HIV-positive widow said about her daughter, “I haven’t tested her now because I don’t believe she is sick—she looks and acts healthy.”⁷³ Older children in particular are usually only taken for medical care when they are visibly ill—their mothers tend to consider them healthy otherwise. A nurse commented,

Older children are usually brought in by parents or guardians to be tested because they are sickly. But if the child is not sick-looking, they don’t want them to be tested. I get the sense that there are many children in this country who are [HIV]-positive but not getting tested, they are falling through the cracks.⁷⁴

Parents might also avoid getting a child tested because otherwise they will have to explain to the child what is happening.

⁷⁰ M. Hamra, “The relationship between expressed HIV/AIDS-related stigma and beliefs and knowledge about care and support of people living with AIDS in families caring for HIV-infected children in Kenya,” *AIDS Care*, vol. 17, no. 7, 2005, pp. 911-922; Human Rights Watch interview with paralegal, Shibuye Community Health Workers, Kakamega district, Western province, August 2, 2007.

⁷¹ Human Rights Watch interview with Protus Lumiti, manager, Nyumbani orphanage, Nairobi, August 7, 2007.

⁷² Human Rights Watch interview with counselor at the Siaya Peasant Community Outreach Project (SPECOOP) VCT, Unguja, Siaya district, August 3, 2007.

⁷³ Human Rights Watch interview with HIV-positive widow, Kanyumba, Siaya district, Nyanza province, August 4, 2007.

⁷⁴ Human Rights Watch interview with nurse, Ambira sub-district hospital, Siaya district, Nyanza province, August 3, 2007.

Many patients distrust antiretroviral drugs or lack information about them. We interviewed the guardian of 10-year-old Sarah in Mathare slum, Nairobi, who told us that she had taken the girl off antiretroviral therapy after four days, as the drugs made her weak.⁷⁵ During the interview, Sarah was leaning on her aunt's shoulder, visibly sick.

A community health worker in a rural area of Nyanza province told us about a similar case that led to a girl's death:

I took this young girl to be tested... But the problem is, I couldn't now monitor this girl and make sure she was adhering to the treatment—she lived too far away for me to go all the time. There is this myth in the community that if you take the ARV you become very weak. So as the child was showing some side effects, the grandmother stopped giving her the medication, and the girl died. She was around six or seven years old.⁷⁶

In another case, parents took a baby co-infected with HIV and tuberculosis off antiretroviral drugs after she showed side effects: she did not eat well and her eyes turned yellow. After the baby got worse, they started her on tuberculosis medicine a second time.⁷⁷ But when patients stop and start ART, there is an increased risk that they will become resistant to the medicine.

Stigma, Fear, and Silence as Barriers to HIV Testing and Treatment

The stigma of AIDS

HIV/AIDS is not only a public health crisis but also a social crisis. Many people avoid speaking about AIDS and avoid testing. If they do get tested and treated, they go to great efforts to keep this confidential. This situation particularly affects children who are dependent on their parents or guardians' care. Some progress has been made in

⁷⁵ Human Rights Watch interview with guardian of Sarah, age 10, Mathare slum, Nairobi, August 14, 2008.

⁷⁶ Human Rights Watch interview with community health worker, Shibuye Community Health Workers, Shinyalu division, Kakamega district, Western province, August 2, 2007. It is also sometimes believed that ART makes the skin look like plastic. Human Rights Watch interview with counselor at Tuungane Youth Center, Kisumu, August 1, 2007.

⁷⁷ Human Rights Watch interview with the baby's mother, Kisumu, August 15, 2008.

addressing stigma and discrimination against people living with HIV in the workplace, schools, and health facilities, particularly in urban areas.⁷⁸ For example, there are now people speaking openly about their HIV-positive status; HIV support groups have been set up where those living with HIV share experiences. The success of treatment for people who seemed close to death and have recovered may have contributed to this change.

Many people, however, continue to live in fear and face stigma and discrimination. Such persons may avoid going to nearby health facilities known to provide HIV-related services because they do not want to be seen by neighbors or other members of the community. Many go to health facilities that are further away despite the increased cost of transport, or they do not go for medical help at all.⁷⁹ Certain health centers that are known solely as places for HIV services may also be avoided.⁸⁰ A counselor in a voluntary counseling and testing (VCT) center in Siaya district, Nyanza province, told us,

[N]ow that ARVs are available at the government hospital in Lower Ambira, you still have many people accessing the drugs at Siaya District Hospital because they don't want to be seen there at Lower Ambira. So we give people several places they can go and get the drugs, and let people make their own decisions based on where they are most comfortable.... For example, I have seen men and women who live in Nairobi now, that come back to Siaya hospital to get their drugs so they are not seen. And even one person I know in Lower Ambira goes to Kisumu to get his drugs so that he is not known around here as being HIV-positive.⁸¹

⁷⁸ Stigmatization is a process related to the perception that there has been a violation of a set of shared attitudes, beliefs or values. One can distinguish between felt stigma, which refers to fears of discrimination, and enacted stigma, that refers to a real experience of discrimination. Lisanne Brown, Kate Macintyre, and Lea Trujillo, "Interventions to reduce HIV/AIDS Stigma: What have we learned?" *AIDS Education and Prevention*, vol. 15, no. 1, 2003, pp. 49-69. A somewhat similar definition is provided in Kenya AIDS NGOs Consortium, "Training Guide on Stigma and Discrimination in Relation to HIV&AIDS," 2007, pp. 7-8.

⁷⁹ See chapter IV, section "Economic Barriers to Testing and Treatment," on transport as an economic barrier.

⁸⁰ Human Rights Watch interview with counselor at Tuungane Youth Center, Kisumu, August 1, 2007.

⁸¹ Human Rights Watch interview with counselor at the Siaya Peasant Community Outreach Project (SPECOOP) VCT, Unguja, Siaya district, Nyanza province, August 3, 2007.

A community health worker in Mathare slum, Nairobi, told us how some Kenyans suspect children of being bewitched when they have HIV or when their parents have died of AIDS.⁸²

Secrecy in the home: Women's vulnerability to pressure and abuse by husbands

The silence and stigma that surround HIV reach right into the family. Many women are afraid to tell their husbands about their status for fear of abuse or abandonment, and as a result find it difficult to take their children for testing and treatment. Some women suffer stigmatization, violent assault, and separation when their husbands find out about their status; some are thrown out of the house, often with the children.⁸³ A social worker in the Rift Valley commented that there are “sadly... too many cases where the husband leaves her when he finds out she is positive.”⁸⁴ Women in polygamous marriages worry “that the husband will ignore them and go with the other wife,” according to a counselor we spoke with.⁸⁵ Some women test for HIV secretly and then hide their drugs or keep them with neighbors.⁸⁶

Men are generally less closely in contact with the health system and often refuse to get tested. With regard to medical care for children, it is usually the mother's role to take a child to a health center. One activist stated, “Ninety percent of women shoulder the responsibility of taking children to health facilities.”⁸⁷ Some women's groups have started programs to encourage men to support their wives and children in seeking health care.⁸⁸ A leader of an HIV support group in a Nairobi slum told us,

⁸² Human Rights Watch interview with community health worker, GROOTS Mothers Development Center, Mathare slum, Nairobi, August 7, 2007.

⁸³ Human Rights Watch interviews with HIV-positive, divorced women, Mathare slum, Nairobi, August 7, 2007, and August 14, 2008; Human Rights Watch interview with social worker, AMPATH, Burnt Forest, Uasin Gishu district, August 21, 2008.

⁸⁴ Human Rights Watch interview with social worker, AMPATH, Burnt Forest, Uasin Gishu district, August 21, 2008.

⁸⁵ Human Rights Watch interview with counselor, Woman Fighting AIDS in Kenya (WOFAK), Mombasa, August 15, 2007.

⁸⁶ Human Rights Watch interviews with representative of Woman Fighting AIDS in Kenya (WOFAK), Mombasa, August 14, 2007; social worker, Kibera slum, Nairobi, August 10, 2007; and social worker, Mathare slum, Nairobi, August 14, 2008. For discussion of a similar situation in Zambia see Human Rights Watch, *Hidden in the Mealie Meal: Gender-Based Abuses and Women's HIV Treatment in Zambia*, vol. 19, no. 18(A), December 2007, <http://hrw.org/reports/2007/zambia1207/>.

⁸⁷ Human Rights Watch interview with representative of Woman Fighting AIDS in Kenya (WOFAK), Mombasa, August 15, 2007.

⁸⁸ *Ibid.*

At first we had only women. Then last year, we had 10 men in a support group. So now we have some mixed groups—men, women, children. Men are sometimes opposed to testing.... Many men also don't tell their wives if they have done the test.... Some couples are both on ARV but do not tell each other. Some people divorce because of the test. We have some women in our support group who have not told their husband about their status.⁸⁹

The secrecy in the home can become an obstacle for child health care. This starts right after birth: women raise suspicions when they do not breastfeed their baby, as it is now known that breastfeeding can lead to HIV infection. Due to intense pressure, many HIV-positive women breastfeed or feed babies a mix of formula and breast milk; both approaches increase the risk of HIV transmission.⁹⁰

We interviewed a community health worker in Nyangoma village, Nyanza district, who is looking after Prisca, age four. Prisca is HIV-positive and on cotrimoxazole, and her mother is taking antiretroviral drugs. Prisca is the child of her mother's second marriage; her mother remarried after her first husband died, likely of AIDS. The mother has not told her new husband about her HIV status, and has also not told him about Prisca having HIV, as this would reveal her status as well. She has managed so far to treat her child secretly, but as Prisca is developing side effects and further health complications, this is proving increasingly difficult.⁹¹

Stigma and discrimination in health facilities

A few years ago, stigma and discrimination against AIDS patients were rampant in health facilities. This situation has improved, according to many counselors and health professionals. Most people interviewed during this research did not have any

⁸⁹ Human Rights Watch interview with caregiver, GROOTS Mothers Development Center, Mathare slum, Nairobi, August 10, 2007.

⁹⁰ According to the WHO, breastfeeding by an infected mother increases the risk of transmission by 5–20 percent to a total of 20–45 percent. WHO, *Antiretroviral Drugs for Treating Pregnant Women And Preventing HIV Infection In Infants: Towards Universal Access: Recommendations for a public health approach* (Geneva: WHO, 2006), www.who.int/hiv/pub/guidelines/pmtctguidelines3.pdf (accessed April 10, 2008), p. 5.

⁹¹ Human Rights Watch interview with community health worker, Nyangoma, Bondo district, Nyanza province, August 18, 2008. We learned of similar cases in Mathare. Human Rights Watch interview with social worker, Mathare slum, Nairobi, August 14, 2008.

discriminatory experiences to relate; some lauded the care that health personnel of HIV clinics provided. However, more subtle forms of discrimination in the health sector continue.

A recent study measured stigma and discrimination in a sample of Kenyan health facilities.⁹² On the positive side, 99 percent of all healthcare providers interviewed said that patients with HIV should not be isolated. Over 90 percent also disagreed with statements that describe HIV as a punishment from God and blame people with HIV for bad behavior.⁹³ On the other hand, the study also found that although most facilities analyzed knew about HIV protection policies (75 percent) only 27 percent reported implementing such policies, and that a significant percentage of healthcare providers had fears about providing care to HIV-positive patients.⁹⁴ Experts on pediatric HIV confirmed to Human Rights Watch that some health workers fear treating children, partly due to general fears surrounding HIV and partly due to a lack of training and information about pediatric HIV.⁹⁵

Some patients interviewed by Human Rights Watch spoke about experiences of discrimination by health personnel. A 27-year old woman with HIV told us how she was treated at Provincial Coast General Hospital in Mombasa: “At the hospital, some of the nurses say, ‘You people with HIV, you are disturbing us.’ Things like that. So where should we go?”⁹⁶

An HIV-positive man told us how his doctor “didn’t want to go near me, he kept his distance.”⁹⁷ Several women complained about stigmatizing behavior at Pumwani maternity hospital. They said that HIV test results were sometimes announced in front of other waiting patients, breaching basic confidentiality rules. They also

⁹² J. Kamau, P. Odundo, and J. Korir, “Measuring the degree of S&D in Kenya: An Index for HIV/AIDS facilities and providers,” USAID, July 2007, <http://www.kit.nl/smartsite.shtml?ch=fab&id=24144> (accessed October 15, 2007).

⁹³ *Ibid.*, pp. 10, 30.

⁹⁴ *Ibid.*, pp.7-10, 45-53.

⁹⁵ Human Rights Watch interviews with Prof. Dorothy Ngacha, Kenyatta National Hospital. Department of Pediatrics, and Gerald Macharia, Country Director of the Clinton Foundation, Nairobi, August 20, 2008. On lack of training of health workers, see also Chapter VI.

⁹⁶ Human Rights Watch interview with HIV-positive woman, Mombasa, August 16, 2007.

⁹⁷ Human Rights Watch group interview with HIV-positive men and women, members of Organization for Positive Living Kamukunji (OPLAK), Nairobi, August 17, 2007.

recounted situations where patients were asked in front of others where they got the virus from or whether they have been having sex.⁹⁸

Health workers sometimes blame mothers for infecting their children, in particular when they breastfeed.⁹⁹ Some health workers even believe HIV-positive women should not have children; in the study mentioned above, 20 percent of health providers said they had told an HIV-positive woman not to have children.¹⁰⁰ Poor treatment of mothers or other caregivers in health facilities can deter them from taking children for HIV testing and treatment. Blame, public disclosure of their status (or their child's status), or discriminatory attitudes and behavior by health workers can constitute barriers to accessing treatment.

The situation of HIV-positive children in schools

At present, overt discrimination in schools seems to be somewhat reduced. However, more subtle forms of discrimination against HIV-positive children in school continue. HIV-positive children who are aware of their HIV status often feel great pressure to keep their situation secret at school, and those in boarding schools sometimes take their drugs secretly.¹⁰¹ A 16-year-old HIV-positive boy explained,

I go to a boarding school in [name withheld]. The children and teachers do not know my status.... If you tell your friends at school, you get a lot of rejection. I only have two friends at school. I have to find my time to take the medication when nobody is watching. I do it in the dormitory. In the morning, I do it when everybody is still asleep.¹⁰²

⁹⁸ Ibid.

⁹⁹ Human Rights Watch interviews with James Kamau, KETAM, Nairobi, August 12; and nurse in HIV clinic, Mathare slum, Nairobi, August 14, 2008.

¹⁰⁰ Kamau, Odundo, and Korir, "Measuring the degree of S&D in Kenya," p. 10.

¹⁰¹ Human Rights Watch interview with counselor at Tuungane Youth Center, Kisumu, August 1, 2007; Human Rights Watch interviews with HIV-positive orphans at Nyumbani orphanage, August 11, 2007.

¹⁰² Human Rights Watch interview with Carl, age 16, Nairobi, August 11, 2007.

According to a nurse at an HIV/AIDS clinic, children may stop taking treatment altogether when going to school.¹⁰³ Until a few years ago, blatant discrimination against HIV-positive children in schools was widespread. Those who revealed their status were refused admittance or kicked out of school. A mother told us about her nine-year-old HIV-positive daughter, Charlotte:

At first she was attending a government school. She had problems with her eyes and rashes on her body. When I went to talk to the teacher, I got a hard time to talk to them. Later on, they told me that my child will infect the others and she was chased away.... She is now at a mission school because at government schools, there is a lot of stigma and discrimination.¹⁰⁴

In 2003 the Nyumbani orphanage for children living with HIV went to court after some of its children were refused admittance at a high school, and won a judgment that government schools would have to admit children from the orphanage. But up to the present, several schools that Nyumbani orphanage sends children to have asked Nyumbani staff to keep quiet about the health status of the children they are sending and to remove all Nyumbani signs from their cars to prevent local people from realizing that children with HIV are attending the school.¹⁰⁵

Most other children we interviewed did not tell their classmates about their status as they feared negative reactions from the other pupils. Parents also said they often avoided telling schoolteachers about their child's illness, although it would be important for teachers to know in case the child became suddenly ill.¹⁰⁶ However, we also interviewed several parents who had courageously informed teachers about their child's illness without any negative consequences. The guardian of eight-year-old Milicend told us,

¹⁰³ Human Rights Watch interview with nurse, HIV/AIDS clinic, Mathare slum, Nairobi, August 14, 2008.

¹⁰⁴ Human Rights Watch interview with mother of Charlotte, age nine, GROOTS Mothers Development Center, Mathare slum, Nairobi, August 7, 2007.

¹⁰⁵ Human Rights Watch interview with managing director of Nyumbani orphanage, Nairobi, August 7, 2007.

¹⁰⁶ Human Rights Watch interview with mother of two HIV-positive children, ages four and eight, Nyangoma, Bondo district, August 18, 2008.

I had to tell the teacher that she was HIV-positive, but she was very understanding, there has been no problem at school.... The teacher told me that [Milicend] is the only HIV-positive student in her class, but that there are many others at the school.¹⁰⁷

Lack of Care, Neglect, and Abuse of Children Living with HIV

Parents or other primary caregivers have a duty to ensure the child's well-being, and to look after their physical and emotional development.¹⁰⁸ HIV-positive children—just as all children—are in great need of love and care, but at the same time, they are particularly vulnerable to neglect and abuse; girls are particularly vulnerable to sexual abuse and exploitation.¹⁰⁹ The failure to provide basic material and emotional support constitutes neglect and is far too common for children with HIV. Neglected children are much less likely to get HIV testing and treatment. In our research, we found that boys and girls are equally affected by such neglect.

The vulnerability of children with HIV-positive mothers

When a husband throws an HIV-positive woman and their children out of the house, she and her children are often left with almost no belongings at all. When a husband dies, the experience of widows and children often falls far short of the protections provided in Kenyan inheritance law¹¹⁰: in-laws often seize the property¹¹¹ (disinheritance of AIDS orphans is discussed below). A widow and mother of an HIV-positive girl in Kibera slum, Nairobi, told us what happened after her husband died:

My husband's family took the land and the household property. They left the whole house completely empty.... They isolated me and so I

¹⁰⁷ Human Rights Watch interview with guardian of Milicend, age eight, Mathare slum, Nairobi, August 14, 2008.

¹⁰⁸ CRC, art. 27. See below, Chapter VII, The Legal Framework.

¹⁰⁹ UNICEF, *Africa's Orphaned and Vulnerable Generations. Children Affected By AIDS* (New York: UNICEF, 2006), http://www.unicef.org/publications/files/Africas_Orphaned_and_Vulnerable_Generations_Children_Affected_by_AIDS.pdf (accessed September 29, 2008).

