

**“I Will Fight to My Last Breath”:
Barriers to AIDS Treatment for Children in China
April 2009**

Executive Summary

In recent years, China has taken steps to expand AIDS treatment around the country, but the state still faces challenges in ensuring it reaches the people who need it. Though the government has committed to providing free AIDS treatment to children, Asia Catalyst’s field research in China shows that in practice, significant barriers still limit children’s access to this treatment. Thousands of HIV-positive children may not be receiving the medicines they need to survive.

The challenges are many, in part because China’s AIDS epidemic has hit hardest at impoverished rural regions where health services are weak. The state AIDS treatment program provides some pediatric medicines supplied by an international donor, but not all children can obtain these, and many take adult medications that can cause serious side effects. In interviews, families and AIDS advocates also spoke of the urgent need for second-line AIDS treatment for children who had developed resistance to the first line of AIDS drugs; these expensive medicines are also not covered by the state program. Local hospitals pass on many treatment-related costs—everything from rubber gloves, to treatment for opportunistic infections—to families. These high costs force many families to make terrible sacrifices. One boy told Asia Catalyst how his parents had gone deeply into debt and sold everything they owned to pay for his treatment, and said that his sister had given up her own schooling in order to work and earn money for his care. Six months later, the family ran out of funds, and the boy passed away.

While the state has trained many doctors to treat children with HIV/AIDS, there are not enough of them. Families in Henan and Yunnan, two epicenters of China’s AIDS epidemic, spoke of rural doctors who failed to recognize its symptoms, and of hospitals that turned away HIV-positive patients out of unfounded fear of contagion. Despite efforts by China’s leaders to promote tolerance, discrimination and stigma are still widespread: several children said they had been told to leave their schools, and that other children and family members had cut off contact with them. Because of the devastating effect that discrimination can have on the whole family, and their lack of financial resources to pay for medical care, some parents are reluctant to even test their children for the AIDS virus.

The cumulative effect of all these challenges can be overwhelming for children and their parents. Some children interviewed by Asia Catalyst showed signs of severe depression and withdrawal. A few were abandoned by their overwhelmed families; in one case, parents left their HIV-positive teenager laying at a hospital door. Counseling and support

are largely unavailable to help young people, and their families, to cope with the burden of growing up HIV-positive.

In December 2007, President Hu Jintao said, “AIDS prevention and control is an international problem. The Chinese government has paid special attention to the issue, always provided the greatest care to HIV-positive people and AIDS patients, and has earnestly fulfilled promises to curb the spread of the illness.” China has made progress in the fight against AIDS; but the voices of children in this report call on China and international supporters to expand their efforts.