

By Shelley Seale

Yesu Babu of Vambay Colony in Vijayawada is 12. He has lost both his parents to AIDS. His younger brother is positive. There are almost 2 million AIDS orphans like him in India. But the national and global response to the HIV/AIDS crisis in India has virtually ignored children



Durgamma outside her house in Vambay Colony Imagine you are a 12-year-old boy. You live in India, on the outskirts of a town called Vijayawada. Your name is Yesu Babu.

Your home is a tiny two-room concrete block, approximately 200 square feet, in a slum known as the Vambay Colony. Imagine that you share this small home with your grandmother, Durgamma, and your 9-year-old brother. You live with your grandmother because your parents died of AIDS – first your father, who brought the infection home, in 2001, then your mother in 2004. There was no one left to take care of you and your brother except your elderly grandmother, who never expected to be raising two more children at this age.

Soon you learn that although you are HIV-negative, your young brother is HIV-positive. He begins to grow ill. He battles many infections. He cries in the night when he's sick and calls for his mother. There is no one else to provide an income for this new family that has formed. So you let your brother go to school, although for what future is painfully unclear, while you go to work.

You are 12 years old. You know you should be in school. You should have a childhood, but it has been traded in far too soon for adult work and worries, for hardships that no 12-year-old should ever have to face. But what can you do? There is no one else. There is no other way. From a normal life with a mother and father, school, a childhood, possibilities – to this previously unimagined reality.

This is your new normal. Imagine.

The children are everywhere in India. They fill the streets, the railway stations, the villages. Many of them are homeless, overflowing the orphanages and other institutional homes to live on the streets. Amidst the growing prosperity of India, there is an entire generation of parentless children growing up – 25 million in all, with nearly 4 million more being added each year. Many are trafficked into prostitution or child labour in conditions amounting to slavery. They are invisible children, shunned by society and often their own families. Left to fend for themselves, they are virtually unnoticed by the world.

Nowhere is this more true than among the nearly 2 million children who have lost their parents to AIDS, the most AIDS orphans of any country and expected to double within five years. India is now home to the largest HIV-positive population in the world with 5.7 million infected, accounting for 15% of all cases globally. In May 2006, the Joint United Nations Programme on HIV/AIDS (UNAIDS) reported that India had overtaken South Africa to become the first non-African country to report such alarming numbers. The disease is silently spreading and reaching critical proportions. Almost 1% of people in India's six most populous states are HIV-positive, and 20 out of 37 states show high-prevalence areas. The sheer size of India's population – more than 1 billion – makes a widespread AIDS pandemic almost unimaginable. The one percentage figure is deeply disturbing to health officials because it is regarded as the tipping point, at which a smoldering health crisis can explode into an epidemic of vast magnitude.

Sitting in her small house, Grandmother Durgamma spoke to me about her life. “It is very hard taking care of my two grandchildren. I have leg pains, I cannot run with them. I want to take care of them but it is hard. I am only one. I am always thinking about their futures. If something happens to me, when I die, what will happen to them? I don't need anything for myself. I am living only for my grandsons.”

Hers is a familiar story in Andhra Pradesh, the epicenter of the crisis with the highest infection rates in the country. The pandemic has created a secondary human rights crisis – the orphaning of children on a massive scale. UNAIDS reports, “Orphaning remains the most visible, extensive, and measurable impact of AIDS on children.”

The trend of grandparents raising grandchildren has become so prevalent – as many as 40% of these orphans live with their grandparents – that VMM (Vasavya Mahila Mandali) and similar organisations have started what they call Granny Clubs. These are social and educational networks of women (and some men) like Durgamma who are caring for orphaned grandchildren. The granny clubs generally have 10 to 15 members who meet once a month, with social time and education about various topics. At one meeting, they might learn about HIV medications and treatment, at another, the subject might be nutrition. The time is also used to make friendships, share problems, and offer solutions.

“Sometimes we play games or sing,” Durgamma told me about her club. “We have become friends, like sisters, and we support each other. We are older people who have watched our children die. We share our joys and our sorrows.”

Ramulamma is another active granny club member in Vambay Colony. She lives with her granddaughter and great-grandson Krishna, who is HIV-positive. Krishna was so tiny I would have guessed him to be a boy of four or five years old, when I inquired I was told that he is nine. Krishna's mother, the breadwinner of the family, was at her job as a hotel maid in Vijayawada the day I visited. She earns Rs 40 per day, although it costs her Rs 10 to travel into town and back. They are a family with three generations affected by HIV: Krishna's father died two years ago, and his grandfather died just the month before my visit, both from AIDS. Krishna and his grandmother gazed at me listlessly as we spoke, both of them with the same vacant, hopeless eyes. In Vambay, it seemed death was not a feared stranger but a constant, familiar

companion.

VMM provides doctor care and medicine every month for Krishna, as well as a local physician who is available for immediate needs, but he is not on ART therapy currently because he is not deemed sick enough. In India, CD4 blood count levels must be 200 or below to qualify for ART drugs – the level at which HIV is medically considered to have become full-blown AIDS. Only 7% of HIV-positive people were receiving any Anti-Retroviral Treatment in 2005. In the United States, ART is started well before this time to prevent AIDS, generally at CD4 levels of 300 to 350. Krishna continues to have regular blood tests so that ART drug treatment can be started as soon as his condition qualifies.