¹¹⁰ Law of Succession Act, Chapter 160 of the Laws of Kenya, July 1, 1981, http://www.kenyalawreports.or.ke/kenyalaw/klr_app/frames.php (accessed June 16, 2008).

¹¹¹ Human Rights Watch, *Double Standards: Women's Property Rights Violations in Kenya*, vol. 15, no. 5(A), March 2003, <http://www.hrw.org/reports/2003/kenya0303/kenya0303.pdf>.

decided to go to Nairobi with the children. I am doing cash work [temporary work]; currently I am packing vegetables.¹¹²

Other women told similar stories. When they were chased away, they often went to Nairobi with their children where they now live in the slums under very poor conditions. They often are unemployed or do temporary work, which is sporadic and poorly paid.¹¹³ A community health worker in Kakamega district, western Kenya, explained what local NGOs are doing to stop disinheritance:

[W]e discovered that women were being chased away when their husbands died by relatives, and accused of killing their husbands.... So we tell these women, if your husband dies, don't close your eyes and cry. Cry, but keep one eye open to see what is happening with your land.¹¹⁴

In recent years, women's rights organizations such as GROOTS (Grassroots Organizations Operating Together in Sisterhood) have worked with traditional leaders in Nyanza province to change practices. As a result, traditional courts now sometimes allow women to repossess marital property.¹¹⁵

A particular problem is the tradition of "wife inheritance" among the Luo ethnic group in western Kenya. Wife inheritance means that a widow marries the deceased husband's brother or other male relative who has the responsibility to build her a new house and raise her children as his own.¹¹⁶ Some widows now oppose wife inheritance and end up breaking relations with their in-laws. Others accept it but find that the practice has changed and they receive less support than was traditionally required. Many newly remarried widows live in deep poverty, sharing very small,

¹¹² Human Rights Watch interview with mother of Anna, age six, Kibera slum, Nairobi, August 10, 2007.

¹¹³ Human Rights Watch interview with widows, Mathare slum, Nairobi, August 7 and 10, 2007; Human Rights Watch interview with representatives of NGO supporting widows, Kanyumba center, Siaya district, August 4, 2007.

¹¹⁴ Human Rights Watch interview with representative of Shibuye community health workers group, Kakamega district, August 2, 2007. The group is affiliated to the national NGO GROOTS.

¹¹⁵ Ibid.; Human Rights Watch interview with GROOTS representatives, Nairobi, August 7, 2007.

¹¹⁶ Prince and Geissler, "The Land is Dying"; Erick O. Nyambehda, Simiyu Wandibba, Jens Aagaard-Hansen, "Changing patterns of orphan care due to the HIV epidemic in western Kenya," *Social Science & Medicine*, No. 57, 2003, pp. 301-311.

unfinished houses with a large number of children, as the new husband has not fully delivered on his duty to build her new house.¹¹⁷

The special vulnerability of AIDS orphans

There are about 1.2 million AIDS orphans in Kenya—children who have lost their mother, father, or both (double orphans).¹¹⁸ A significant number of these orphans are themselves HIV-positive. Over 50 percent of orphans in Kenya live with grandmothers; others live with extended family members.¹¹⁹ Some live with guardians who are friends of their deceased parents, others with complete strangers. Still others live in orphanages, in child-headed households, or on the street.

Under Kenyan law, when parents die, parental responsibility for the child goes to a guardian appointed in a parent's will, or to a guardian appointed by the Children's Court, or in the absence of such a person, to a relative.¹²⁰ Most parents do not leave a will when they die but make informal arrangements for child fostering.

The loss of a generation of young adults has fundamentally transformed the lives of the older generation. Older people are no longer retiring as before, but instead continue to work hard to be able to care for their grandchildren. Often extremely poor themselves, many struggle to look after their grandchildren properly.¹²¹ Traditional patterns of child fostering have also changed. For example, in Luo society, prominent members of the father's family traditionally decided who—usually within the father's family—should bring up an orphan. Nowadays, dying mothers make this decision

¹¹⁷ Human Rights Watch interview with widow, Nyangoma, Bondo district, Nyanza province, August 18, 2008. Human Rights Watch, *Double Standards*, pp. 12-13.

¹¹⁸ WHO/UNAIDS/UNICEF, "Kenya, Epidemiological Fact sheet on HIV and AIDS, 2008 Update," July 2008, http://www.who.int/globalatlas/predefinedReports/EFS2008/full/EFS2008_KE.pdf (accessed September 4, 2008).

¹¹⁹ Steven Lewis Foundation, "Grandmothers and children affected by AIDS in sub-Saharan Africa," Fact Sheet, 2008, <http://www.stephenlewisfoundation.org/documents/Grannytripfactsheet-REVISEDAPRIL2008.doc> (accessed September 4, 2008).

¹²⁰ The Children's Act, No.8 of 2001, Laws of Kenya, art. 27 (1).

¹²¹ Erick O. Nyambedha, Simuyu Wandibba and Jens Aargaard-Hansen, "'Retirement Lost' – the new role of the elderly as caretakers for orphans in western Kenya," *Journal of Cross-Cultural Gerontology*, no. 18, 2003, pp. 33-52.

often by themselves, and it has become more common for orphans to be raised in their maternal family.¹²²

Violence and abuse against AIDS orphans

AIDS orphans are particularly vulnerable to exploitation and abuse. Access to medical treatment can also be very difficult for such children. Children who live with non-parent guardians may face violations of property rights, labor exploitation, sexual harassment and abuse, and violence.¹²³ They are also often not able to get an education because guardians cannot or do not want to spend money on school fees or related costs, or want the child to work.¹²⁴ Orphaned girls sometimes suffer sexual harassment and abuse in the host family.¹²⁵ AIDS orphans left economically bereft may exchange sex for food, lodging, or money. Sexual abuse and transactional sex places AIDS orphans who are not already HIV positive at high risk of contracting the disease.¹²⁶

Many orphans told us about beatings and other physical mistreatment they suffered.¹²⁷ James, a 14-year-old boy, ran away from home and was forced to live on the streets, where he was vulnerable to further abuse. He told us,

I cannot remember when my parents died. I think I was about 10. An uncle took us, me and my sister, with him, to his house in Kibera. He was harassing and beating me, for example when I played for too long

¹²² Nyambehda, Wandibba, and Aagaard-Hansen, "Changing patterns of orphan care due to the HIV epidemic in western Kenya," *Social Science & Medicine*.

¹²³ Human Rights Watch, *Suffering in Silence: The Links Between Human Rights Abuses and HIV Transmission to Girls in Zambia* (New York: Human Rights Watch, 2002), <http://www.hrw.org/reports/2003/zambia/zambia1202.pdf>; UNICEF, *Africa's Orphaned and Vulnerable Generations*.

¹²⁴ Human Rights Watch, *Letting Them Fail: Government Neglect and the Rights to Education for Children Affected by AIDS*, vol. 17, no. 13 (A), October 2005, <http://hrw.org/reports/2005/africa1005/index.htm>.

¹²⁵ UNICEF, *Enhanced Protection for Children affected by AIDS* (New York: UNICEF, 2007) http://www.unicef.org/publications/files/Enhanced_Protection_for_Children_Affected_by_AIDS.pdf (accessed September 29, 2008), p. 18.

¹²⁶ Erick O. Nyambehda, "Vulnerability to HIV infection among Luo female adolescent orphans in Western Kenya," *African Journal of AIDS Research*, vol. 6, no. 3, 2007, pp. 287-295; Population Council/Constella Futures, "Situation Analysis of the Sexual and Reproductive Health and HIV Risks and Prevention Needs of Older Orphaned and Vulnerable Children in Nyanza Province, Kenya," March 2007, http://www.popcouncil.org/pdfs/Kenya_OVC_report.pdf (accessed November 10, 2008).

¹²⁷ Human Rights Watch interview with orphans, Stara center, Kibera slum, Nairobi, August 10, 2007.

outside. He wanted me to stay inside. My sister [who was healthy] was not beaten; she stayed inside and worked as domestic. My uncle often beat me on the back, with belts or other objects he could find. He would do it every couple of days. I ran away. But the uncle found me and brought me back. He would beat me then, too. He saw me as a burden after my parents passed away. He told me that I should have died instead of my parents.... Once I ran away to Karen [a Nairobi suburb], for a few days. I stayed in the street and in the forest, begging. I was alone there. Another time I ran away to Buru Buru [a Nairobi suburb] where I met other street children who faced similar problems as me. I stayed there for six months. I found a good samaritan who allowed me to sleep in his kiosk. He was also giving me tea. Finally, the man sent me and the other three children to a children's home in Buru Buru. I stayed there for six months. The other three children were picked up by their mother. Then I ran away from the children's center. A gentleman brought me to the police station in Kilimani where I was detained in a container for about one week.¹²⁸

At the time of the interview, James was staying in a small shelter in Kibera and getting antiretroviral drugs and other medical care through a community project.

Frederic, a 13-year-old orphan in Kibera, said he was scared that he might lose the only caregiver he has left, even though his home situation was far from the caring environment a child needs:

I live with my uncle. My mom died in 2000 and my dad in 2003. I don't know why they died, my uncle doesn't talk about it.... My uncle's wife ran away when he got sick. He has sores all over his body. It's just the two of us.... Always I go to bed hungry. I do all the work in the house—I get water, cook, wash clothes and dishes—but there's never enough food or even money to buy water. My uncle doesn't let me play even when the work is done. If he sees me playing, he beats me. I don't

¹²⁸ Human Rights Watch interview with James, age 14, St. Vincent Rescue Home, Kibera slum, Nairobi, August 10, 2007.

know why. I'm afraid that he will die. I don't know who I can stay with.¹²⁹

While AIDS orphans are vulnerable to abuse, not all children are actually subjected to violence, abuse, and exploitation. Many guardians do their utmost to care for AIDS orphans living with them.¹³⁰ The situation of orphans—as well as children living with their biological parents—is multifaceted, not least because children themselves are able to negotiate and change situations.¹³¹

Disinheritance of AIDS orphans

On paper, Kenyan inheritance law provides children with important protections.¹³² When both parents die without leaving a will, their property is to be divided equally among their children, whether male or female. If the child is under 18, a public trustee will administer the property until the court appoints a person who administers the property on the child's behalf; this may be the guardian or any other adult.¹³³

Yet, in reality, many children in Kenya do not inherit the property they are entitled to from their deceased parents, such as a house or apartment, land, or movable property.¹³⁴ For AIDS orphans in particular this can mean denial of basic social and economic rights, including the right to health and education.¹³⁵ Children rarely know their rights, how to get a lawyer, or how to access the Office of the Public Trustee. In many cases, surviving relatives grab the property they are meant to administer for

¹²⁹ Human Rights Watch interview with Frederic, age 13, Stara center, Kibera slum, Nairobi, August 10, 2007.

¹³⁰ Traditionally, relations between grandmothers and grandchildren were very strong. R.J. Prince and P.W. Geissler, "Shared Lives, Exploring Practices of Amity Between Grandmothers and Grandchildren," *Africa*, 2004, vol. 74(1), pp. 95-120.

¹³¹ Erick O. Nyambedha, "Children and HIV/AIDS: Questioning Vulnerability in Western Kenya," PhD dissertation, Institute of Anthropology, University of Copenhagen, June 2006 (unpublished).

¹³² Law of Succession Act, Chapter 160 of the Laws of Kenya, July 1, 1981, http://www.kenyalawreports.or.ke/kenyalaw/klr_app/frames.php (accessed June 16, 2008).

¹³³ Law of Succession, arts. 38, 41, and Fifth Schedule, arts. 7 and 8.

¹³⁴ See also Human Rights Watch, *In the Shadow of Death*; Open Society Institute, "Ensuring Justice for Vulnerable Communities in Kenya. A Review of HIV and AIDS-related Legal Services," 2007, http://www.soros.org/initiatives/health/focus/law/articles_publications/publications/kenya_20070416/kenya_20070416.pdf (accessed June 13, 2008).

¹³⁵ Human Rights Watch, *Letting Them Fail*.

the child; in other cases, relatives seeking to safeguard a child's inheritance face numerous bureaucratic obstacles. Sometimes children are chased away from their parent's property. A counselor at Nyumbani orphanage told us,

Families strip children of their property and then place them here at the orphanage. For example, we had a case of a child staying with her aunt. The mother had died and left a flat. The aunt took the flat and then placed the child here.¹³⁶

When children demand their inheritance, their relatives sometimes react with threats.¹³⁷ In a rare case, the Child Legal Action Network (CLAN), a local nongovernmental organization, managed to assist several orphans in Makindu, eastern Kenya, whose relatives had evicted them from their parents' property. The NGO helped to get a court order to reverse the eviction.¹³⁸

Caregivers' Failure to Take Children for HIV Testing and Medical Care

Caring for a child who is HIV-positive constitutes a heavy responsibility. Caregivers need to take children for testing, particularly if the mother has died of HIV or if the child shows signs of illness. Caregivers must ensure that children take their medicine regularly, at the right time, and with sufficient and nutritious food. They must take children back to health facilities for regular monitoring, check-ups, and drugs. Caregivers also must support the child emotionally.

Importance for medical treatment of having a consistent caregiver

Children with HIV who do not have a consistent, attentive caregiver may be less likely to get tested and may not have the daily supervision necessary to comply with the medical treatment of HIV. This was the case with Carolyn, an eight-year-old girl in Kisumu. She lives with her grandmother, who brews alcohol for a living and is often away from home. The girl frequently stays during the day with her aunt, who lives nearby and who has become her real caregiver. The aunt told us,

¹³⁶ Human Rights Watch interview with counselor, Nyumbani orphanage, Nairobi, August 7, 2007.

¹³⁷ Human Rights Watch interview with Protus Lumiti, August 7, 2007.

¹³⁸ Human Rights Watch interview with representatives of CLAN, Nairobi, August 9, 2007. The case occurred in 2006.

[Carolyn's] mum died when she was four years old. After her mum's death a relative took [Carolyn] to Nakuru town. They had her until recently. But [Carolyn] refused to go back there, she said she was going without food and not sent to school.... She is living with her grandmother [now] but there is little food, and no one reminds her of the drugs. The grandmother also beats her sometimes... [Carolyn] had rashes and got often sick. I took her to a test at Tuungane [Youth Center, a VCT center]. She was HIV-positive and is now on ARV. I make sure she takes the drugs. She often stays with me during the day but the grandmother does not like that.¹³⁹

A local human rights organization reported a case where a father interrupted his children's HIV treatment when he separated from the mother. He took his children from Nairobi with him to Nyanza province and failed to provide the children with medical treatment. This NGO obtained a court order for the children to come back to Nairobi.¹⁴⁰

Even a short separation from the main caregiver—such as a visit to other relatives—can be fatal if the child's medical care is disrupted. In Nyangoma village, Nyanza district, we interviewed the aunt of Stephen, who died around May 2008. He was living with his maternal grandmother, aunt, and other relatives. He was HIV-positive and was put on tuberculosis medicines and then on antiretroviral treatment. Stephen's aunt told us,

He improved greatly. He went to primary school class four. Then, during the Easter break in April, his paternal family [in Kisumu] wanted him to visit. They mishandled him. He did not take his drugs there. He came back alone, on a vehicle, very weak and sick. They did not escort him and did not take him to the hospital. It was as if they did not want him anymore and sent him back. When he came back, we took him to Bondo Hospital. He died the same night. We took him for burial at the

¹³⁹ Human Rights Watch interview with aunt of Carolyn, age eight, Kisumu, August 16, 2008.

¹⁴⁰ Human Rights Watch interview with representatives of CLAN, Nairobi, August 9, 2007.

home of the paternal family. They showed sorrow but we blame them.¹⁴¹

When health workers and social workers suspect that a caregiver is neglecting a child, they sometimes decide not to start ART because they fear that the child may not get the supervision necessary to take the drugs consistently. As stated above, failure to take the drugs regularly can lead to drug resistance.¹⁴²

Abandonment, abuse, and denial of HIV treatment

Some parents or guardians willfully harm HIV-positive children, or completely abandon them. Social workers and other professionals assisting children told us about foster parents' tendency to shift responsibility by moving the child among relatives. A leader of an HIV support group said,

When guardians notice a child is HIV-positive, they give the child often to other relatives. They don't want to be associated with these children. There are many situations of abuses of those children.¹⁴³

In December 2006 Nyumbani orphanage received an eight-year-old boy with AIDS. He had been abandoned by his aunt at the Kenyatta hospital. The boy had suffered beatings, despite his apparent illness and frail physical condition.¹⁴⁴

Unfortunately, HIV testing is also not always done out of concern for the child. Instead, guardians have taken orphans for testing just to find out if the child is HIV-positive and then kicked the child out of their home.¹⁴⁵

Seventeen-year-old Christine placed her trust in a complete stranger when she was badly treated by her stepmothers:

¹⁴¹ Human Rights Watch interview with aunt of Stephen, Nyangoma, Bondo district, Nyanza province, August 18, 2008.

¹⁴² Human Rights Watch interview with representative of Lea Toto community project, Kibera slum, Nairobi, August 8, 2007.

¹⁴³ Human Rights Watch interview with HIV support group leader, Mathare slum, Nairobi, August 10, 2007. A similar statement was made to Human Rights Watch by a representative of Lea Toto community project, Kibera slum, Nairobi, August 8, 2007.

¹⁴⁴ Human Rights Watch interview with Protus Lumiti, August 7, 2007.

¹⁴⁵ Human Rights Watch interview with representative of Pandipieri, Kisumu, August 3, 2007.

