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COMMITTEE ON THE RIGHTS OF THE CHILD THEME DAY ON EARLY CHILDHOOD, 2004

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India's explosive AIDS epidemic is being fueled by widespread abuses against children who are affected by HIV/AIDS, some of whom are very young. The Indian government's failure to address these abuses is undermining its anti-AIDS policy and putting millions of lives at risk.

Many doctors refuse to treat or even to touch HIV-positive children. Some schools expel or segregate children because they or their parents are HIV-positive. Many orphanages and other residential institutions reject HIV-positive children or deny that they house them. Children from families affected by AIDS may be denied an education, pushed onto the street, forced into the worst forms of child labor, or otherwise exploited, all of which puts them at greater risk of contracting HIV.

We hope that the Committee on the Rights of the Child will take on this crucially important issue and make recommendations to the Indian government as suggested below.

I. Summary

Six-year-old Anu P.'s teacher sent her home from kindergarten in 2003, instructing her older sister to tell her "please not to come again to the school." Her grandfather, who had been caring for Anu and her siblings since their parents died of AIDS, explained, "The teacher didn't allow her to come to school because she believes Anu is HIV-positive. I believe that other parents were talking amongst themselves, so the teacher said she shouldn't come." Her grandfather told us he was afraid that if he protested, Anu's older sister might be sent out as well. A nearby private doctor told Anu's family not to bring the girl to his clinic "because if you do, other people won't come." The reason the man gave, her uncle said, was because of HIV. Anu's sixty-six-year-old grandmother had been taking her on foot to the government hospital, but the distance had become too far for her to walk, her grandfather explained.

Sharmila A., age ten, was HIV-positive and had lost both of her parents to AIDS. She stopped going to school in the fourth grade, she said. "When I went to school, I sat separately from the other children, in the last mat. I sat alone. The other children wanted to be with me, but the teacher would tell them not to play with me. She said, 'This disease will spread to you also, so do not play with her.'" When Sharmila developed tuberculosis, she began traveling some four to five hours to reach a government-run hospital for free medical care. However, the hospital did not provide antiretroviral drugs, and her health did not improve. Sharmila died in January 2004.

Kannammal P. put her oldest daughter in an orphanage when she became unable to care for all of her children, she told us. Shortly thereafter, her husband was diagnosed with HIV. She went back to the orphanage and asked them for help. Instead, she said, "they asked the child to be tested, and then they wanted her to leave. . . . Despite pleading with the school authorities, they said, 'Sorry, please find another place. We are not free to take her.'" Her daughter's HIV test, she told us, was negative.

Millions of Indians, including at least hundreds of thousands of children, are living with human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS). Many more children are otherwise seriously affected by India's burgeoning epidemic—when they are forced to withdraw from school to care for sick parents, are forced to work to replace their parents' income, or are orphaned (losing one or both parents to AIDS).

Yet HIV/AIDS-affected children, including those living with the disease, are nearly invisible in the Indian government's policy response to the country's devastating epidemic. Children affected by HIV/AIDS are being discriminated against in education and health services, denied care by orphanages, and pushed onto the streets and into the worst forms of child labor. Gender discrimination makes girls more vulnerable to HIV transmission and makes it more difficult for them to get care. Many children, especially the most vulnerable, as well as the professionals who care for them, are not getting the information about HIV they need to protect themselves or to combat discrimination. This report documents abuses against India's HIV/AIDS-affected children and calls on the Indian government to recognize their plight and to take immediate action to protect them from discrimination and exploitation.

All of India's states have reported AIDS cases, and in at least six states, according to the government, HIV/AIDS has spread beyond persons considered “high risk” to the general population. Among young children especially, perinatal transmission is the most common source; however, children in India are also acquiring HIV through sexual contact, including sexual abuse; blood transfusions; and unsterilized syringes, including injection drug use. Most of those dying of AIDS are between fifteen and forty-nine years old, the age when many are raising children. The number of AIDS orphans has not been adequately measured, but some calculate more than a million children under age fifteen in India have lost one or both parents to AIDS, and that the numbers are growing.

Although India’s HIV/AIDS policy has sorely neglected children, some government officials have started to speak out about the need to reach children who are seen to be “innocent victims.” The government has also begun programs designed to prevent the transmission of HIV from mother to child. However, the exclusive focus on persons considered “high-risk” and the moral judgment that has colored the government’s response and, in turn, the public’s perception, have obscured the situation of children. Government and internationally-funded prevention programs have targeted adults such as sex workers, truck drivers, and drug users, but the government has failed to protect the human rights of those whom it recognizes to be at high risk—including sex workers and men who have sex with men—an essential element in preventing the spread of HIV. Some government officials also deny that children are engaging in behavior that puts them at risk. If not simply overlooked, children who face high HIV risk, such as street children, are not seen as innocent victims but instead, like adults, are blamed for their “bad behavior” and are especially stigmatized. The government has made little effort to find out the true numbers of children living with or affected by HIV/AIDS, and state officials downplayed to Human Rights Watch the numbers of children living with HIV/AIDS in their states. The mechanisms to collect those numbers are rudimentary.

