

## India failing children orphaned by AIDS

Despite being signatory to international conventions on children and HIV/AIDS, India is apathetic to the plight of children orphaned by the disease, say campaigners. Bharathi Ghanashyam reports.

13-year-old Seema lives with her grandmother Susheela and three other orphaned cousins, in a dark, poorly ventilated two-room tenement in a slum in Bangalore, the capital city of Karnataka state, southern India. She has lost her parents to AIDS, is HIV-positive, visibly malnourished, and has cataracts in both eyes. Seema is not yet on antiretroviral therapy (ART) as she has a healthy CD4 cell count, but she often becomes ill with fevers and body pain, which her grandmother attributes to the “worms” that she has in her blood.

Susheela, who is the sole guardian of the children, has asthma and a heart ailment. She was running a small business selling short-eats from a pavement stall until recently, but is too ill to work now and has no income. The family has no access to support other than some food items provided to them once a month by Milana, a family support group for HIV-positive people based in Bangalore.

Seema is just one of the indeterminate numbers of children that have been orphaned by HIV/AIDS in India. Stories similar to hers are being played out in thousands of homes across India and in Karnataka. But India's response to caring for these children remains wanting, say campaigners.

3 years into National AIDS Control Programme Phase III (2006–11), which places special focus on medical treatment and after care, access to schooling, and adequate nutrition, government interventions for AIDS orphans are conspicuous by their absence in any area other than paediatric ART.

While estimates for children orphaned by AIDS are unavailable there is evidence that 3.8% (nearly 100 000) of an estimated 2.5 million people living with HIV/AIDS in India

are children. UNICEF estimates that there could be about 4 million affected children in India, located mostly in the high HIV-burden states of south and northeast India (affected children include those living with HIV or those who are orphaned by AIDS, and children whose parents are living with HIV).

**“2 years after the policy framework was released, it exists largely on paper, and children continue to be deprived of most of their rights.”**

Jyothi Kiran, founder of Milana, which gives comprehensive support to roughly 300 children affected by HIV says, “children are the worst affected by the problems that HIV brings with it. They suffer severe stigma and neglect and are very often abandoned. Orphaned children are denied even basic necessities like food and nutrition by their extended families. If they are themselves HIV-positive, the situation becomes worse and their very existence is threatened”.

If they have ailing parents, children are likely to be withdrawn from school

to care for them or to go out and earn. 10-year-old Anand is HIV-positive and has lost his father to AIDS. His father was the only working member of the family and after his death they have no income. His mother is HIV-positive too and unable to work. Anand and his mother live in rented premises, from which they expect to be evicted soon because they have not paid the rent for over 6 months. He has been withdrawn from school as Anand's mother cannot afford his school fees. He often goes to the ART centre alone for his monthly medication and there are occasions when he has missed appointments because his mother cannot afford the bus fare.

India has a duty to care for children like Anand, especially since it is a signatory to several international conventions and declarations on children and HIV/AIDS. The Government of India acceded to the UN Convention on the Rights of the Child (CRC) including protection against HIV/AIDS in 1992. Further, at the UN General Assembly Special Session on HIV/AIDS in 2001, India pledged to protect children affected by the epidemic. In June, 2006, the UN General



An Indian woman who is foster mother to an HIV-positive girl holds her in her arms outside her home



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Non-governmental organisations provide educational support for Indian children orphaned by HIV/AIDS

Assembly adopted the Political Declaration on HIV/AIDS, which reiterated government commitment to "addressing as a priority the vulnerabilities faced by children affected by and living with HIV; providing support and rehabilitation to these children and their families, women and the elderly, particularly in their role as caregivers; promoting child-oriented HIV/AIDS policies and programmes and increased protection for children orphaned and affected by HIV/AIDS;...and building, where needed, and supporting the social security systems that protect them".

Following on from this declaration, in July, 2007, the Ministry of Women and Child Development and National AIDS Control Organization released the *Policy Framework for Children and AIDS*. This policy acknowledges the need to realise the basic rights for all children as under the UN CRC for children affected by HIV/AIDS and has a goal of reaching 80% of the children most in need by 2010.

2 years after the policy framework was released, it exists largely on paper, and children continue to be deprived of most of their rights. Suresh Shastri, regional coordinator, Karnataka state AIDS Prevention Society, says: "We have achieved a degree of success with testing and access to treatment, but

there are still gaps in other areas such as education, nutrition, etc, and we are working on plans to address them."

At the beginning of 2009, the Department of Women and Child Development, Government of Karnataka, allocated a yearly budget of Rs 1 crore (US\$200 000) specifically for the needs of affected children. But 10 months later, the budget remains unspent. Narmada Anand, deputy director of the department, rationalises the delay, "we are in the process of determining how best this money can benefit affected children. It is important to put systems into place and governmental procedures cannot be hastened".

Christy Abraham, theme leader for HIV and AIDS for Action Aid India, says: "The situation points to apathy on the part of the state. The excuse is that there is no knowledge on the number of children who need help and where these children are. Is the state not capable of developing a system for identifying the children most in need and providing them protection?"

This situation means that it is mainly non-governmental organisations and HIV-positive network groups that are working to reduce the effect of HIV/AIDS on children in India. They provide nutrition supplements, referrals to testing and treatment

facilities, treatment for opportunistic infections, education support, and linkages with existing government child welfare schemes for children who need them.

"We are able to reach only a fraction of those in need of help. The value of our interventions, however, lies in the fact that we have established the difference that comprehensive support can make to the lives of affected children", says Lloyd Troy Cunningham, care and support specialist for orphaned and vulnerable children at Engender Health, an organisation that works with these children in Karnataka.

Ivonne Camaroni, chief of UNICEF's HIV programme in India points out, "As a nodal ministry, MWCD [Ministry of Women and Child Development] is in a strategic position to ensure access to basic services for affected children in collaboration with other concerned departments, especially through its two flagship programmes Integrated Child Development Scheme and Integrated Child Protection Scheme."

But campaigners are worried about the amount of time that it will take to get plans and programmes specifically for children orphaned by HIV/AIDS off the ground. They fear that in bureaucratic India, the government will have to wade through yards of red-tape before putting systems into place.

The National Commission for Protection of Child Rights, in collaboration with Action Aid, held a public hearing in December, 2009, to draw attention to the plight of children affected by HIV/AIDS in India. Shanta Sinha, chairperson of the commission, presiding over the public hearing pointed out that there was a wide gap between policy formulation and the plight of children. She said: "Government and non-government organisations should put their heads together to fill up these gaps. We need to evolve specific solutions without waiting for larger policy initiatives."

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The names of all children and their relatives have been changed to protect their identities.