Both my parents died. I had two stepmothers who were married to my father. I lived with them. Sometimes they gave me food, sometimes not. My older sister ran away. Once, when we came to the stepmothers' from our grandmother's house, they took away all the food she had given us.... I was sometimes sick. They put me outside the house during the day and left for work. I would stay like that until they come back. I just laid down, people used to pass. One day, a stranger lady came and found me sleeping outside. She took me with her to her home. I stayed with her for some time, but then she became mean to me. She cooked my food separately from hers and she prepared it badly. I was sick then, and she did nothing about it.¹⁴⁶

Christine was HIV-positive but only received treatment when her sister, who had run away from the household, took her to Kenyatta hospital. She is now living in Nyumbani orphanage. Another example of neglect and denial of treatment is that of 15-year-old Leah from Kisumu, who is now receiving ART. She told us about her experience of living with her brother and sister-in-law after her mother's death:

My brother took me to Tuungane Youth Center for the test when I was 14. He took me there because I was often sick.... When his wife found out about my status, she was mistreating me. She told other people. She did not allow me to use the same cups [as] the rest of the family. She beat me and sometimes refused to give me food. Also, she would close the door during the day and not allow me to go into the house to get the medicine. The time for taking drugs would pass. I would tell the woman but she just disregarded this and closed the door. I told my brother too, and then there would be quarrels. The lady would be even more angry with me. So I decided not to tell my brother any of my problems.¹⁴⁷

¹⁴⁶ Human Rights Watch interview with Christine, age 17, Nyumbani orphanage, August 11, 2007.

¹⁴⁷ Human Rights Watch interview with Leah, age 15, Kisumu, August 16, 2008.

A staff member of Pandipieri, a large VCT center in Kisumu, told us about the case of a 13-year-old boy who was “so sick that the teacher at the school referred him to us. When we finally took over his care, we got him tested, his CD4 count was nine; it was too late. He died soon after. The guardian had the means but just didn’t take him to the hospital.”¹⁴⁸

Trauma and self-blame

Sometimes, neglect is caused by stress on the parent or guardian, for example when many other people around the person have already died of AIDS. People may not take their children for testing because they are afraid of the results and feel they cannot cope with the bad news of an infected child. An HIV-positive mother explained to a community health worker that she did not take her child for testing because she could not live with an HIV-positive child; she would blame herself for the sickness.¹⁴⁹ A community health worker in western Kenya recounted the case of a girl being cared for by her grandmother:

This girl is not on ARV yet... The grandmother has a very negative attitude towards her and is not interested in taking her to the clinic for checkups. She is ignorant about these things even after I have talked to her. All her sons have died of AIDS, and then this mother and other wives too. This has affected the grandmother psychologically. She can’t deal with it properly even though I have talked to her. Now I see this girl, she is having a skin disease on her head, and her health is looking poor. I love this girl. She is now nearly 11, but she can’t go by herself to get help.¹⁵⁰

Failure to disclose: Violations of the child’s rights to information

Parents usually do not tell their children that they are HIV-positive until they reach adolescence. We interviewed children between the ages of 8 and 14 who had not

¹⁴⁸ Human Rights Watch interview with representative of Pandipieri, Kisumu, August 3, 2007.

¹⁴⁹ Human Rights Watch interview with community health worker and HIV support group leader, GROOTS Mothers Development Center, Mathare slum, Nairobi, August 10, 2007.

¹⁵⁰ Human Rights Watch interview with community health worker, Shibuye community health workers group, Kakamega District, Shinyalu Division, Western province, August 2, 2007.

been told about their HIV status. For example, Angeline, a healthy looking 14-year-old whose mother died of AIDS, is taking antiretroviral drugs every day but her father has not told her why she is doing so.¹⁵¹

Parents refuse to tell their children about their HIV status because they do not want children to talk about HIV in front of others: They are afraid that a younger child might “spill the secret” unwittingly and hence breach confidentiality.¹⁵² This is especially a problem for many women whose own HIV-positive status would also likely be revealed to their husband or to others. Many parents are also deeply afraid of telling their child; they naturally want to protect them from bad news. Parents also lack support and information on how to disclose to their children, and are sometimes afraid the child will blame them. But, caregivers’ failure to disclose HIV-related information to children in their care may lead to psychological problems. Also, if not explicitly told by their caregivers, children may inadvertently learn about their illness in a manner that is not supportive. We interviewed the mother of Elaine, age 12, about her daughter’s reaction when she accidentally found out that she was HIV-positive:

Two or three days ago [Elaine] found out that she was positive. She overheard some people here in the [IDP] camp talking about it. She took the news very badly, she was very hostile. She heard that the medicines that she is taking are for people with HIV/AIDS. So she was very aggressive.... For the first two days she refused to take them [the ART], but now we have talked about it a little bit and she is taking them again.¹⁵³

Children are able to sense that their caregivers are concerned about them, and they might feel there is a “conspiracy of silence” surrounding them if information about their HIV-positive status is withheld from them. If adults refrain from speaking to

¹⁵¹ Human Rights Watch interview with representative of GROOTS Mothers Development Center, Mathare slum, Nairobi, August 10, 2007.

¹⁵² Human Rights Watch interviews with representative of Lea Toto community program, Kibera slum, Nairobi, August 8; and HIV-positive caregiver, GROOTS Mothers Development Center, Mathare slum, Nairobi, August 10, 2007.

¹⁵³ Human Rights Watch interview with mother of Elaine, age 12, Eldoret ASK Showgrounds IDP camp, August 19, 2008.

them about this for years, such children may live in great anxiety, and in fact suffer more than if they were told about their status.¹⁵⁴ Experiences in other settings show that disclosure can work well, if the process is well-managed and caregivers are ready. In a project in Thailand, children who were screened for and then participated in a disclosure program were on average 10 years old.¹⁵⁵ Studies indicate that children with knowledge of their HIV status have higher self-esteem than children who are unaware of their status.¹⁵⁶

Denying older children information about their HIV status violates a child's right to information and privacy, and the child's right to voluntary, confidential HIV counseling and testing. It also compromises a child's ability to participate in his or her own medical care, which is an important part of the right to health.¹⁵⁷

Disclosure should take into consideration the child's age, maturity, family dynamics, and the clinical context. At a minimum, children must know about their HIV status as soon as they start to become sexually active—otherwise they risk infecting others. The American Academy of Pediatrics has closely studied the issue of disclosure and recommended that children from school age should receive age-appropriate information and counseling about their HIV status.¹⁵⁸ A Kenyan pediatrician working with HIV-positive children explained his experience:

I would say any time the child starts asking questions about why I am here, why am I taking these medications, is the right time to tell the child. [Disclosure] can be a gradual process. If the child is able to recognize what he or she is doing, then a parent should start disclosing in a small way. I would say this can be from age 7 to 10. At

¹⁵⁴ American Academy of Pediatrics, "Disclosure of Illness Status to Children and Adolescents With HIV Infection," *Pediatrics*, vol. 103, no. 1, January 1999, <http://aappolicy.aappublications.org/cgi/reprint/pediatrics;103/1/164.pdf> (accessed September 4, 2008), p. 165.

¹⁵⁵ Rangsim Lolekha, "A Pediatric HIV Disclosure Model: Lessons Learned from Thailand," 2008, http://www.kaisernetwork.org/health_cast/uploaded_files/14_3082_Lolekha.pdf (accessed September 4, 2008).

¹⁵⁶ American Academy of Pediatrics, "Disclosure of Illness Status to Children and Adolescents With HIV Infection," pp. 164-166.

¹⁵⁷ See Chapter VII, The Legal Framework.

¹⁵⁸ American Academy of Pediatrics, "Disclosure of Illness Status to Children and Adolescents With HIV Infection."

the very least, a child above 10 should know their status. There is a gap in training in the country on how to do disclosure to children.¹⁵⁹

(The issue of the age at which a child should appropriately be allowed to be tested for HIV without parental consent is discussed below, in Chapter VI.)

Children with No Caregivers: Child-Headed Households and Street Children

Child-headed households

The number of households where everyone is younger than 18—child-headed households—has increased dramatically since the HIV epidemic started.¹⁶⁰ Children in such households face many difficulties; they are vulnerable to exploitation, violence and abuse, and often fail to get the medical treatment they need.¹⁶¹ A woman working with street children in Kisumu described one such household:

I knew of three orphans living on their own. They would come by sometimes and we would give them food supplements. We didn't see them for a while. Finally an older one came and asked us to help the younger girl. We took her to be tested, but it was also too late, her CD4 count was 13, she died three weeks later. I don't think this was a case of purposeful neglect, but the older sibling who was still a child didn't have the education to think to get help for HIV. She didn't know these things [services] were free, and no one stepped in to help.¹⁶²

A social worker in Nairobi dealt with the case of two boys, ages roughly 10 and 12, who were taken to western Kenya by their relatives after their mother died. Their mother had tested HIV-positive in Nairobi, and the boys were keen to get tested themselves, he told us. But relatives stripped them of the little property they had left,

¹⁵⁹ Human Rights Watch interview with Winstone Nyandiko, associate program manager, AMPATH, Eldoret, August 19, 2008.

¹⁶⁰ Human Rights Watch, *In the Shadow of Death*.

¹⁶¹ International HIV/AIDS Alliance and Family Health International, "Child Headed Households," <http://www.ovcsupport.net/sw3256.asp> (accessed September 5, 2008).

¹⁶² Human Rights Watch interview with representative of Pandipieri, Kisumu, August 3, 2007.

so the boys decided to go back to Nairobi by themselves. They worked until they had enough money for the bus fare and returned back to the Nairobi clinic where their mother had taken the test. Luckily both boys were HIV-negative.¹⁶³

Street children

There are an estimated 300,000 street children in Kenya, according to the government.¹⁶⁴ Many of them have escaped abuse at home. Street children face serious difficulty in getting medical treatment. Hospitals are ill-prepared to deal with children without a home and may withhold ART out of fear that treatment adherence would be low.¹⁶⁵ For the same reasons, NGOs are currently refraining from starting street children on ART unless they move into a shelter.¹⁶⁶ By the time street children seek assistance in a shelter or orphanage, however, it is often too late, and they die.¹⁶⁷ Some street children also do not trust social workers and refuse HIV testing, as a social worker explained:

We talk to the boys also about venereal diseases, and we have tried to test them, but many of them don't want us to draw their blood. Unless you know a boy really well, he doesn't trust us. Many believe that we are taking their blood for magic purposes.... We lost quite a number of boys on the street. You can tell that they had full-blown AIDS.¹⁶⁸

The situation of street children is complicated by the fact that they are sometimes treated as criminals. Police have repeatedly rounded up and detained street children. Street children are also often subject to police brutality, sexual abuse and exploitation, and economic exploitation. Girl sex workers living on the street have

¹⁶³ Human Rights Watch interview with social worker, Mathare slum, Nairobi, August 14, 2008.

¹⁶⁴ "Step up sensitization on the plight of street children, urges VP," Kenya Broadcasting Corporation, October 1, 2007, <http://www.kbc.co.ke/story.asp?ID=45397> (accessed September 5, 2008).

¹⁶⁵ "Kenya: HIV services are scarce on the street," *PlusNews*, July 29, 2008, <http://www.plusnews.org/Report.aspx?ReportId=79505> (accessed September 5, 2008).

¹⁶⁶ Human Rights Watch interview with representatives of WEMA, Mombasa, August 13, 2007; Human Rights Watch interview with representative of Pandipieri, Kisumu, August 3, 2007.

¹⁶⁷ Human Rights Watch interview with Protus Lumiti, August 7, 2007.

¹⁶⁸ Human Rights Watch interview with representatives of WEMA, Mombasa, August 13, 2007.

been raped by police.¹⁶⁹ Sexual exploitation and abuse increase children's vulnerability to HIV transmission.

Economic Barriers to Testing and Treatment

Poverty is one of the main reasons children cannot access testing and treatment. Kenya is ranked 148 out of 177 countries on the Human Development Index.¹⁷⁰ Per capita income is roughly US\$580 per year, which is less than \$2 per day; 46 percent of Kenyans are living below the food poverty line.¹⁷¹ The country has been hard-hit by the recent rise in global fuel prices, in turn affecting transport costs and food prices.¹⁷²

For children to fully access health care, they need money for transport, for adequate food, and for drugs, tests, and other health-related user fees. In general, out-of-pocket expenditures for health are high in Kenya. Patients also lose income while going to health facilities and waiting to be treated. A social worker in an HIV clinic in Mathare slum noted, "Coming here means wasting a day without income. Many come too late as a result."¹⁷³

Recently MSF-Belgium undertook an analysis of all "defaulters," that is patients on ART who had stopped their treatment. Among those who were still alive, a lack of transport and food were the main reasons patients stopped treatment.¹⁷⁴ A research study in Nairobi's Kibera slum also found that lack of food was "the single most

¹⁶⁹ Human Rights Watch interviews with social worker at Solwodi, NGO working with sex workers, Mombasa, August 14; and representatives of WEMA, Mombasa, August 13, 2007. Past abuses were documented by Human Rights Watch in *Juvenile Injustice: Police Abuse and Detention of Street Children in Kenya* (New York: Human Rights Watch, 1997), <http://www.hrw.org/reports/1997/kenya/>.

¹⁷⁰ UNDP, "Kenya, The Human Development Index," http://hdrstats.undp.org/countries/country_fact_sheets/cty_fs_KEN.html (accessed September 8, 2008).

¹⁷¹ United Kingdom Department for International Development (DFID), "Key Facts: Kenya," <http://www.dfid.gov.uk/countries/africa/Kenya-facts.asp> (accessed October 17, 2008).

¹⁷² USAID, "Horn of Africa – Complex Emergency," June 20, 2008, [http://www.reliefweb.int/rw/RWFiles2008.nsf/FilesByRWDUnidFilename/LRON-7FYHCE-full_report.pdf/\\$File/full_report.pdf](http://www.reliefweb.int/rw/RWFiles2008.nsf/FilesByRWDUnidFilename/LRON-7FYHCE-full_report.pdf/$File/full_report.pdf) (accessed July 3, 2008).

¹⁷³ Human Rights Watch interview with social worker, Mathare slum, Nairobi, August 14, 2008.

¹⁷⁴ Human Rights Watch interview with representatives of MSF-Belgium, Nairobi, August 13, 2008.

important barrier to ART.”¹⁷⁵ As will be explained below, patients on ART have particular nutritional needs and suffer from side effects if they take the drugs with little or no food.

Physical access: Transport

Physical access to healthcare facilities is a major problem in Kenya, particularly in rural areas. In some areas of Kenya, around one-third of patients are more than five kilometers away from the nearest health facility.¹⁷⁶ If a child is found to be HIV-positive, regular travel is necessary. The child usually needs to get a CD4 cell count, as well as other tests. If the child is put on ART, the caregiver has to come back regularly with the child to get new drugs, and also for regular check-ups, treatment of opportunistic infections, and monitoring of drug side effects and resistances. When a child is not on antiretroviral treatment, he or she must get regular checkups and usually has to get supplies of antibiotics.

A study among caregivers and HIV-positive children using the nearest health facility found that 43 percent of respondents said they could not afford the amount of money the transport had cost them. Twenty-one percent stated that they had delayed seeking treatment because of transport costs.¹⁷⁷

While transport to the nearest health facility already poses challenges, HIV/AIDS patients are not always served at the nearest dispensary or health center. Children in particular are often referred to higher-level health facilities, such as district hospitals; this means caregivers and their children have to travel considerably farther. Adults in need of ART who have HIV positive children may have to organize separate transport to different health facilities for their and their children’s treatment. A Ministry of Health official explained,

¹⁷⁵ O. Muhenje et al., “Misperceptions surrounding the use of antiretroviral drugs in an urban slum, Nairobi, Kenya,” *International Conference on AIDS*, vol. 15, 2004.

¹⁷⁶ A. M. Noor et al., “Defining equity in physical access to clinical services using geographical information systems as part of malaria planning and monitoring in Kenya,” *Tropical Medicine and International Health*, vol. 8, no. 10, October 2003, pp. 917-926.

¹⁷⁷ Horizons/Population Council, “‘If You Build It, Will They Come?’ Kenya Healthy Start Pediatric HIV Study: A Diagnostic Study to Investigating Barriers to HIV Treatment and Care Among Children,” June 2008, http://www.popcouncil.org/pdfs/horizons/Kenya_PediatricHIVTreatment.pdf (accessed October 10, 2008), pp. 33-34.

We think that children are dying of AIDS before they reach higher levels [of health facilities]. Dispensaries and health centers... do not test often, but we are hoping to move down to this level... In areas with the highest prevalence we have reached the lower levels already.¹⁷⁸

A mother living in Bondo district, Nyanza province—the province with the highest prevalence in Kenya¹⁷⁹—explained to us her problems in getting her now deceased six-year-old son, Andrew, to Bondo district hospital, 10 kilometers away:

He was on ART. He had to go to Bondo every month. I used to find it too difficult to go to Bondo. Sometimes I could not find the money for transport, so I went by foot with [Andrew]. I carried him on my back. I got up at 5am and arrived around 10 a.m. I left around 3 p.m. and was back by 7 [p.m.]. We did not miss a single day of treatment.¹⁸⁰

This HIV-positive mother, like many others, underwent major physical exertion to ensure her child got treatment, despite her weakened physical condition.¹⁸¹ Andrew died during the post-election crisis when he could not get medical care; his case is discussed below in Chapter V. Unlike this mother, other parents told us that transport costs kept them from taking children to health facilities. Also in Nyangoma, Bondo district, a grandmother told us that she did not have the money to travel repeatedly to the district hospital with her 20-month-old grandson, Daniel. Daniel is HIV-positive and was hospitalized at some point. After some time at home, his health deteriorated, so his grandmother took him back to Bondo hospital:

He took tuberculosis and CD4 tests in Bondo, and they showed that his CD4 cell count was down. I went to the Nyangoma health center [the local mission health center] with the X-ray but the doctor who had

¹⁷⁸ Human Rights Watch interview with Dr. Lyndon Marani, ART program manager, NASCOP, Ministry of Health, Nairobi, August 13, 2008.

¹⁷⁹ Nyanza province has prevalence of 15.3 percent. Ministry of Health, “Kenya AIDS Indicator Survey, preliminary report,” p. 14.

¹⁸⁰ Human Rights Watch interview with mother of Andrew, who died age six in March 2008, Nyangoma, Bondo district, Nyanza province, August 18, 2008.

¹⁸¹ *Ibid.*

recommended the X-ray was no longer there, and no one could read X-rays, so I was told to go back to Bondo to get the X-ray results. But I have not been able to as it is expensive. [Daniel] coughs a lot and sometimes he has diarrhea.¹⁸²

A woman in Mombasa explained to us why her nine-year-old daughter, who is living with the grandmother in Nyanza province, is not getting treatment:

Today, my daughter is no longer with me. She is staying in the village with my grandmother... but she is not on ART. The grandmother is old and can't take proper care of her. The hospital is too far away and there is no money for transport. The nearest hospital is in Migori District in Nyanza province. But the grandmother's village is Awendo village in Kisumu district. The grandmother has asked me to come to get the girl because she has a wound on her leg that is not getting better. But I can't take care of her now. I don't have a place to live myself.