The Indian government has done little to protect children already living with HIV/AIDS and is virtually ignoring the larger and growing category of otherwise affected children, including orphans. Discrimination against people living with HIV/AIDS hits children in schools, in medical facilities, in orphanages, in their neighborhoods, and in their own homes. Doctors, both government and private, have refused to treat and sometimes even touch HIV-positive children. Discrimination, combined with corruption and a failing public health system, leaves many children living with HIV/AIDS without even the rudiments of health care. There is a direct connection between children not being treated for HIV and being discriminated against in schools and the community: in addition to suffering pain and disfigurement, untreated children are more likely to be identifiably ill, and teachers, classmates, and parents of other students are more likely to suspect them of being HIV-positive. Schools have expelled or segregated children because they or their parents are HIV-positive. Fear of discrimination discourages people from doing anything that might identify them as HIV-positive, such as getting tested for HIV, seeking treatment and support, and taking other measures to protect themselves and others. A few acts of discrimination can have a wide deterrent effect.

Children already facing other forms of discrimination, such as sex workers, children of sex workers, street children, children from lower castes and Dalits (so-called untouchables), suffer more. Sexual abuse and violence against women and girls, coupled with their long-standing subordination in Indian society, make them especially vulnerable to HIV transmission. When living with AIDS, they may be the last in the family to receive medical care. Girls are also more likely to be pulled out of school to care for a sick family member or to take over domestic work. Children, especially girls, who are in school are less vulnerable to contracting HIV, as long as schools themselves are not a source of sexual violence and abuse.

While some national level government officials acknowledged to Human Rights Watch that discrimination against children is a problem, many state officials denied that children were being excluded from education and health care. A few states, including Kerala and Andhra Pradesh, have adopted policies prohibiting schools from discriminating against children living with HIV/AIDS. These policies are a commendable step, but they have not yet been implemented. Moreover, they are no substitute for nationwide protection for all people living with HIV/AIDS in education, health, employment, and other areas. The Indian government should make discrimination on the basis of HIV status illegal, create mechanisms for victims of discrimination to seek redress, and provide penalties for violations. Government officials who allow or fail to address discrimination in the areas in which they work should also be held accountable. At the time of writing, national legislation on discrimination against people living with HIV/AIDS was being drafted.

In addition to the association of HIV/AIDS with people already deeply stigmatized by society, discrimination against people living with the disease, including children, is connected in large part to the widespread public misperception that HIV can be transmitted by casual contact. A critical element of addressing discrimination against people living with HIV/AIDS, as well as preventing the spread of HIV, is accurate and comprehensive information about how the disease is and is not transmitted. Children as well as adults have a right to age-appropriate information to protect themselves against transmission. But most states have failed in part or in whole to provide this information to children. According to the most recent data provided by India's National AIDS Control Organization (NACO) and UNICEF, less than half of secondary schools offer HIV/AIDS education. While states such as Andhra Pradesh and Tamil Nadu have gone farther than most in implementing HIV/AIDS education, research by other organizations raises questions about whether the material being taught contains the practical information children need to protect themselves. Moreover, when HIV/AIDS education is offered, it is typically introduced in grades eight or later. By then, the majority of children in India, especially girls, have dropped out of school, and the poorest, most vulnerable children thus lose the opportunity to learn how to protect themselves from HIV. Beyond formal education, the government is utterly failing to provide information to millions of India's children who are not in school but on the streets, at work, in institutions, in non-formal schools, and at home. Thus, the children who are most vulnerable are the least likely to get lifesaving information about HIV/AIDS.

Although some state governments, like that of Tamil Nadu, have begun programs to educate the general public, most have not. Teachers, doctors, government officials, and the general public still lack basic information about HIV/AIDS. Moreover, some awareness programs have been poorly conceived, containing messages that promote fear over knowledge, lack adequate information about how HIV is transmitted and how to protect oneself, and enhance stigma against people considered to be “high risk.”