The woman is a sex worker with no permanent home. At the time of the interview, she lived with her seven-month-old baby on another woman's verandah. She said about her baby,

My baby girl was getting septrin [antibiotic] but we have run out. I missed my last two appointments at the hospital because I didn't have money for transport to get there on the days I was supposed to go.¹⁸³

A staff member at a center for child testing and treatment in Kisumu told us,

Two weeks ago, I had a child who had come from very far. The grandmother was with her and she begged us to enroll the child in our program. But we had to refuse, she lived too far away. There was no

¹⁸² Human Rights Watch interview with grandmother of Daniel, age one, Nyangoma, Bondo district, August 17, 2008.

¹⁸³ Human Rights Watch interview with HIV-positive mother, Mombasa, August 16, 2007.

way that she could adhere to our programs because the grandmother did not have the means to pay for the transport, which was KSh400 [US\$ 5.20] round trip.¹⁸⁴

Problems of transport are more serious in rural areas where people live farther away from health centers. However, we also met a guardian in a slum area of Nairobi who said it was impossible to pay transport to the hospital to get a renewal prescription of antiretroviral drugs for her foster child, even though the boy was coughing and developing rashes.¹⁸⁵

In some cases, there have been domestic conflicts because husbands do not want to pay for a child's transport to a health center. For example, a grandmother wanted to take her grandson—who was ill with tuberculosis and HIV—for treatment, but her husband refused.¹⁸⁶

Lack of food

Lack of food is a major challenge for people needing antiretroviral treatment, as they have higher energy needs than healthy people. HIV-positive children need about 10 percent more food than HIV-negative children when they are showing no signs of HIV infection. Children who have full-blown AIDS and are experiencing weight loss need an energy increase of between 50 and 100 percent.¹⁸⁷ Antiretroviral drugs are also more efficacious when taken with the right types of food. Different types of drugs require different types of nutrition. If there is not enough food, or food with little nutritional value, a patient may suffer from severe side effects such as nausea, vomiting, diarrhea, or liver or kidney damage. This could also mean that the drugs will ultimately not work.¹⁸⁸

¹⁸⁴ Human Rights Watch interview with counselor, Tuungane Youth Center, Kisumu, August 1, 2007.

¹⁸⁵ Human Rights Watch interview with guardian of seven orphans, Eastleigh, Nairobi, August 11, 2007.

¹⁸⁶ Human Rights Watch interview with community AIDS worker and paralegal, Shibuye community health workers group, Kakamega District, Shinyalu Division, Western province, August 2, 2007.

¹⁸⁷ Ministry of Health, "Kenyan National Guidelines on Nutrition and HIV/AIDS," April 2006, <http://www.health.go.ke/> (accessed July 3, 2008), p. 46.

¹⁸⁸ HIV infection increases nutrition requirements. A balanced diet should include high-energy foods, rich in carbohydrates and sugar. Low carbohydrate foods should be prepared with fat and oils. Furthermore, HIV-positive children have increased protein requirements, such as milk products, meat, beans, lentils, and groundnuts. For example, a balanced diet for one day

Almost half of the Kenyan population does not have secure access to food resources to adequately meet their daily needs, and 31 percent of children are stunted due to malnutrition.¹⁸⁹ Many caregivers find it impossible to provide the children in their care with the food they need. As one community health worker in western Kenya explained,

Any person on ART is told they need to have nutritious food. During this period of the year [March to August], posho [cornmeal], maize, beans are very expensive to buy. During this period, it is hard for grandmothers to get food, and the child is very hungry and tired. Sometimes the children only have a cup of tea in the morning, and by lunch time they are nauseous and dizzy because of the medicine. So, we see these grandmothers not wanting to give the kids the medicine. They are too old to try to cultivate [food] themselves, and the children are too young to do too much. Nutrition that is needed to go with the medication is a real struggle for many taking care of HIV-positive orphans.¹⁹⁰

Food security is also a major problem in Nairobi's slums, where most inhabitants do not cultivate food.¹⁹¹ A community health worker in Mathare slum told us,

Some guardians or parents do not want to take children for testing. They fear that if the children start taking ART, they will not have enough food to eat. When children take ART and do not have enough food, they will get other diseases. They get very weak. They get stomach pains and feel dizzy. There are children who are given ART but they do not take them because of this.¹⁹²

could consist of 6 servings of whole maize meal, 1 serving dried beans, 1 ¼ cups of cooked vegetables without water, 1 serving meat or fillet, 5 teaspoons of fat, 1 cup of milk, 2 oranges. *Ibid.*, pp. 9-18, 49-50.

¹⁸⁹ *Ibid.*, p. 1.

¹⁹⁰ Human Rights Watch interview with community health worker, Shibuye community health workers group, Kakamega District, Shinyalu Division, Western province, August 2, 2007.

¹⁹¹ Human Rights Watch group interview with community workers at GROOTS Mothers Development Center, Nairobi, August 14, 2008.

¹⁹² Human Rights Watch interview with Joyce, community health worker, GROOTS Mothers Development Center, Mathare slum, Nairobi, August 7, 2007.

Sometimes caregivers start children on ART, but when they have no food, they leave out one dose, or several.¹⁹³

Many of Kenya's poor live on KSh50 (appr. US\$0.65) a day, and may be trying to survive on as little as one meal per day. Under those conditions, health workers try to give realistic advice to caregivers about food.¹⁹⁴

A particular problem arises when HIV-positive mothers are unable to pay for their baby's formula. As HIV can be transmitted through breastfeeding, HIV-positive mothers are counseled to use formula milk, if it is affordable, feasible, acceptable, sustainable and safe.¹⁹⁵ A mother of an 18-month-old baby, George, told us,

When I was pregnant I was told to come back for the birth, it would be safer. But I had no money, so I gave birth at home. Afterwards, I asked my neighbor to take the child to the hospital for testing so I could decide [what to do about] breastfeeding.... At [the clinic] they only provide formula for six weeks. I am struggling to get milk and porridge [cereal-based food for older babies].¹⁹⁶

User fees and lack of information on health costs

Under the current health finance policy, patients pay only a nominal fee for medical care at lower-level public health facilities. This so-called "10/20 policy," which was instituted in 2004, requires patients to pay a fee of KSh10 (appr. US\$0.13) at dispensaries and a fee of KSh20 (appr. US\$0.26) at health centers.¹⁹⁷ Health services

¹⁹³ Human Rights Watch interview with grandmother of Albert, age three, living in IDP camp, Mathare slum, Nairobi, August 13, 2008.

¹⁹⁴ Human Rights Watch interview with nurse in HIV clinic, Mathare slum, Nairobi, August 14, 2008.

¹⁹⁵ However, UNICEF and other UN agencies recommend exclusive breastfeeding for HIV-infected women for the first six months of life if replacement feeding is not acceptable, feasible, affordable, sustainable, and safe. UNICEF, "UNICEF policy on Infant feeding and HIV," undated, http://www.unicef.org/media/media_41250.html (accessed October 28, 2008).

¹⁹⁶ Human Rights Watch interview with mother of George, age 18 months, Mathare slum, Nairobi, August 13, 2008.

¹⁹⁷ National Coordinating Agency for Population and Development (NCAPD), Ministry of Health (MOH), Central Bureau of Statistics (CBS), ORC Macro, Kenya Service Provision Assessment Survey 2004, Nairobi, Kenya 2005, http://www.measuredhs.com/pubs/pub_details.cfm?ID=561&srchTp=advanced (accessed July 4, 2008), p. 24; Rob Yates, "DFID Health Resource Center, International Experiences in Removing User Fees for Health Services – Implications for Mozambique," June 2006, http://www.dfidhealthrc.org/publications/health_sector_financing/o6Yates01.pdf (accessed September 9, 2008), pp. 4-8.

for children under the age of five should be free under the current policy.¹⁹⁸ Current health policies aim to reduce user fees for patients, including at higher-level health facilities, and aim to strengthen other health financing systems, such as exemptions, pre-payment schemes, and insurance.¹⁹⁹

The government controls a little more than half of Kenya's health facilities; the rest are run by missions, NGOs, and other private organizations. About 40 percent of Kenya's health services are delivered by church-based health facilities, with Roman Catholic and Protestant churches managing roughly equal numbers of health facilities. While these church-based health services are not-for-profit, they charge higher user fees than many public facilities, since they have no state subsidies to rely upon.²⁰⁰ User fees are significantly higher still at private, for-profit facilities.

Some government facilities also continue to charge higher fees than intended by policy. A study found that four in ten facilities charge some form of user fee for sick child services; 15 percent of those facilities were government-managed.²⁰¹ A waiver system for poor patients does exist but is not functional.²⁰²

In 2006, the government made antiretroviral treatment free of charge. This has been a major step forward in helping people get on treatment.²⁰³ Medicines for malaria, and for all sexually transmitted diseases, are also free for everyone.

But medicines for many opportunistic diseases and pain relief have to be paid for. An HIV-positive woman caring for her five-year-old infected daughter in Turbo, Rift Valley province, told us,

¹⁹⁸ Kenya Service Provision Assessment Survey 2004, p. 77.

¹⁹⁹ Ministry of Health, "The Second National Health Sector Strategic Plan of Kenya (NHSSP II 2005-10)," May 2005, <http://www.health.go.ke/hpdcon.htm> (accessed October 28, 2008).

²⁰⁰ Human Rights Watch interview with Peter Ngare, Christian Health Association in Kenya (CHAK), Nairobi, August 20, 2008.

²⁰¹ Kenya Service Provision Assessment Survey 2004, p. 77.

²⁰² Center for Reproductive Rights and Federation of Women Lawyers Kenya, *Failure to Deliver. Violations of Women's Human Rights in Kenyan Health Facilities* (New York/Nairobi: Center for Reproductive Rights and Federation of Women Lawyers Kenya, 2007). For current efforts to reform health financing, see GTZ, "Strategy for German-Kenyan Cooperation in the priority area health in the sub-sectors Reproductive and Sexual Health and Health Financing," November 2003, <http://www.gtz.de/de/dokumente/en-strategy-health-kenya.pdf> (accessed July 4, 2008).

²⁰³ "Kenya to provide free AIDS drugs," *BBC.com*, June 2, 2006, <http://news.bbc.co.uk/2/hi/africa/5040240.stm> (accessed July 4, 2008).

Sometimes at the clinic, the treatment there is not so good. We are asked to pay small [amounts] for when there is an extra disease, for example. Asked for payment for this and that.... when these other diseases [malaria and other infections] rose up, we had to pay for the medicines.²⁰⁴

Patients are typically charged for CD4 cell count and other baseline tests that are done prior to starting antiretroviral treatment; these include a liver function test, a tuberculosis test, and a hemoglobin test. We were given contradictory information about the cost of these tests: the lowest figure, provided by staff at Kenyatta National Hospital (a public hospital) in Nairobi, was KSh100 (appr. US\$1.30) for in-patients and outpatients.²⁰⁵ However, several interviewees told us that patients had to pay significantly more for tests, up to KSh1,600 (appr. US\$20).²⁰⁶

As a result of the complex and sometimes inconsistent user fee policy, patients often assume that they have to pay for health services, even when the services are free or cost relatively little. Many people are also unaware that antiretroviral drugs are now available for free.²⁰⁷ The misperception that they will have to pay can keep people from seeking health services.

²⁰⁴ Human Rights Watch interview with mother of Liliane, age five, Turbo, Uasin Gishu district, Rift Valley province, August 20, 2008.

²⁰⁵ Human Rights Watch interview by Kenyan journalist with doctors at Kenyatta National Hospital, Nairobi, September 2008.

²⁰⁶ Human Rights Watch interview with health worker, Kisumu, August 15, 2008.

²⁰⁷ Human Rights Watch interview with nurse in HIV clinic, Mathare slum, Nairobi, August 14, 2008.

V. Treatment Access during the 2008 Post-Election Violence

Between late December 2007 and February 2008, Kenya experienced serious political and ethnic violence. The violence was triggered by election fraud and controversy over the results of the presidential elections that took place on December 27, 2007. In response to opposition protests, police used excessive force against demonstrators and killed and wounded hundreds of citizens. Opposition supporters committed serious acts of violence against members of the Kikuyu ethnic group—the country’s largest ethnic group—suspected of voting for President Kibaki’s Party of National Unity (PNU); and Kikuyu militias carried out violent attacks against Luo, Kalenjin, and other communities viewed as opposition supporters.²⁰⁸ Over 1,000 people were killed. At least 300,000 people were displaced, possibly many more; an estimated 100,000 children were displaced.²⁰⁹

Impact of Post-Election Violence on the Health Sector and on ART

The violence had a direct impact on those in need of health care. Many health workers fled their workplaces or were unable to return, due to threats against them and members of their ethnic group.²¹⁰ At the same time, the post-election violence greatly increased the need for medical care, due to injuries and sexual violence.²¹¹

²⁰⁸ Human Rights Watch, *Ballots to Bullets: Organized Political Violence and Kenya’s Crisis of Governance*, March 2008, vol. 20, no. 1 (A), <http://hrw.org/reports/2008/kenyao308/>.

²⁰⁹ “Kenyan post-election violence displaces over 100,000 children,” UN News Center, January 17, 2008, <http://www.un.org/apps/news/story.asp?NewsID=25328&Cr=kenya&Cr1=unicef> (accessed September 22, 2008). According to the Kenyan Red Cross, 300,000 persons lived in IDP camps. However, others who fled their homes lived outside the camps, that is, with relatives in their home areas. Wilfred Ndolo, director of migration and resettlement in the Ministry of State for Special Programs, estimates that the total number of IDPs might have been around 650,000. Human Rights Watch interview with Wilfred Ndolo, Nairobi, August 12, 2008. According to UNHCR, an estimated 11,000 persons fled into neighbouring Uganda and another 1,000 to Tanzania; their situation is not dealt with in this report.

²¹⁰ AMREF, “Post election violence leads to humanitarian emergency in Kenya,” January 7, 2008, <http://uk.amref.org/news/postelection-violence-leads-to-humanitarian-emergency-in-kenya/> (accessed September 23, 2008); HERAF, “The Right to Health: The aftermath of the post election violence,” January 10, 2008, <http://physiciansforhumanrights.org/library/documents/statements/heraf-post-election-statement.pdf> (accessed September 22, 2008).

²¹¹ “Post elections violence report: More than 400 sexually abused,” The Gender & Governance Program in Kenya, <http://www.gendergovernancekenya.org/featured/78> (accessed September 23, 2008).

At this writing, health facilities continue to be plagued by the absence of health workers who fled.²¹² In addition, it has been reported that ethnic tensions have increased in some health facilities. For example, patients have complained that health workers give preference to patients from their own ethnic group, and have avoided seeking treatment from health workers who are not of their own ethnic group.²¹³ A Kikuyu woman caring for her five-year-old HIV-positive granddaughter described her experience in the Rift Valley:

The staff are Nandi or Kalenjin... The time it takes, sometimes we wait for hours, while the Kalenjin show up and get seen right away. This is because they [the Kalenjin] are running the clinics. For example, yesterday I was at the clinic and had to wait there for six hours before I got treated. Others that came in long after I did got their treatment before me. It is not fair.²¹⁴

At the start of the violence, many patients on antiretroviral treatment—whether displaced or not—stopped their treatment. In early January 2008 the Academic Model for the Prevention and Treatment of HIV (AMPATH) reported that only 5 percent of its patients in the Rift Valley had come to refill their prescriptions for antiretroviral drugs.²¹⁵ Patients in the poorer areas of Nairobi also stopped taking their drugs.²¹⁶ MSF-Belgium found that the default rate of their patients in Mbagathi and Kibera doubled in January.²¹⁷ In some parts of the country, supply chains were interrupted, and antiretroviral drugs were unavailable. This was the case in Bondo district, where several children died when their ART was interrupted. A mother told Human Rights Watch researchers about the death of her son, Andrew, who died in March 2008:

²¹² Human Rights Watch interview with Kenny Rogers, UN OCHA, Eldoret, August 19, 2008.

²¹³ “Kenya: Drug resistance risk as displaced ARV patients skip ARV doses,” *PlusNews*, January 17, 2008, <http://www.plusnews.org/Report.aspx?ReportId=76288> (accessed October 19, 2008); Human Rights Watch interview with HIV-positive woman, former resident of Burnt Forest camp, Uasin Gishu district, Rift Valley province, August 21, 2008.

²¹⁴ Human Rights Watch interview with mother of Liliane, age five, Turbo, Uasin Gishu district, Rift Valley province, August 20, 2008.

²¹⁵ “Kenya: Drug resistance risk as displaced ARV patients skip ARV doses,” *PlusNews*.

²¹⁶ “HIV treatment in times of civil strife: Serious threats to antiretroviral drug access in the Kibera slum following the Kenyan elections,” *AIDS*, vol. 22, no. 13, 2008, pp. 1693-1694; Human Rights Watch interviews with HIV-positive mothers and guardians of HIV-positive children in Mathare slum, Nairobi, August 13, 2008.

²¹⁷ Human Rights Watch interview with representatives of MSF-Belgium, Nairobi, August 13, 2008.

During the post-election violence, there were no drugs. The roads were blocked. Nevertheless I took [Andrew] to Bondo [district hospital] but he passed away. I went twice to Bondo during the violence but there were no drugs. The third time I went there, he was given the treatment. That was in late February. But he died after a week. He had herpes, and his body was swollen all over.... During the crisis I also met two other women in Bondo hospital whose children passed away because they could not get ARV. They came from elsewhere in Bondo district.²¹⁸

At present, there are no figures available on the total number of AIDS deaths due to the post-election violence.

The Emergency Response Treatment in IDP and Transit Camps

According to government figures, an estimated 21,000 people living with HIV were displaced; the real figure might be considerably higher.²¹⁹ The initial situation in the camps was dire, as many people living with HIV had stopped taking their drugs or were otherwise in need of health care. According to a UNICEF worker,

Health generally was a problem in the camps at first because people were afraid to access services outside of the camps. But once the camps got established, the health services were there.²²⁰

Lack of health care during the crisis affected those on ART, and also pregnant women in need of PMTCT. Some patients on ART stopped taking it due to lack of food, and babies were breastfed because there was no formula available.²²¹ An HIV-positive

²¹⁸ Human Rights Watch interview with mother of Andrew, who died age six in March 2008, Nyangoma, Bondo district, Nyanza province, August 18, 2008. The children were two girls, ages six and seven.

²¹⁹ United Civil Society Coalition for AIDS, TB and Malaria (UCCATM), "HIV&AIDS: Impact of Post-election violence," PowerPoint presentation at NACC conference, February 4, 2008, unpublished document, on file with Human Rights Watch.

²²⁰ Human Rights Watch interview with UNICEF staff member, Eldoret. August 19, 2008.

²²¹ Human Rights Watch interview with representative of Kenyan Red Cross, Nairobi, August 14, 2008; see also statement from Margaret Wambete at the 17th International AIDS conference in Mexico, quoted in "Conflicts Make Women More Vulnerable to HIV conference told," *Womensphere*, <http://womensphere.wordpress.com/2008/08/11/conflicts-make-women-more-vulnerable-to-hiv-conference-told/> (accessed September 23, 2008). Civil society organizations expressed serious concern about the situation at the time. See, for example, HERAF, "The Right to Health"; "Post election crisis threatens gains made in fighting HIV and AIDS," UCCATM press release, January 29, 2008.

mother, who already has an older child living with HIV, told us about the lack of PMTCT programs:

My youngest girl [Helen] is now six-and-a-half months old, she was born on February 4 of this year, and at that time, I was living in the [Burnt Forest IDP] camp. At that time there was no one really working at the hospital here, so I gave birth inside a tent in the camp.²²²

A teacher leading a support network for HIV-positive teachers in Eldoret described her efforts to get ART into the camps and remembered the situation of people living with HIV:

We lost about 10 persons during that time because of lack of care. Those left had to fend for themselves.... Some refused to take their drugs because the food rations were not enough.²²³

One of the problems at the start of the post-election violence was the absence of any civil emergency plan.²²⁴ Once the crisis happened, though, the government and many agencies took action to address the situation, and did succeed in getting patients back on treatment. The emergency response was coordinated through a national-level humanitarian services committee, and through health clusters at each camp.²²⁵ While the Kenyan Red Cross was the lead agency providing food and organizing camp management, the Ministry of Health and international agencies led the organization of health care.²²⁶ The Kenya Red Cross set up some HIV support groups in camps.²²⁷ Local NGOs and churches also mobilized.²²⁸ The actors involved

²²² Human Rights Watch interview with mother of Helen, age six months, Burnt Forest, Uasin Gishu district, Rift Valley province, August 21, 2008. At the time of the interview she was awaiting the test results for Helen.

²²³ Human Rights Watch interview with Margaret Wambete, Teachers Living Positively, Eldoret, August 21, 2008.

²²⁴ Human Rights Watch interview with representatives of HERAF, Nairobi, August 12, 2008; Human Rights Watch interview with representatives of MSF-Belgium, Nairobi, August 13, 2008; "Post election crisis threatens gains made," UCCATM press release.

²²⁵ Human Rights Watch interview with Wilfred Ndolo, Nairobi, August 12, 2008.

²²⁶ Among the international agencies involved were AMPATH, Médecins Sans Frontières, International Medical Corps, and Medical Emergency Relief International (MERLIN).

²²⁷ Human Rights Watch interview with representative of Kenyan Red Cross, Eldoret, August 19, 2008.

set up permanent clinics in larger IDP camps and organized mobile clinics in smaller camps. The government and agencies also used the radio, newspapers, posters, and other publicity tools to encourage patients to seek treatment at their nearest health facility. Médecins Sans Frontières (MSF) launched a hotline for people who had defaulted on their treatment and did not know what to do.²²⁹

In the Rift Valley, AMPATH played a crucial role; it has about 30,000 patients enrolled in its antiretroviral treatment program, 3,000 of them children. At ASK Showground IDP camp in Eldoret, the Ministry of Health established a dispensary; AMPATH also set up an HIV/AIDS clinic in the camp. AMPATH also ran a mobile clinic operating in camps and other locations of the Rift Valley, the region where it is based, and carried out tent-to-tent testing in some camps.²³⁰

According to AMPATH, many patients who fled without their medication were able to get back on treatment within a few weeks at most.²³¹ But despite the rapid scale-up of HIV/AIDS-related services in the camps, patients continue to suffer from several HIV-related problems. Food in the camps is sometimes insufficient and not of the kind needed by patients on ART.²³² Another problem is the lack of blankets, warm clothing, and mattresses to protect the displaced against the cold and wet climate in some parts of the Rift Valley. As a result of these living conditions, many displaced suffer from frequent illnesses.²³³ People with immune systems compromised by HIV

²²⁸ Human Rights Watch interview with Margaret Wambete, August 21, 2008.

²²⁹ Human Rights Watch interview with representatives of MSF-Belgium, Nairobi, August 13, 2008. Perhaps not surprisingly, the secretary-general of the International Federation of Red Cross and Red Crescent Societies has praised his organization's response to the crisis as a success. International Federation of Red Cross and Red Crescent Societies, *World Disasters Report. Focus on HIV and AIDS*, <http://www.ifrc.org/Docs/pubs/disasters/wdr2008/WDR2008-full.pdf> (accessed October 8, 2008), pp.8-9, 134-135.

²³⁰ Human Rights Watch interviews with AMPATH clinical officer, Turbo, Uasin Gishu district, August 20; and IDP camp manager, Kenyan Red Cross, Eldoret ASK Showground IDP camp, August 19, 2008; "Turmoil disrupts AIDS care in Kenya," *Bulletin of the WHO*, vol. 86, no. 3, March 2008, <http://www.who.int/bulletin/volumes/86/3/08-030308.pdf> (accessed September 22, 2008), pp. 168-169.

²³¹ Human Rights Watch interview with Winstone Nyandiko, associate program manager, AMPATH, Eldoret, August 19, 2008. This was confirmed by the mother of an HIV-positive girl in Eldoret ASK Showgrounds IDP camp who managed to get the girl back on treatment after about one week of interruption, thanks to AMPATH intervention in the camp. Human Rights Watch interview with mother of Judith, age 12, Eldoret ASK Showgrounds IDP camp, August 19, 2008.

²³² Human Rights Watch group interview with members of HIV support group in Eldoret ASK Showgrounds IDP camp, August 19, 2008; "Kenya: Camp conditions harsh for HIV-positive displaced people," *PlusNews*, April 29, 2008, <http://www.plusnews.org/Report.aspx?ReportId=77973> (accessed September 23, 2008).

²³³ Human Rights Watch group interview with members of HIV support group in Eldoret ASK Showgrounds IDP camp, August 19, 2008; Human Rights Watch interview with representative of Kenyan Red Cross, Eldoret, August 19, 2008.

are even more vulnerable to these secondary infections. The mother of a two-year-old HIV-positive girl, Dora, told us about Eldoret ASK Showgrounds IDP camp:

Things are not working here in the showgrounds. There is no money for me to buy fruits and other balanced diet items for [Dora], so I am not getting a balanced diet for her. It is cold at night in our tent, so the risk is there for her or me to get sick.²³⁴

Another problem in the camps is the lack of privacy. As a result of congestion, people's movements can be easily monitored, and some have been afraid to be tested, seek treatment, or take their drugs.²³⁵

Operation Rudi Nyumbani and the healthcare situation in transit camps

On May 5, 2008, the Kenyan government launched "Operation Rudi Nyumbani" (Return Home), a program to return internally displaced people to their home areas. In contravention of international standards for the protection of IDPs, many displaced were forced to return.²³⁶ Those IDPs who returned home often found that their houses had been burnt or were occupied, and many of them are currently squatting or living in some kind of provisional arrangement.²³⁷ Ethnic tensions have also sometimes persisted and make reintegration of displaced people difficult.²³⁸

As many were afraid to go home or had nowhere to go as their homes and belongings had been destroyed, so-called transit camps started to spread across the Rift Valley. These were smaller camps that people moved to after they were told to leave the IDP camps. By September 2008, only 12,000 people remained in 26 camps

²³⁴ Human Rights Watch interview with mother of Dora, age two, Eldoret ASK Showgrounds IDP camp, August 19, 2008.

²³⁵ Human Rights Watch group interview with members of HIV support group in Eldoret ASK Showgrounds IDP camp, August 19, 2008; "Kenya: Camp conditions harsh for HIV-positive displaced people," *PlusNews*.

²³⁶ "Kenya: Stop Forcing Displaced People to Return Home," Human Rights Watch news release, May 22, 2008, <http://hrw.org/english/docs/2008/05/22/kenya18922.htm>.

²³⁷ Human Rights Watch interviews with former camp residents in Turbo, Uasin Gishu district, Rift Valley province, August 20, 2008; and in Burnt Forest, Uasin Gishu district, August 21, 2008.

²³⁸ Human Rights Watch interview with Kenny Rogers, August 19, 2008.

in Rift Valley province, but another 100,000 displaced people were living in 160 transit sites near their home areas.²³⁹

While the larger IDP camps had on-site medical care, smaller IDP camps and transit sites usually lack such services and require patients to go to ordinary district- and sub-district-level health facilities.²⁴⁰ As many displaced persons do not know the area, and sites are not always strategically located, this sometimes means long travel distances to the nearest health facility. Sometimes international agencies pay transport costs for patients, but this does not reach all people affected. A Red Cross representative found,

The challenge for people in the transit camps is that some are now far from the clinics and dispensaries, especially where such services were provided for them in the IDP camps themselves before. So in some cases we have found that people have stopped taking their medications again. We have contacted AMPATH to do transit site visits to see how people are doing in the camps.²⁴¹

In June 2008 the government and several agencies observed that “currently a formal strategy on the provision of assistance to transit camps is not in place.”²⁴² The government reported that “there are no funds for the establishment and delivery of basic services in transit camps.”²⁴³ This situation in transit camps was still of

²³⁹ USAID, “Kenya – Complex Emergency,” September 17, 2008, [http://www.reliefweb.int/rw/RWFiles2008.nsf/FilesByRWDocUnidFilename/Y SAR-7JKMPZ-full_report.pdf/\\$File/full_report.pdf](http://www.reliefweb.int/rw/RWFiles2008.nsf/FilesByRWDocUnidFilename/Y SAR-7JKMPZ-full_report.pdf/$File/full_report.pdf) (accessed October 8, 2008).

²⁴⁰ Margaret Aguirre, “A New Emergency in Kenya,” June 24, 2008, <http://www.imc-la.com/content/article/detail/1826/> (accessed October 8, 2008); Central Emergency Response Fund, “CERF allocates \$1.5 million to support displaced persons in Kenya,” <http://ochaonline.un.org/CERFaroundtheWorld/Kenya2008/tabid/3519/language/en-US/Default.aspx> (accessed October 8, 2008).

²⁴¹ Human Rights Watch interview with representative of Kenyan Red Cross, Eldoret, August 19, 2008.

²⁴² “Cluster Meeting Nairobi,” June 24, 2008, http://www.humanitarianreform.org/humanitarianreform/Portals/1/cluster%20approach%20page/Kenya/Intercluster%20meeting%20minutes_24_June08.pdf (accessed October 8, 2008).

²⁴³ Ibid.

concern when the Kenyan government announced the closure of all IDP camps by September 30, 2008.²⁴⁴

A particular problem is the situation of children whose parents returned to their home areas without them, as they felt it was not safe for the children to return. These children are highly vulnerable and often not able to get any medical care.²⁴⁵

²⁴⁴ “Kenya: IDPs struggle to rebuild their lives,” *IRIN*, September 30, 2008, <http://www.irinnews.org/report.aspx?ReportId=80665> (accessed October 8, 2008).

²⁴⁵ Human Rights Watch interview with IDP camp manager, Kenyan Red Cross, Eldoret ASK Showground IDP camp, August 19, 2008; “Kenya: Separated children eking a living in Rift Valley town,” *IRIN*, September 10, 2008, <http://www.reliefweb.int/rw/rwb.nsf/db900sid/ASAZ-7|CHDS?OpenDocument&rc=1&cc=ken> (accessed November 11, 2008).

VI. First Adults, Then Children? Government Health and Protection Policies

Pediatric HIV Policies and Practice in Kenya

HIV policies have failed to address the special needs of children. Over the past two years, donors and the government have started to initiate measures aimed at improving access to treatment for children, but far more needs to be done.

While the need for PMTCT as a prevention mechanism has been recognized for many years, pediatric treatment is often approached as a secondary concern. A medical doctor noted, “Pediatric programs started about one year ago [2006]. Until then, children were ignored. Some thought that children should not get on ARV.”²⁴⁶

Until recently, there was an assumption that children on ART would still die before adulthood. A pediatrician specializing in HIV explained that many people asked, “Is it worth it? Does this only add five years more [to a child’s life]?”²⁴⁷ When the Clinton Foundation came to Kenya in 2005, there were only about 1,500 children on treatment, and only in donor-funded facilities. There were few discussions about the situation of children within the Health Ministry’s National AIDS and STD Control Programme (NAS COP). As the local head of the Clinton Foundation put it, this lack of attention represented a “huge gap” in the country’s HIV/AIDS policy.²⁴⁸

The current Kenya National HIV/AIDS Strategic Plan still does not mention the importance of ensuring that children get access to treatment. It does mention children in the context of PMTCT; HIV/AIDS and sex education when entering adolescence; and protection of orphans and other vulnerable children.

²⁴⁶ Human Rights Watch interview with Dr. Bactrin Kilingo, Kenya Hospice and Palliative Care Association, Nairobi, Nairobi, August 6, 2007.

²⁴⁷ Human Rights Watch interview with Prof. Dorothy Ngacha, Kenyatta National Hospital. Department of Pediatrics, August 20, 2008.

²⁴⁸ Human Rights Watch interview with Gerald Macharia, country director of the Clinton Foundation, Nairobi, August 20, 2008.

Despite this gap, change is finally underway. The government has acknowledged its failure to do enough for pediatric treatment. In July 2007 the then director of medical services in the Ministry of Health, Dr. Nyikal, recognized that more than 90 percent of children living with HIV cannot access antiretroviral drugs because of difficulties in diagnosis, unavailability of pediatric formulations, and other issues.²⁴⁹ Recent policy measures to improve pediatric testing and treatment include: routine offers of testing for infants of HIV-positive mothers or mothers whose HIV status is unknown; making cotrimoxazole more widely available; scaling up pediatric treatment at lower-level health facilities; and routinely treating all HIV-positive infants with ART. Still, progress regarding pediatric HIV lags behind. An official in the Ministry of Health observed self-critically, “We have met every single target we have set ourselves for adults, despite the election violence. But on children we don’t reach the targets.”²⁵⁰

In that regard, it is indicative that the country’s major AIDS survey, the Kenya AIDS Indicator Survey, published in July 2008, excludes data about children under age 15 entirely.²⁵¹

The need to reach more pregnant women for PMTCT programs

In the past few years there has been a significant scale-up of PMTCT programs in Kenya, as part of the National HIV/AIDS Strategic Plan.²⁵² In 2007 about 800,000 pregnant women were tested, of a total of about 1.2 million pregnant women. About 57,000 pregnant women tested HIV-positive.²⁵³

²⁴⁹ John Oywa, “Kenya: ARVs Inaccessible to Children, Says Nyikal,” *The East African Standard* (Nairobi), July 19, 2007, <http://allafrica.com/stories/200707181436.html> (accessed October 13, 2008).

²⁵⁰ Human Rights Watch interview with Dr. Lyndon Marani, ART program manager, NASCOP, Ministry of Health, Nairobi, August 13, 2008.

²⁵¹ Ministry of Health, NASCOP, “Kenya AIDS Indicator Survey, preliminary report,” July 2008.

²⁵² National AIDS Control Council, “Kenya National HIV/AIDS Strategic Plan 2005/6 – 2009/10. A Call to Action,” June 2005, www.nacc.or.ke/downloads/KNASP_2005-2010_Final_Report.doc (accessed November 11, 2008), p. 22; “Kenya: Government introduces combination therapy for PMTCT,” *PlusNews*, December 4, 2006, <http://www.plusnews.org/report.aspx?reportid=62708> (accessed September 27, 2007); Pathfinder International, “Preventing Mother-to-Child Transmission in Kenya,” June 2005, <http://www.pathfind.org/site/DocServer/Pathfinder.PMTCT4-lite.pdf?docID=4041> (accessed November 10, 2008), p. 23; National AIDS Control Council, *UNGASS 2008: United Nations General Assembly Special Session on HIV and AIDS, Country Report - Kenya*, 2008, http://data.unaids.org/pub/Report/2008/kenya_2008_country_progress_report_en.pdf (accessed September 16, 2008).

²⁵³ Human Rights Watch interview with Dr. Lyndon Marani, ART program manager, NASCOP, Ministry of Health, Nairobi, August 13, 2008; National AIDS Control Council, *UNGASS 2008*, p. 21. There are now over 1,000 PMTCT sites.

But many women are still not reached. An estimated 40 percent of HIV-positive women do not participate in PMTCT programs.²⁵⁴ Those who give birth at home might not participate in PMTCT programs; if they do, there is little control over whether they take the Nevirapine prescribed to them.²⁵⁵ Some women might not participate in PMTCT programs due to stigma and fear of disclosure.²⁵⁶

In many cases, there is no follow up from PMTCT programs even when a woman has been found to be HIV-positive. A medical doctor working in an HIV program in Mombasa remarked that there is sometimes no connection between antenatal and postnatal care: “Women are coming in sometimes for services after their children are born, but at that point, they may not get the child tested.”²⁵⁷

Such lack of monitoring leaves many HIV-positive children with no medical help. Some donor agencies have recognized this and started what is called “PMTCT Plus” programs, which offer ART to the HIV-positive mother, the child, and other family members.²⁵⁸ Most health facilities do not use such an integrated approach yet. However, a first step has been made in linking PMTCT and infant testing.

The need to improve pediatric testing policies

Infant testing—promising policies that need to be implemented

As AIDS kills 50 percent of infected children before their second birthday, infant testing is a vital first step toward treatment. The Kenyan government’s new infant testing policies are promising, but still need to be implemented in large parts of the country.

²⁵⁴ Human Rights Watch interview with Dr. Mukui, ART programme officer, NASCOP, Ministry of Health, Nairobi, August 14, 2008. Coverage with antenatal clinics is about 88 percent. WHO, UNAIDS, UNICEF, *Towards Universal Access: Scaling up priority HIV/AIDS interventions in the health sector - Progress Report 2008*, http://www.who.int/hiv/pub/towards_universal_access_report_2008.pdf (accessed October 13, 2008), p. 84.