Despite government denials, non-governmental organizations (NGOs) and others assert that AIDS is leaving increasing numbers of children in need of state protection and care. Discrimination against HIV-positive parents and guardians, and discrimination against women in employment, property rights, and inheritance rights leaves them less able to pay for children’s school fees, medical expenses, food, and other basic necessities. AIDS-affected families face both discrimination and the economic devastation of increased medical expenses and the loss of family wage earners to AIDS. The government’s failure to provide basic medical care for people living with HIV/AIDS impoverishes those who are forced to pay for private practitioners willing to treat them and forces those who cannot pay to go without care. Struggling families caring for HIV/AIDS-affected children find it even harder to pay school fees and related costs, further preventing some children from attending school. While the extended family has traditionally absorbed many orphans and other children whose parents are unable to care for them, misinformation and fear cause some families to reject children who are HIV-positive or who are perceived to be so because their parents died of AIDS. For others, it is an insuperable economic burden. Some HIV-positive parents also give up their children to others in the mistaken belief that they will transmit the virus through casual contact. When extended families do take in children whose parents cannot care for them, these children may still need state protection. Children whom the state fails to protect may be denied an education, pushed into the street, forced into the worst forms of child labor, or otherwise exploited, putting them at greater risk of contracting HIV themselves.

Government officials, as a matter of policy, look to orphanages and other institutions as the first and virtually only solution for children whose families are unable to care for them. The potential harms to children from institutionalization have been well documented. Short-term institutional care might be the only possible solution for some children, but it must be used as a measure of last resort, and children must be provided with adequate care in accord with their best interests. While provisions for foster care exist in Indian law, many officials maintain that the care currently available in orphanages and other institutions is an adequate solution for the increasing numbers of children orphaned by AIDS. The government should take steps to implement alternatives to institutionalization, including fostering and other forms of community-based care.

Moreover, many orphanages and other residential institutions reject HIV-positive children or deny that they house them, suggesting that children in state care who are HIV-positive may not be getting needed services. Government officials also told us that they are not providing children in state care with HIV/AIDS education they need to protect themselves and others.

In December 2003, the government of India announced that it planned to provide antiretroviral treatment to up to 100,000 children, mothers, and others who need it in six high-prevalence states beginning April 1, 2004. At the time of this writing, the program had begun administering treatment to small numbers of people living with AIDS in a few areas. Human Rights Watch welcomes this development. In addition to ARV medicines, people with HIV/AIDS have a desperate need for other basic medical care, which India's public health system has failed to provide, especially to the poor and marginalized. It will also be important that people already facing discrimination, such as sex workers, children of sex workers, street children, and Dalit and low caste children, are not discriminated against in the administration of the antiretroviral program, and that testing is done and drugs provided in such a way that does not reveal to the rest of the community that a person is HIV-positive, thus exposing her or him to discrimination. If the program is successful, more people will be tested, learn their status, and be treated: more HIV-positive children may well be living in India's communities, schools, health care facilities, and orphanages. Thus, it is crucial that the Indian government immediately put into place protections against discrimination for people living with HIV/AIDS.

In particular, Human Rights Watch recommends that the Indian government:

- Make discrimination against people living with HIV/AIDS illegal everywhere in India by enacting and enforcing national legislation prohibiting discrimination against people living with HIV/AIDS and their families in health facilities, schools, places of employment, and other institutions. All government departments should take an active role in combating discrimination in the areas in which they work, instead of relying solely on NACO and the state AIDS control societies.
- Ensure that children living with HIV/AIDS receive all available medical care, including antiretroviral treatment, without discrimination, and use all possible means to remove barriers to care.
- Plan for the protection of children whose parents are unable to care for them by developing alternatives to institutionalization. At the same time, prohibit institutions from discriminating against HIV/AIDS-affected children in their care and ensure that those children receive adequate care.
- Provide all children, both in and out of school, with age-appropriate information about HIV/AIDS that is both comprehensive and accurate.
- Address gender discrimination in employment, divorce, inheritance, and property laws, and longstanding practices of discrimination against girls in education and health that make women and girls especially vulnerable to HIV transmission and imperil their ability to care for their children.

India is a party to a number of international treaties that prohibit discrimination and obligate states to take affirmative steps to protect children living with and affected by HIV/AIDS. These treaties also establish the rights to education and to the highest attainable standard of health. The committee that interprets the Convention on the Rights of the Child has underlined “the necessity of providing legal, economic and social protection to affected children to ensure their access to education, inheritance, shelter and health and social services.” Regarding children orphaned by HIV/AIDS, the committee has noted that states must provide assistance “so that, to the maximum extent possible, children can remain within existing family structures,” that where this is not possible, states should provide, “as far as possible, for family-type alternative care (e.g. foster care),” and that “any form of institutionalized care for children should only serve as a measure of last resort.”