²⁵⁵ In the first half of 2007, about 52 percent of HIV-positive pregnant women did take Nevirapine. NACC, “UNGASS 2008, Country Report – Kenya,” p. 21.

²⁵⁶ Janet Fleischman, “Strengthening HIV/AIDS Programs for Women; Lessons for U.S. Policy from Zambia and Kenya,” 2005, Center for Strategic and International Studies; Pathfinder International, “Preventing Mother-to-Child Transmission.”

²⁵⁷ Human Rights Watch interview with Dr. Luchters, International Center for Reproductive Health, Mombasa, August 13, 2007.

²⁵⁸ The German HIV Peer Review Group, “Prevention of Mother-to-Child-Transmission of HIV”; International Center for AIDS Care and Treatment Programs, “MTCT-Plus Initiative,” <http://www.columbia-icap.org/whatwedo/mtctplus/index.html> (accessed October 13, 2008).

Up until 2006, the large majority of health facilities did not test infants and told parents to wait until the child reached 18 months. A study carried out in 2005 found that none of the 58 health facilities visited had copies of the national guidelines for HIV testing in clinical settings or in-house guidelines on testing children.²⁵⁹

The only reliable method to carry out an HIV test on a child under 18 months old is by PCR, a complicated and costly method.²⁶⁰ There are only a few PCR testing stations in Kenya. In the past two years, a network for the collection and referral of blood samples has been established, allowing any health facility to use the PCR stations.²⁶¹ The Clinton Foundation has funded PCR machines as well as the logistical support needed to provide dry blood spot testing (small samples of blood are collected, spotted and dried on paper, and sent to laboratories in Kenya), including safe and speedy transport of the specimens.²⁶² However, sometimes PCR test results take longer than expected to come back to healthcare providers, and patients come in vain to their health center to ask for the result.²⁶³ Staff also sometimes lack training to collect dry blood spot specimens for PCR testing.²⁶⁴

In a policy circular in mid 2007, the Ministry of Health took the important step of requiring that routine testing be offered for infants who are born to HIV-positive mothers or to mothers whose HIV status was unknown.²⁶⁵ All such infants are to be tested at 6 weeks, 12 months, and 18 months, if the mother (or other caregiver) consents. This policy is an important step toward saving children's lives.²⁶⁶ In the words of Dr. Nyikal, now permanent secretary in the Ministry of Health, "We need to

²⁵⁹ Peter Cherutich et al., "Optimizing pediatric HIV care in Kenya: challenges in early infant diagnosis," *Bulletin of the World Health Organization*, vol. 86, no. 2, February 2008, <http://www.who.int/bulletin/volumes/86/2/07-040402/en/index.html> (accessed September 16, 2008).

²⁶⁰ *Ibid.*

²⁶¹ *Ibid.*

²⁶² Human Rights Watch interview with Gerald Macharia, August 20, 2008.

²⁶³ Human Rights Watch interview with representatives of MSF-Belgium, Nairobi, August 13, 2008.

²⁶⁴ Cherutich et al., "Optimizing pediatric HIV care," *Bulletin of the World Health Organization*.

²⁶⁵ National STI/AIDS Control Program, "Algorithm for Early Infant Diagnosis for HIV-Exposed Children," (Nairobi: Ministry of Health, 2007).

²⁶⁶ Matthew Chersich and Marlise Richter, "HIV testing and ARV prophylaxis for newborns without their mothers' consent," *The Southern African Journal of HIV Medicine*, Autumn 2008. The article is followed by a rebuttal.

link child treatment to PMTCT, and this is the best way to recruit children. The loop has to be made. It has not been made enough.”²⁶⁷

While this policy is a step in the right direction, the practice on the ground is changing only slowly. According to an official in the Ministry of Health, about 25 percent of facilities currently offer infant testing.²⁶⁸ During a Human Rights Watch visit to a dispensary in Bondo district, Nyanza province, medical staff explained that the clinic did not routinely offer HIV testing for infants at six weeks, and seemed unaware of the Ministry’s policy.²⁶⁹

Another challenge is the issue of parental consent. For a mother, the HIV test on her infant amounts to disclosure of her own status. Counselors and medical staff have the important task of ensuring that proper consent is being sought and avoiding accidental disclosure of a woman’s HIV status to her husband or other relatives.²⁷⁰ Community health workers and other staff need to explain to mothers the implications of refusing a test for their child. Yet they have to do so without undue pressure, rather aiming to convince the mother in order to engage her in the process of providing health care for her child.

Insufficient attention to testing older children and adolescents

As explained Chapter IV, older children are taken less often than younger children for testing as caregivers are afraid of the child’s questions, and assume children are HIV-negative unless they show signs of illness. This situation is further complicated by the current guidelines on voluntary testing and counseling, which stipulate that anyone under the age of 18 needs parental consent for testing. Adolescents over the age of 15 can only be tested without parental consent under certain circumstances. According to the government’s guidelines,

²⁶⁷ Human Rights Watch interview with Dr. Nyikal, permanent secretary, Ministry of Health, Nairobi, August 20, 2008.

²⁶⁸ Human Rights Watch interview with Dr. Mukui, August 14, 2008.

²⁶⁹ Human Rights Watch interview with nurse-in-charge, Uywai dispensary, Nango, Bondo district, Nyanza province, August 18, 2008.

²⁷⁰ Joanne Csete and Richard Elliott, “Scaling up HIV testing: human rights and hidden costs,” *HIV/AIDS Policy & Law Review*, vol. 11, no. 1, April 2006; C. Hamilton et al., “Potential for abuse in the VCT counseling room: service provider’s perception in Kenya,” *Health Policy and Planning*, August 13, 2008.

Young people under 18 who are married, pregnant, parents, engaged in behavior that puts them at risk or are child sex workers should be considered “mature minors” who can give consent for VCT, although the counselor should make an independent assessment of the minor’s maturity to receive VCT services.²⁷¹

The expression “mature minor” is not defined further in the guidelines, but many health facilities have interpreted the guidelines to mean that testing children over the age of 15 without their parents’ consent should be an exception.²⁷² Children under the age of 15 are even less likely to get a test by themselves, as the guidelines recommend that “testing of minors under 18 who are not mature minors, especially those under 15, should be done with the knowledge and participation of their parents or guardians.”²⁷³ A VCT counselor in a rural area commented on the guidelines,

This VCT policy is a challenge to us.... We have a situation where it is quite possible that the child is HIV-positive because he or she is showing signs. But the caregiver is not there yet, not ready for the child to be tested, so how to help this child? We continue counseling the caregiver but it doesn’t always work or the caregiver doesn’t come back. This leaves me in a difficult place, this is why these guidelines are problematic.²⁷⁴

The current regulations discourage testing of children and adolescents who do not wish to speak to their parents about the test. This may be due to lack of trust between the child and the caregiver, or taboos around sexuality. Human Rights Watch takes the position that all such children, without restriction, should be able to

²⁷¹ National AIDS and STD Control Programme, “National guidelines for voluntary counseling and testing,” 2001, p. 5. The guidelines are currently under review; changes with regard to the issue of parental consent are not expected. The HIV/AIDS Prevention and Control Act, which is yet to be agreed upon and become law, has similar language on testing children.

²⁷² Some health providers interpret current testing guidelines to mean that mature minors can only be tested in centers where ART is available. Human Rights Watch interview with counselor at VCT, Unga, Siaya district, Nyanza province, August 3, 2007.

²⁷³ National AIDS and STD Control Programme (NASCO), “National guidelines for voluntary counseling and testing,” (Nairobi: Ministry of Health, 2001), p. 5.

²⁷⁴ Human Rights Watch interview with counselor at VCT, Unga, Siaya district, Nyanza province, August 3, 2007.

exercise their right to information about their own health and be able to get tested for HIV at least from age 15 onwards, and possibly earlier (from age 12), depending on their cognitive and emotional maturity.²⁷⁵

Tuungane Center in Kisumu provides prevention, HIV testing, and treatment for youth under one roof. Most youth come to the center by themselves, without adult supervision.²⁷⁶ Over 3,000 young people between the ages of 13 and 21 have tested there.²⁷⁷ There are similar services in other major urban areas but nowhere else. Many health services are often not geared toward the situation of adolescents, and adolescents avoid going to general health centers.²⁷⁸ Counselors in VCT centers are not always equipped to respond to the situation of adolescents adequately. A pediatrician described the situation of adolescents as “no man’s land.”²⁷⁹

The need to improve treatment of HIV-positive children

Treatment with antibiotics—a life saver that must be universally available

Progress has been made in rolling out treatment with the antibiotic cotrimoxazole, but the drug is still not reaching all children living with HIV. Until recently, the importance of cotrimoxazole prophylaxis for HIV-positive children has been underestimated. It was only in 2006 that the World Health Organization published guidelines on this issue, recommending that all children younger than one year receive cotrimoxazole prophylaxis, regardless of symptoms or the CD4 percentage. The WHO also recommended cotrimoxazole as prophylaxis for HIV-positive children between ages one and five under certain conditions.²⁸⁰ The Kenyan government introduced a similar policy shortly after, and during 2007 devoted great efforts to

²⁷⁵ The ability to understand medical treatment and consent to it has sometimes been defined as “Gillick competence.” Gillick competence is a term originating in an English legal case which has been used in several countries to decide whether a child is able to consent to his or her own medical treatment, without the need for parental permission or knowledge, based primarily on the child’s ability to understand the proposed treatment. See *Gillick v West Norfolk and Wisbech Area Health Authority* [1985] 3 All ER 402 (House of Lords).

²⁷⁶ Human Rights Watch interview with counselor at Tuungane Youth Center, Kisumu, August 16, 2008.

²⁷⁷ Kawango Agot et al., “Youth-specific services: A partnership to combine prevention & treatment,” <http://www.faces-kenya.org/publications/tuungane-poster.pdf> (accessed September 17, 2008).

²⁷⁸ Ibid.

²⁷⁹ Human Rights Watch interview with Prof. Dorothy Ngacha, August 20, 2008.

²⁸⁰ WHO, *Guidelines on Co-Trimoxazole Prophylaxes for HIV-related Infections among Children, Adolescents and Adults*, 2006, <http://www.who.int/hiv/pub/guidelines/ctxguidelines.pdf> (accessed October 13, 2008).

make cotrimoxazole widely available.²⁸¹ Between April 2006 and October 2007, availability of cotrimoxazole in Kenya rose from 59 percent to 100 percent in the public sector, and from 81 to 90 percent among mission health facilities.²⁸²

However, the fact that cotrimoxazole is widely available in health facilities does not mean that it reaches all children in need. There are no nationwide figures on cotrimoxazole coverage among HIV-positive children at present; a study was underway in September 2008.²⁸³ According to a UN report, during 2007 only 6 percent of exposed infants were put on cotrimoxazole prophylaxis within two months of birth.²⁸⁴ One of the reasons for this is probably that the infant testing policy has not been widely implemented. This statistic shows the need for integrating HIV testing and treatment into regular pediatric care.

The need for better availability and formulation of pediatric ART

While adult formulations of ART are widely available and easy to use, there are several problems with pediatric formulations. These formulations are not always widely available. Some formulations for children are also difficult to use in resource-low settings.

Adult and pediatric antiretroviral medicines in Kenya are mostly imported from India²⁸⁵ and procured through the Kenya Medical Supplies Agency, the central supply agency for medicines. Mission for Essential Drugs and Supplies (MEDS) is another supply agency that provides medicines to mission health structures. In Kenya, the Clinton Foundation has negotiated prices with drug companies and currently procures all pediatric drugs in Kenya.²⁸⁶ Since 2006, pediatric syrups and pediatric

²⁸¹ Human Rights Watch interview with pharmacist, NASCOP, Ministry of Health, Nairobi, August 9, 2007; Human Rights Watch interview with Chris Ouma, UNICEF, Nairobi, August 6, 2007.

²⁸² Ministry of Health, "Summary Report October 2007," *MMePA (Monitoring Medicine Prices and Availability) Quarterly*, p. 2.

²⁸³ Email to Human Rights Watch from Chris Ouma, UNICEF, September 19, 2008.

²⁸⁴ WHO, UNAIDS, UNICEF, *Towards Universal Access: Scaling up priority HIV/AIDS interventions in the health sector - Progress Report 2008*, http://www.who.int/hiv/pub/towards_universal_access_report_2008.pdf (accessed October 6, 2008), p. 130.

²⁸⁵ Human Rights Watch interview with Gerald Macharia, August 20, 2008; Ranbaxy Laboratories, "Anti HIV/AIDS," <http://www.ranbaxy.com/socialresponsibility/AntiHIV.aspx> (accessed October 13, 2008).

²⁸⁶ Human Rights Watch interview with Gerald Macharia, August 20, 2008.

single pills—which have to be taken in a combination of three drugs—are in principle available in Kenya.²⁸⁷

However some health facilities lack the syrups for small children.²⁸⁸ Others lack pediatric tablets for older children, and simply break up adult tablets. For example, a Roman Catholic health facility in Nyangoma, Bondo district, just started treating children in 2008; health workers there break up adult tablets for children over the age of 10.²⁸⁹ Other health facilities break up adult tablets for children as young as eight.²⁹⁰ This can lead to incorrect dosage as the medicine is not always equally distributed in the tablet.²⁹¹

Both syrups and single pills are impractical. Liquid formulations must be stored in a cool place and are heavy.²⁹² It has therefore been recommended that research be carried out to develop pediatric tablets for dispersal or sprinkle formulations, which can be added to food for small children.²⁹³

Fixed-dose combinations for children have been developed only recently, as the pharmaceutical industry did not consider this a lucrative market. They are gradually being introduced in Kenya.²⁹⁴ A child has to take only two such pills a day, which makes treatment adherence much easier.

²⁸⁷ Human Rights Watch interview with Christa Cepuch, Health Action International, Nairobi, August 8, 2007. In general, supply chains for drugs—through KEMSA and MEDS—do not always work well. There was also a disruption of drug supplies during the post-election violence, as documented above.

²⁸⁸ Human Rights Watch interview with CHAK representative, Nairobi, August 20, 2008. However, there are limited second line drugs for children in syrup formulation (second line drugs are given to patients who are resistant to the ART that is given in the first place).

²⁸⁹ Human Rights Watch interview with nurse, Nyangoma Health Center, Nyangoma, Bondo district, Nyanza province, August 18, 2008.

²⁹⁰ Human Rights Watch interview with aunt of Carolyn, age eight, Kisumu, August 16, 2008.

²⁹¹ American Academy of Pediatrics, “Increasing Antiretroviral Drug Access for Children With HIV Infection,” 2007, <http://aappolicy.aappublications.org/cgi/reprint/pediatrics;119/4/838.pdf> (accessed October 13, 2008).

²⁹² For example, a three-month supply of stavudine, lamivudine, and nevirapine for a 10 kilogram child would weigh almost half as much as the child (4.3 kilograms). American Academy of Pediatrics, “Increasing Antiretroviral Drug Access for Children With HIV Infection.” Syrups are also more expensive than pills; in Kenya, the Clinton Foundation has procured them.

²⁹³ American Academy of Pediatrics, “Increasing Antiretroviral Drug Access for Children With HIV Infection.”

²⁹⁴ Human Rights Watch interview with Gerald Macharia, August 20, 2008.

The need to make ART for children available at all lower-level health facilities

When ART for adults was rolled out to lower-level health facilities, the same did not happen for children. Health workers lack experience and training in administering the drugs to children, and are often reluctant to treat children. Drugs are administered in different ways, and sometimes incorrectly, despite the existence of treatment guidelines for pediatric formulations.²⁹⁵ There is an official policy to roll out pediatric ART at lower-level health facilities; this needs to be implemented widely. In particular, ART should be integrated into regular Maternal and Child Health (MCH) clinics.

In June 2008 the WHO recommended that all HIV-positive infants should be started on antiretroviral treatment, irrespective of whether they showed symptoms, CD4 cell count, or other criteria.²⁹⁶ The Kenyan government is currently planning a program that aims to implement this recommendation.²⁹⁷ Therefore, it can be hoped that many more infants will benefit from ART, including in lower-level health facilities.

The need for better diagnosis and treatment of tuberculosis in HIV-positive children

Because people living with HIV/AIDS have suppressed immunity, they are much more likely to develop tuberculosis than those who are not infected with the virus. Co-infected children die more quickly than those infected with only HIV/AIDS or tuberculosis. In Kenya, an estimated 29 percent of TB patients are HIV-positive. In recent years TB incidence in Kenya has increased dramatically²⁹⁸ due to this “unnoticed collision.”²⁹⁹

²⁹⁵ Human Rights Watch interview with Prof. Dorothy Ngacha, August 20, 2008.

²⁹⁶ WHO, *Anti-Retroviral Therapy for HIV Infection in Infants and Children*, <http://www.who.int/hiv/pub/guidelines/pediatrico20907.pdf> (accessed October 13, 2008).

²⁹⁷ Human Rights Watch interview with Dr. Lyndon Marani, ART program manager, NASCOP, Ministry of Health, Nairobi, August 13, 2008.

²⁹⁸ Path, “Integrating TB and HIV,” http://www.path.org/files/CP_kenya_tb-hiv_fs.pdf (accessed October 13, 2008).

²⁹⁹ Thom Anso, “Africa: Not Enough Research to Treat TB-HIV Properly, Say Experts,” *COMTEX*, (Cape Town), November 2, 2007, <http://allafrica.com/stories/200711020203.html> (accessed October 13, 2008).

It is rare to achieve a definitive diagnosis of TB in co-infected children. The current tests available date from the late 19th century; there is an urgent need for research and development of better test methods.³⁰⁰

The situation is further complicated insofar as ART and drugs that are used to treat TB cannot be given together, as the drugs interact. HIV-positive children who are not yet receiving ART usually first get tuberculosis treatment, and are then started on ART. Co-infected children sometimes have to go through lengthy TB tests and treatment, and this can become an obstacle to ART. We documented this in the case of one-year-old Daniel in Nyangoma, Bondo district, described above (see Chapter IV): since there were no personnel able to read his X-ray, the TB diagnosis was delayed and he could not start ART.³⁰¹ In order to avoid late diagnosis of HIV, it has been suggested that all TB-infected children should be tested for HIV.³⁰²

No palliative care for children

Palliative care is medical and psychological support for patients who are in the terminal stage of a life-threatening disease, including pain relief. When AIDS patients in Kenya go through serious pain and suffering, there is usually little support for them. Very few health facilities—usually hospices—provide morphine. A doctor working in a hospice commented, “[With] children nobody knows how to treat pain.”³⁰³

Physicians are not trained in providing pain relief to adults or children. They are often afraid to prescribe strong pain relievers such as codeine or morphine out of fear they will kill the patient. Such drugs are also not widely available, due to strict drug regulations. Many doctors do not see palliative care as important, as they consider it

³⁰⁰ MSF, “A Doctor’s Frustration,” <http://www.accessmed-msf.org/resources/field-stories/a-doctor-s-frustration/> (accessed October 13, 2008).

³⁰¹ Human Rights Watch interview with grandmother of Daniel, age one, Nyangoma, Bondo district, August 17, 2008.

³⁰² WHO, *Anti-Retroviral Therapy for HIV Infection in Infants and Children*. For children who are diagnosed with TB while already receiving treatment, ART regimens need to be carefully reviewed, and may need to be adjusted in accordance with official guidelines.

³⁰³ Human Rights Watch interview with Dr. Bactrin Kilingo, August 6, 2007.

normal for patients with life-threatening illnesses to be in serious pain. Some even mistakenly believe that children cannot feel pain.³⁰⁴

Expanding the role of community health workers, social workers, and counselors—An important element in improving children’s access to treatment

Community health workers, social workers, counselors, and other community-based actors play a vital role in assisting communities affected by HIV, for example by providing home-based care, and encouraging testing and treatment.³⁰⁵ Frequently, health facilities or NGOs have such personnel to assist people infected or affected by HIV. Although the government officially recognizes the role of community health workers, social workers, and counselors,³⁰⁶ it does not do nearly enough to support them. There are insufficient numbers of community health workers; they are unpaid, barely trained, and often overworked. Insufficient numbers of community health workers mean that there is insufficient support and monitoring for children’s treatment.

Testing

Community health workers often undertake great efforts to inform caregivers about the need to test children, even if the child does not seem sick, and facilitate testing. In some cases, they even take children for testing when parents cannot do so, although such a scenario is not envisioned in the current testing guidelines, and current permissions are only delivered on an ad-hoc basis.³⁰⁷ A community health worker in western Kenya explained how she managed to get approval for an eight-year-old boy to be tested:

[This] was a child who had lost his mother to HIV and was living with the grandmother, the father was not around.... I was told [at the health center] the child could not be tested because I was not staying with

³⁰⁴ Human Rights Watch interview with Dr. Weru, Nairobi Hospice, Nairobi, August 8, 2007.

³⁰⁵ Charles O. Olango, “An ethnographic study of home-based care for people living with HIV/AIDS in Nyang’oma Division, Bondo District, Western Kenya,” MA Thesis, Institute of Anthropology, Gender and African Studies, University of Nairobi, 2008 (unpublished).

³⁰⁶ Ministry of Health, “Community Strategy Implementation Guidelines,” March 2007.

³⁰⁷ Human Rights Watch interview with Jane, community health worker, GROOTS, Mathare slum, Nairobi, August 10, 2007.

the child, I was not the guardian or the parent. So I told them at the [VCT] center that the grandmother who is taking care of the boy now is too old, she can't come to the center with him, but they said I must go and get a letter to say who I was and why I was testing the child.... I was overburdened at the time because I had used my own money to take the child to get tested. I did eventually get the letter, the boy was tested....You have to go and get tested. Then you have to go and get the results. Then you have to go and get the viral load test. To do all this and to get the letter, I had to consult the grandmother and see the chief to verify the letter. This is difficult. At last I got the child tested and on antiretroviral drugs. But that was only one child; I had to spend a lot of my money and time just for this one child.³⁰⁸

Other community health workers told us how helpless they feel when parents refuse to have their children tested. Testing guidelines should allow parents or other caregivers to more easily authorize third parties, such as community health care workers, to take children for testing.

Treatment adherence

Many patients stop taking the drugs at some point. Adolescents in particular often have difficulty in continuing the treatment, as they may resent being monitored by a caregiver or more generally question the regime laid down for them.³⁰⁹ Government health facilities, international agencies, and NGOs have started to carry out systematic monitoring of adults' and children's ART through community health workers or other staff. Before starting treatment, caregivers are usually given some information on treatment, with the aim of making patients and caregivers "treatment literate." Children themselves are usually not included in treatment literacy efforts,³¹⁰ although children are able at a young age to recognize the importance of their

³⁰⁸ Human Rights Watch interview with community health worker, Shibuye community health workers group, Kakamega District, Shinyalu Division, Western province, August 2, 2007.

³⁰⁹ Human Rights Watch interviews with counselor at Tuungane Youth Center, Kisumu, August 15, 2008; and Protus Lumiti, manager, Nyumbani orphanage, Nairobi, Central province, August 7, 2007.

³¹⁰ Human Rights Watch interview with Prof. Dorothy Ngacha, August 20, 2008.

treatment. For example, we were introduced to an eight-year-old girl who took great care to take her medication regularly and was proud of it.³¹¹

Disclosure and emotional support

Community health workers and counselors also play a crucial role in helping children cope with their emotions. As mentioned above, caregivers often refrain from telling children they are HIV-positive well into adolescence. Disclosure is often initiated by a health worker or a counselor. Larger treatment programs for children have disclosure programs to guide this process. An experienced pediatrician told us,

We start disclosure between ages eight and ten. It is a process. But parents always want to wait longer, so it is difficult. We need to work with them. Parents want healthcare workers to do disclosure for them. Often children react with sadness, grief, and then they get better.³¹²

In the absence of sufficient staff trained in child psychology, HIV-positive children in Kenya lack comprehensive community support and accompaniment during their suffering.³¹³ This includes palliative care in cases of terminal AIDS.

Government Policies to Improve Protection of Children with HIV

Although the government and donors are involved in a multitude of protection activities, child protection systems are weak in Kenya, and children are often left with no one to turn to in case they experience abuse.

Current protection activities can be grouped into the following areas: general child protection; protection for orphans and vulnerable children (OVCs); and protection for people living with HIV. The basis for child protection measures is the Children's Act, which establishes institutions charged with child protection, such as the Children's Courts, the Department of Children's Services and, within it, "children officers." At

³¹¹ Human Rights Watch interview with mother of two HIV-positive children, ages four and eight, Nyangoma, Bondo district, August 18, 2008.

³¹² Human Rights Watch interview with Prof. Dorothy Ngacha, August 20, 2008.

³¹³ African Palliative Care Association, "What is Palliative Care?" <http://www.apca.co.ug/about/whatis.htm> (accessed October 13, 2008).

present, there are 85 children officers working across Kenya³¹⁴ charged with implementing legal protections in the Children's Act. For example, a children officer may take a child in need of care and protection to a place of safety and bring the child before a court.³¹⁵ If a child is in need of medical care, a children officer may take the child to a registered health institution and seek treatment; expenses shall be defrayed out of public funds.³¹⁶ However, in practice, the number of children officers is far too small, leaving them overstretched and unable to carry out any such activities. Instead, they mostly just receive cases in their offices.³¹⁷ The UN Committee on the Rights of the Child observed in June 2007 in respect of Kenya,

[The Committee is] concerned that prevention measures and appropriate mechanisms for responding to abuse remain inadequate. It regrets the lack of updated statistics on victims of reported cases of violence, especially sexual and intra-family, the limited number of investigations and sanctions in relation to such cases, and the lack of available physical and psychological recovery and social reintegration measures.³¹⁸

In recognition of the difficulties faced by children infected or affected by HIV/AIDS, the government has developed a policy and guidelines on orphans and vulnerable children,³¹⁹ although the policy is still awaiting cabinet approval. Through these tools, the government has designed policies on a wide range of issues, including

³¹⁴ Human Rights Watch interview with Esther Murugi Mathenge, minister for gender and children affairs, August 19, 2008. Previously, there was one children officer per district, but a new administrative subdivision has meant that about 70 districts are without child officers. The Department of Children's Services was previously part of the Ministry of Home Affairs and was moved into the newly created Ministry for Gender and Children Affairs in April 2008.

³¹⁵ The Children's Act, No.8 of 2001, Laws of Kenya, art. 120.

³¹⁶ *Ibid.*, art. 121.

³¹⁷ Human Rights Watch interview with Mr. Hussein, director of Children's Services, Nairobi, August 20, 2008.

³¹⁸ UN Committee on the Rights of the Child, "Concluding observations: Kenya," June 19, 2007, CRC/C/KEN/CO/2, <http://daccessdds.un.org/doc/UNDOC/GEN/Go7/425/08/PDF/Go742508.pdf?OpenElement> (accessed September 24, 2008).

³¹⁹ Ministry of Home Affairs, "National Programme Guidelines on Orphans and Other Children Made Vulnerable by HIV/AIDS," March 2003, <http://www.ovcsupport.net/graphics/OVC/documents/0000554e00.pdf> (accessed September 24, 2008); Ministry of Home Affairs, "National Policy on Orphans and Vulnerable Children," November 2005.

access to health care. Both the guidelines and the policy recognize the importance of antiretroviral treatment for HIV-positive children.³²⁰

One of the support and protection mechanisms described in the guidelines is “material support to OVC caregivers and service providers, especially vulnerable caregivers such as psychologically traumatized, economically deprived, child and elderly caregivers.” This policy has been implemented through a cash-transfer program, providing cash on a monthly basis to families caring for orphans. Cash-transfer programs are growing rapidly in Africa with the aim of creating mechanisms of social protection.³²¹ The cash-transfer program in Kenya was started as a pilot project in 2004, later expanded and reaching about 25,000 families by August 2008.³²² Under this program, families in selected districts are getting a monthly cash transfer, between KSh1,000 and 2,000 (appr. US\$13–26), depending on the number of orphans or vulnerable children in the household. There are no conditions attached as to how the money should be spent. The World Bank and the UK Department for International Development are among the donors for this program.³²³ The government’s aim is to reach 65,000 families by June 2009 and 300,000 by 2015.³²⁴ At present, an evaluation is being prepared by the government on the program, in order to assess its impact.

An important tool for the protection of people living with HIV/AIDS is supposed to be the HIV and AIDS Prevention and Control Act. Although the President assented to the law on December 30, 2006, it is still not in force. One of the reasons for this seems to

³²⁰ Ministry of Home Affairs, “National Programme Guidelines on Orphans,” p. 9; Ministry of Home Affairs, “National Policy on Orphans and Vulnerable Children,” p. 19.

³²¹ UNDP, “Cash Transfer Programs in Africa,” <http://www.undp-povertycenter.org/cct/africa.do> (accessed September 24, 2008); Stop Aids Now, “Social Protection for Children affected by AIDS, including Social Cash Transfers,” March 2007, http://www.stopaidsnow.org/documents/SocialProtectionCABA_meeting_FEBo7.pdf (accessed September 24, 2008); Michelle Adato and Lucy Bassett, International Food Policy Research Institute, “What is the Potential of Cash Transfers to strengthen families affected by HIV and AIDS? A Review of the Evidence on Impacts and Key Policy Debates,” 2008, <http://www.ifpri.org/renewal/pdf/Rfbrief10.pdf> (accessed September 24, 2008).

³²² Human Rights Watch interview with Mr. Hussein, August 20, 2008; Statement by His Excellency the Vice-President of the Republic of Kenya Hon. Dr. A.A. Moody Awori on the occasion of the presentation of the second state party periodic report on the Convention on the Rights of the Child, Geneva, Switzerland, January 16, 2007.

³²³ R. Pearson and C. Alviar, “The Evolution of the Government of Kenya Cash Transfer Programme for Vulnerable Children between 2002 and 2006 and prospects for nationwide scale-up,” 2007, <http://www.undp-povertycenter.org/publications/cct/africa/EvolutionGovernmentKenyaCT.pdf> (accessed September 24, 2008).

³²⁴ *Ibid.*, pp. 12-16; Human Rights Watch interview with Mr. Hussein, August 20, 2008.

be that it remains unclear which ministry is supposed to gazette it. Campaigners suspect that beyond the bureaucratic squabbles and delays, there is a lack of political will to put the law into practice.³²⁵

³²⁵ Human Rights Watch interview with Ambrose Rachier, Kenya Ethical and Legal Issues Network on HIV/AIDS (KELIN), Nairobi, August 13, 2008.

VII. Legal Framework

National and international law obliges the Kenyan government to protect the rights of all children, and specifically children living with HIV.

On the international level, Kenya is a state party to the major human rights treaties, all of which contain important protections for children. Kenya has ratified the Convention on the Rights of the Child (CRC),³²⁶ the International Covenant on Civil and Political Rights (ICCPR), the International Covenant on Economic, Social and Cultural Rights (ICESCR), and the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW).³²⁷ On the regional level, Kenya has ratified the African Charter on the Rights and Welfare of the Child³²⁸ and the African Charter on Human and Peoples' Rights.³²⁹

On the national level, key protections are laid down in the Constitution and in the 2001 Children's Act.³³⁰ The Children's Act aims to implement international law, by "[giving] effect to the principles of the CRC and the African Charter on the Rights and Welfare of the Child."³³¹

³²⁶ CRC, ratified December 20, 1990. The latest review on the national implementation of the rights of the child was conducted in 2007, Committee on the Rights of the Child, Second Country report, CRC/C/KEN/2, July 4, 2006; Committee on the Rights of the Child, Concluding Observations Kenya, CRC/C/KEN/CO/2, June 19, 2007.

³²⁷ Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), adopted December 18, 1979, G.A. Res. 34/180, 34 U.N. GAOR Supp. (No. 46) at 193, U.N. Doc. A/34/46, entered into force September 3, 1981, acceded to by Kenya March 9, 1984; International Covenant on Civil and Political Rights (ICCPR), adopted December 16, 1966, G.A. Res. 200A (XXI), 21 U.N. GAOR Supp. (No. 16) at 52, U.N. Doc A/6316 (1966) 999 U.N.T.S. 171, entered into force March 23, 1976, acceded to by Kenya May 1, 1972; International Covenant on Economic, Social and Cultural Rights (ICESCR), adopted December 16, 1966, G.A. Res. 2200A (XXI), 21 U.N. GAOR Supp. (No. 16), U.N. Doc. A/6316 (1966), 993 U.N.T.S. 3, entered into force January 3, 1976, acceded to by Kenya May 1, 1972; Universal Declaration of Human Rights (UDHR), adopted December 10, 1948, G.A. Res. 217A(III), U.N. Doc. A/810 at 71 (1948).

³²⁸ African Charter on the Rights and Welfare of the Child, OAU Doc. CAB/LEG/24.9/49 (1990), November 29, 1999, ratified July 25, 2000.

³²⁹ The African [Banjul] Charter on Human and Peoples' Rights, adopted June 27, 1981, OAU Doc. CAB/LEG/67/3 rev. 5, 21 I.L.M. 58 (1982), entered into force October 21, 1986, acceded to by Kenya January 23, 1992, <http://www1.umn.edu/humanrts/instree/ratz1afchr.htm> (accessed September 8, 2008).

³³⁰ Constitution of Kenya, adopted 1963, amended 1999, <http://www.usig.org/countryinfo/laws/Kenya/Constitution.pdf> (accessed October 6, 2008), Chapter V; The Children's Act, art. 5.

³³¹ The Children's Act, introduction.

International law provides important protections to children, including protection from discrimination, and the right to health, protection, and care. All actions undertaken by the State and by private institutions shall be done in the best interests of the child.

Protection from discrimination

The CRC protects children from discrimination of any kind “irrespective of the child’s or his or her parent’s or legal guardian’s race, color, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status.”³³² The Committee on the Rights of the Child has interpreted “‘other status’... to include HIV/AIDS status of the child or his/her parents(s).”³³³ The African Charter on the Rights and Welfare of the Child and other international treaties ratified by Kenya state a similar right to non-discrimination.³³⁴

The Kenyan constitution contains an anti-discrimination clause,³³⁵ and the Children’s Act provides protection against discrimination “on the ground of origin, sex, religion, creed, custom, language, opinion, conscience, colour, birth, social, political, economic or *other status* [emphasis added], race, disability, tribe, residence or local connection.”³³⁶ The 2007 HIV/AIDS Prevention and Control Act, which is not yet in force, contains a range of protections against discrimination on the grounds of a person’s actual, perceived, or suspected HIV status.³³⁷

³³² CRC, art. 2.

³³³ Committee on the Rights of the Child, General Comment No. 3: HIV/AIDS and the Rights of the Child, CRC/GC/2003/3 (2003), para. 7.

³³⁴ See ICCPR, art. 26; ICESCR, art. 2; CEDAW, art. 2. The UN Commission on Human Rights in 1995 concluded that discrimination on the basis of AIDS or HIV status is prohibited in that it is covered by the term “or other status” in the ICCPR and other UN human rights instruments. Commission on Human Rights, The Protection of Human Rights in the Context of Human Immune Deficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS), Resolution 1995/44, adopted without a vote, March 3, 1995.

³³⁵ Constitution, art. 83.

³³⁶ The Children’s Act, art. 5.

³³⁷ HIV/AIDS Prevention and Control Act, January 2, 2007, art. 31.

The child's right to the highest attainable standard of health

All children have the right to enjoy the highest attainable standard of mental and physical health under the CRC and the ICESCR.³³⁸

The ICESCR obliges states to take the necessary steps to ensure that health services are available, accessible, acceptable, and of good quality.³³⁹ Availability comprises the availability of functioning healthcare services, medical personnel, and drugs, as well as safe water and sanitation. Accessibility means that health facilities should be accessible for everyone, without discrimination, and located within safe physical reach and economically affordable; it also comprises the right to seek and receive information on health services. Acceptability means that all health facilities need to adhere to ethical standards, including the principle of confidentiality.³⁴⁰ The right to the highest attainable standard of health also imposes an obligation on states to take steps necessary for the prevention, treatment, and control of epidemic and other diseases.³⁴¹

The child's right to health is further grounded in the CRC, which obliges states to take measures to diminish infant and child mortality, and to ensure the provision of necessary medical assistance and health care to all children, with an emphasis on primary health care.³⁴² The Committee on the Rights of the Child, in its General Comment on HIV/AIDS and the Rights of the Child, has emphasized states parties' obligations to "ensur[e] that children have sustained and equal access to comprehensive treatment and care, including necessary HIV-related drugs, goods, and services on a basis of non-discrimination."³⁴³

³³⁸ ICESCR, art. 12; CRC, art. 24; CEDAW, art. 12.

³³⁹ Committee on Economic, Social and Cultural Rights, General Comment No. 14: The Right to the Highest Attainable Standard of Health, E/C 12/2000/4, (2000), para. 12.

³⁴⁰ Ibid.

³⁴¹ ICESCR, art. 12(c).

³⁴² CRC, art. 24.

³⁴³ Committee on the Rights of the Child, General Comment No. 3: HIV/AIDS and the Rights of the Child, para. 28. The committee notes, "It is now widely recognized that comprehensive treatment and care includes antiretroviral and other drugs, diagnostics and related technologies for the care of HIV/AIDS, related opportunistic infections and other conditions, good nutrition, and social, spiritual and psychological support, as well as family, community and home-based care."

The child’s right to enjoy the best attainable state of physical, mental, and spiritual health is also stated explicitly in the African Charter on the Rights and Welfare of the Child in language that is similar to the CRC.³⁴⁴ Among other provisions, it stipulates that states parties must “ensure the provision of necessary medical assistance and health care to all children with emphasis on the development of primary health care.”³⁴⁵

The right to the highest attainable standard of health is subject to “progressive realization,” under which states parties have a “specific and continuing obligation to move as expeditiously and effectively as possible towards the full realization of [the right].”³⁴⁶ In doing so, states must guarantee certain core obligations as part of the right to health. These include, among others, ensuring nondiscriminatory access to health facilities, especially for vulnerable or marginalized groups; providing essential drugs; ensuring equitable distribution of all health facilities, goods and services; ensuring reproductive, maternal, and child care; taking measures to prevent, treat, and control epidemic and endemic diseases; and providing education and access to information for important health problems.³⁴⁷

The right to health care of internally displaced people is also explained in the Guiding Principles on Internal Displacement. They state that all wounded and sick displaced people shall receive the medical care and attention they require, without discrimination. Additionally, “special attention should also be given to the prevention of contagious and infectious diseases, including AIDS, among internally displaced persons.”³⁴⁸

The right to health care is not enshrined in the Kenyan constitution, but is in the Children’s Act of Kenya:

³⁴⁴ African Charter on the Rights and Welfare of the Child, art. 14.

³⁴⁵ African Charter on the Rights and Welfare of the Child, art. 14, para. 2 (b).

³⁴⁶ Committee on Economic, Social and Cultural Rights, General Comment No. 14: The Right to the Highest Attainable Standard of Health, paras. 30, 31.

³⁴⁷ *Ibid.*, paras. 12, 43, 44.

³⁴⁸ The Office of the High Commissioner for Human Rights, Guiding Principles on Internal Displacement, E/CN.4/1998/53/Add.2, February 11, 1998, principle 19.

Every child shall have a right to health and medical care the provision of which shall be the responsibility of the parents and the Government.³⁴⁹

The law describes it as a parental duty to provide medical care and defines lack of such care as neglect.³⁵⁰ The state, through its children officers and other appointed officers, also has direct responsibility of providing health care when a child needs it:

- (1) If it appears to an authorized officer... that a child is in need of medical care, he shall forthwith take the child to a registered health institution, and such health institution shall provide the appropriate treatment, care and necessary hospital accommodation for the child....
- (4) Any expenses incurred in connection with the medical treatment or hospital accommodation of a child under this section shall be defrayed out of public funds.³⁵¹

The HIV/AIDS Prevention and Control Act explicitly protects the right to health of persons living with HIV, stating that “every health institution... shall facilitate access to healthcare services to persons with HIV without discrimination on the basis of HIV status.” It also translates international law into national law, stipulating that the government shall, “to the maximum of its available resources, take the steps necessary to ensure access to essential healthcare services.”³⁵²

The child’s right to information, participation, and confidentiality in health care

The CRC provides for the child’s right to “seek, receive and impart information of all kinds.”³⁵³ A child’s views should be given due weight in accordance with the age and maturity of the child.³⁵⁴ In particular, children and their parents should be informed

³⁴⁹ The Children’s Act, art. 9.

³⁵⁰ Ibid., arts. 127 (2), 23. Article 23 defines parental responsibility.

³⁵¹ Ibid., art. 121.

³⁵² HIV/AIDS Act, art. 19.

³⁵³ CRC, art. 13.

³⁵⁴ Ibid. art. 12.

and supported in the use of basic knowledge of child health.³⁵⁵ The Committee on the Rights of the Child has stated that children “have the right to access adequate information related to HIV prevention and care, through formal channels... as well as informal channels.”³⁵⁶ This includes the right of a child to know his or her own HIV status. The Committee emphasizes that effective HIV/AIDS prevention requires states “to refrain from censoring, withholding or intentionally misrepresenting health-related information, including sexual education and information....”³⁵⁷ Healthcare services provided should be responsive to the needs of children, according to the Committee,

[As] children are more likely to use services that are friendly and supportive, provide a wide range of services and information, are geared to their needs, give them the opportunity to participate in decisions affecting their health, are accessible, affordable, confidential and non-judgmental, do not require parental consent and are not discriminatory.³⁵⁸

Adolescents also have the right to participate “actively in planning and programming [...] their own health and development.”³⁵⁹ If they are of sufficient maturity, informed consent shall be obtained from the adolescent her/himself, and parental consent shall not be necessary.³⁶⁰

At odds with the Committee’s position (and as discussed above in Chapter VI), current guidelines on testing in Kenya require anyone under the age of 18 to seek parental consent for testing, unless they are married, pregnant, a parent, or engaged in behavior that puts them at risk. The pending HIV/AIDS Prevention and Control Act retains the same approach and would turn this guideline into national law.

³⁵⁵ CRC, art. 24(2)(e).

³⁵⁶ Committee on the Rights of the Child, General Comment No. 3: HIV/AIDS and the rights of the child, para. 16.

³⁵⁷ *Ibid.*

³⁵⁸ *Ibid.*, para. 17.

³⁵⁹ Committee on the Rights of the Child, General Comment No. 4: Adolescent health in the context of the Convention on the Rights of the Child, U.N. Doc. CRC/GC/2003/4 (2003), paras. 39(b), 39(d).

³⁶⁰ *Ibid.*, para. 32.

International law requires states to protect children against “arbitrary or unlawful interference” with privacy,³⁶¹ and in national law The Children’s Act protects the right to privacy in article 19. The Committee on the Rights of the Child has commented that states must protect the confidentiality of HIV test results, and that information on a child’s HIV status may not be disclosed to third parties, including parents, without the child’s consent.³⁶² Interpreting the parallel provision of the ICCPR, the Human Rights Committee further specifies that states must take effective measures “to ensure that information concerning a person’s private life does not reach the hands of persons who are not authorized by law to receive, process and use it, and is never used for purposes incompatible with the Covenant.” Individuals have the right to request rectification or elimination of files containing incorrect personal data or data collected or processed contrary to the law.³⁶³ States parties should enact laws or regulations to ensure that confidential advice concerning medical treatment is provided to adolescents so that they can give their informed consent.³⁶⁴

Food as a determinant of health

The right to health embraces a wide range of socioeconomic factors that promote conditions in which people can lead a healthy life. This includes food and nutrition.³⁶⁵ Hence, states are obliged to ensure equal access for all to the underlying determinants of health, such as nutritiously safe food and potable drinking water.³⁶⁶ The Committee on the Rights of the Child has also stated that comprehensive treatment and care includes good nutrition.³⁶⁷

³⁶¹ CRC, art. 15; ICCPR, art. 17.

³⁶² Committee on the Rights of the Child, General Comment No. 3: HIV/AIDS and the Rights of the Child, para. 24.

³⁶³ CCPR, General Comment No. 16: The right to respect of privacy, family, home and correspondence, and protection of honour and reputation (Art. 17), 08/04/88, para. 10.

³⁶⁴ *Ibid.*, paras. 32, 33.

³⁶⁵ UN Committee on Economic, Social and Cultural Rights, General Comment No. 14: The Right to the Highest attainable Standard of Health, paras. 4, 11.

³⁶⁶ *Ibid.*, paras. 36, 43.

³⁶⁷ Committee on the Rights of the Child, General Comment No. 3 (2003): HIV/AIDS and the rights of the child, para. 28.

The right to food is also set out in the ICESCR and the Guiding Principles on Internal Displacement in a more general way. Everyone has a right to an “adequate standard of living,” including “adequate” or “essential” food.³⁶⁸

The child’s right to protection and care

Under the CRC, the state has an obligation to realize the child’s right to an adequate standard of living.³⁶⁹ At the same time, the convention also emphasizes the responsibilities of caregivers. Parents, guardians, and other persons in whose care a child finds himself or herself, have the “primary responsibility to secure, within their abilities and financial capacities, the conditions of living necessary for the child’s development.”³⁷⁰

The CRC requires states to take all appropriate measures to protect children from “all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse, while in the care of parent(s), legal guardians(s) or any other person who has the care of the child.”³⁷¹

The African Charter on the Rights and Welfare of the Child has similar protections against all forms of torture, inhuman or degrading treatment, neglect, injury, or abuse.³⁷² Children who are deprived of their family environment, or whose best interests do not allow them to remain in that environment, are entitled to special protection and assistance provided by the state. The state must ensure alternative care of the child, which can include foster placement, adoption, or placement in suitable institutions for the care of children.³⁷³

³⁶⁸ ICESCR, art. 11, speaks about “adequate” food. The UN Guiding Principles on Internal Displacement, art.18, speaks about “essential” food.

³⁶⁹ CRC, art. 27.

³⁷⁰ *Ibid.*, art. 27.

³⁷¹ *Ibid.*, art. 19.

³⁷² African Charter on the Rights and Welfare of the Child, arts. 16, 25.

³⁷³ CRC, art. 20. This provision reinforces article 24(1) of the ICCPR, which guarantees every child “the right to such measures of protection as are required by his status as a minor.”

In Kenyan national law, under The Children’s Act, children are “entitled to protection from physical and psychological abuse, neglect, and any other form of exploitation including sale, trafficking or abduction by any person.”³⁷⁴ A child that is, in his or her best interest, separated from his parents by a court order shall be provided with the best alternative care available.³⁷⁵ When one of the parents dies, the remaining parent shall exercise parental responsibility alone or together with a testamentary guardian appointed by the deceased parent.³⁷⁶ If both parents die, parental responsibility shall be exercised by a testamentary guardian appointed by the parents or court, or in absence of this, a relative of the child.³⁷⁷

Protection against arbitrary disinheritance

The Universal Declaration of Human Rights stipulates that “[e]veryone has the right to own property alone as well as in association with others” and “no one shall be arbitrarily deprived of his property.”³⁷⁸ The right to property is also protected under article 14 of the African Charter on Human and Peoples’ Rights, which provides that “[property rights] may only be encroached upon [...] in accordance with the provisions of appropriate laws.” International law also requires that all rights be implemented in a nondiscriminatory way.³⁷⁹

Kenyan inheritance law contains more specific protections for children.³⁸⁰ The Law of Succession Act states that when both parents die and do not leave a will, the property will be administered by an appointed adult until the oldest child is 18.³⁸¹ The law states that no one other than the administered person “shall, for any purpose, take possession or dispose of, or otherwise intermeddle with, any free

³⁷⁴ The Children’s Act, arts. 13, 15.

³⁷⁵ *Ibid.*, art. 6.

³⁷⁶ *Ibid.*, art. 27 (1).

³⁷⁷ *Ibid.*, art. 27 (1).

³⁷⁸ UDHR, art. 17.

³⁷⁹ African Charter on Human and People’s Rights, art. 14.; CEDAW, art. 2.

³⁸⁰ Law of Succession Act, Chapter 160 of the Laws of Kenya, July 1, 1981, http://www.kenyalawreports.or.ke/kenyalaw/klr_app/frames.php (accessed June 16, 2008).

³⁸¹ *Ibid.*, section 41. The court appoints the legal guardian or another individual to administer the estate under a procedure outlined in section 7 of the Fifth Schedule to the act.

property of a deceased person.”³⁸² If there is no one else to administer the property, the Office of the Public Trustee is meant to ensure that the property is put in trust until the eldest surviving child reaches majority.³⁸³

³⁸² *Ibid.*, section 45(1).

³⁸³ *Ibid.*, art. 41.

VIII. Detailed Recommendations

To the Government of Kenya

To the Ministry of Public Health and the Ministry of Medical Services

- Ensure equal access to health care for all children and in particular to HIV testing and treatment.
- Integrate pediatric HIV testing and treatment into regular child health care—such as Maternal and Child Health clinics—by routinely offering voluntary counseling and testing (VCT) at all points of contact between children and the health system, including at dispensaries and health centers.
- Integrate pediatric HIV testing and treatment into facilities offering adult testing and treatment, to ensure that children are able to access treatment together with adult family members.
- Implement the current policy of routinely offering testing for infants at age 6 weeks, 12 months, and 18 months. In addition, instruct health facilities to offer testing for all children under the age of five who have not had a test yet, and for all children who have HIV-related symptoms.
- Change existing testing guidelines on parental consent to:
 - Give children aged 15 and older the right to seek or refuse HIV testing or treatment, regardless of parental consent;
 - Give children aged 12 and older the right to seek or refuse HIV testing or treatment, depending on their cognitive and emotional maturity; and
 - Allow third parties such as community health workers to take children for testing if parents or guardians agree.
- Develop a policy on disclosure of HIV diagnosis to children, aiming for disclosure starting at age six, taking into account their cognitive and emotional maturity. Establish programs that provide guidance on disclosure to parents and caregivers.
- Strengthen the role of community-based health workers, social workers, and counselors in health facilities by expanding their numbers, introducing

- compensation fees to pay for their services, and providing additional training, in particular on pediatric HIV and child psychology.
- Reach out to families with HIV-positive children by:
 - Publicizing information about pediatric HIV services available in each local area, including information about ART and cotrimoxazole as life-saving treatment for children;
 - Creating treatment literacy courses for adults administering ART to children;
 - Establishing HIV support groups for caregivers of HIV-positive children and for children themselves; and
 - Making special efforts to involve fathers in family health issues.
 - Carry out an awareness-raising campaign to inform the public about the availability of free HIV treatment, encourage sick people to seek care at local health facilities, and caution against reliance on non-medical AIDS cures.
 - Develop and implement guidelines on palliative care for children.
 - Ensure that children under the age of five do not have to pay user fees, in accordance with the current policy.
 - Ensure that user fees for health services for children over the age of five do not constitute a barrier for HIV testing or treatment.
 - Carry out an awareness-raising campaign to fight stigma and discrimination, including by:
 - Training health workers on HIV-related issues, including issues affecting mothers and children living with HIV;
 - Using radio and other media to sensitize the public to the rights of people living with HIV, with particular reference to the problem of stigma within families and communities;
 - Using radio and other media to show positive examples of women and men living with HIV and receiving antiretroviral treatment;
 - Including the topic of protection from stigma and discrimination in school curricula.

To the Kenya Food Security Steering Group

- Take measures to address endemic food security problems. This should include specific measures for children, including free school meals.
- Help set up schemes to provide adults and children on ART with key nutrients through food supplements or with funds for income-generating activities.
- Help set up programs that provide infant formula for at least six months after birth to those HIV-positive mothers who are advised to feed their babies formula, in accordance with WHO guidelines for acceptable, feasible, affordable, sustainable, and safe infant feeding.

To the Ministry of Special Programs, including the National Aids Control Council (NACC)

- Ensure that existing donor funds for the fight against AIDS benefit the general health system.
- Verify that internally displaced people living in transit sites, including children, have access to health care, including HIV testing and treatment.
- Ensure that internally displaced people living in camps and transit sites have adequate nutrition, clothing, housing, and protection from violence.
- Develop an emergency preparedness strategy that addresses interruption of HIV treatment.

To the Ministry of Gender and Children Affairs

- Strengthen the current child protection system by significantly increasing the number of children officers throughout the country.
- Implement the recommendations of the UN Study on Violence against Children. As a first step, set up a task force to develop and implement a plan of action to end violence against children, including children living with HIV.
- Liaise with traditional leaders and communities in western Kenya with the aim of developing practices that provide alternatives to traditions such as widow inheritance.

- Provide access to HIV treatment for child-headed households through targeted programs to provide them with HIV-related services wherever possible.
- Provide access to HIV treatment for street children through outreach programs wherever possible.

To the Ministry of Justice and the Ministry for Gender and Children Affairs

- Ensure that cases of disinheritance, child neglect, and abuse are investigated and prosecuted in accordance with international legal standards.
- Ensure that sexual and gender-based violence against HIV-positive women are investigated and prosecuted in accordance with international legal standards.
- Take measures to improve access to justice for children suffering abuse or disinheritance. In particular:
 - Set up schemes for free legal aid for vulnerable children;
 - Train legal professionals on children’s rights, and employ them to represent children’s interests, particularly in rural areas;
 - Do outreach with traditional leaders on property rights issues of children;
 - Carry out awareness-raising on children’s rights, including on the child’s right to health, protection from violence, and property;
 - Train judicial and law enforcement personnel on children’s rights; and
 - Ensure that inheritance cases of HIV-positive children are treated as priorities.
- Ensure that programs for orphans and vulnerable children include measures to improve access to health care and protection.

To the Attorney General

- Inform the public about the role of property rights of children and the role of the public trustee.
- Ensure public trustees proactively take up cases of orphans, as a priority.

To UNAIDS, the World Health Organization (WHO), the United States, and Other Donor Agencies Working on HIV/AIDS

- Assist the government, through technical and financial support, with the design and implementation of the public health measures outlined above.
- Strengthen the capacity of the health system by better integrating HIV/AIDS programs into existing health system structures.

To the United National Children's Fund (UNICEF) and Other Donor Agencies Working on Child Protection

- Offer the government technical and financial support with the design and implementation of child protection measures as outlined above.

To Donor Countries

- Fund research and development of drug formulations that are suitable for children in resource-poor settings, such as tablets in smaller sizes, tablets that can be divided easily, and tablets that can be sprinkled or dispersed.
- Fund research on new, more effective tuberculosis drugs that can be taken together with antiretroviral drugs, and on a test that can accurately diagnose tuberculosis in children.

To the African Union (AU) Commissioner for Social Affairs

- Ensure that efforts to implement the Abuja Call for Accelerated Action Towards Universal Access to HIV and AIDS, Tuberculosis and Malaria Services in Africa focus on treatment access for children.
- Urge the Kenyan government to allocate 15 percent of government expenditure to the health sector, in accordance with the Abuja Declaration of African governments.

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