In spite of their plight Krishna and Yesu are among the lucky children because they have family to live with. For every child fortunate enough to live in a family home there are a thousand more who have nowhere to turn. Those without any kinship ties – or whose families refuse to take them in because of the stigma of AIDS – often end up in institutional homes, forming child-headed households, or simply on the streets. They are the missing face of AIDS, these children left behind.

India's crisis is acute in part because the country has done little to protect children affected by HIV/AIDS, and has no provisions at all for those orphaned. At the VMM office before my visit to Vambay Colony, Keerthi Bollineni said that the national and global response to the HIV/AIDS crisis in India has virtually ignored children. It is a sentiment I heard over and over, from every organisation and social worker I talked to. Resources for orphans and other children made vulnerable by HIV/AIDS have increased in recent years, but funding for these programmes is nevertheless small. An enormous gap exists between what is needed and what is actually being done to address the needs of children affected by AIDS.

The response to AIDS in India has focused primarily on high-risk target groups: the sex trade, truckers who spread the infection from town to town, and drug users. 80% of AIDS funding goes toward prevention in the high-risk populations, and only 20% to caring for children and families living with HIV. Kanika Singh, Executive Director of Heroes Project India, confirmed this. "Young people and women are the two vulnerable groups today. One out of every three people infected with HIV is a woman, and 80% of these women are housewives. That has a direct link to children. They unknowingly pass on the infection to their child." Mother to child transmission is the most common source of infection in children at a rate of 30,000 per year, but they are also acquiring HIV through blood transfusions, syringe injections, and consensual or non-consensual sexual contact. But, added Kanika, "Nobody talks about HIV-positive children."

Stigmatised through no fault of theirs, these children are far more vulnerable to abuse and exploitation. A Human Rights Watch investigation uncovered discrimination on a constant basis: segregation and expulsion from schools, refusal of treatment by doctors, rejection from orphanages and even their own family homes. "Children are being turned away from schools, clinics and orphanages because they or their family members are HIV-positive," reported Zama Coursen-Neff, a senior researcher with Human Rights Watch. "If the Indian government is serious about fighting the country's AIDS epidemic, it should stop ignoring children affected by AIDS and start protecting them from abuse."

Becoming orphaned is not the only way children are affected by this epidemic. There is also a devastating impact on their emotional and psychological wellbeing. “They are missing their entire childhoods,” said Dr Deeksha Pillarisetty, Medical Director of VMM. “They go immediately into adulthood at a very young age.” VMM estimates that 25% of children affected by AIDS live in child-headed households, a trend of particular concern. Dr Pillarisetty described the trauma these children face with no adult support. They are the most common caregivers for sick parents and eventually watch those parents die – after which they all too often must step into adult roles themselves, becoming the guardians of younger siblings or working to support their remaining family. They may be denied their property and inheritance rights, often face discrimination from their neighbours, and must deal with fears for their own health. Alarming new evidence by UNAIDS found that orphans and vulnerable children have a higher risk of exposure to HIV than non-affected children.

Girls are especially vulnerable. They are more likely to be removed from school to care for sick parents or other family members and are often the last in the family to receive medical care. Loss of family income can push them into the sex trade and inability to control safe sex, even within marriage, puts them at a disadvantage. Less access to education, sexual abuse and child marriage all place girls at higher risk of becoming infected. Many families marry daughters off at increasingly young ages so the girls will have someone to care for them after their parents die. Parents are also afraid of HIV rendering them unmarriageable, a finding that the Human Rights Watch investigation corroborated. This has the added effect of creating a lot of very young widows. Dr Pillarisetty sees a lot of girls widowed by the age of 18. One of them was married at the age of 13, widowed at 14, and is now 15 years old and living with HIV. Often these widows are blamed for the husband’s death and outcast by his family.

On the flip side, the potential impact these children will have on the epidemic as they grow up is also an area of concern. As they become sexually active, the lack of education about transmission and prevention and poor role models are likely to contribute to the spread of the infection. Missing family ties, they often form unhealthy attachments in which they are vulnerable to abuse. “They just want a relationship – it doesn’t matter what kind it is,” Dr Pillarisetty said. “There is nobody for them, nobody wants them. They are very traumatised.”

There are more children living in India today with HIV-positive parents than children already orphaned. If those parents are not treated and continue to die the worst impact on children is still to come, and scarcely comprehensible.

The face of India’s future if it fails in the battle against HIV lies in a small village called Cherlopalem in rural Andhra Pradesh. Cherlopalem is home to 30 families of dalits, a farming community surrounded by lush green fields that now stand empty. Three-fourths of the residents have been affected by AIDS. Seven people have died within the past eight months and dozens more are in the last stages, leaving many children behind without any sort of supervision. On April 8, 2007 the Eenadu newspaper reported, “The village, known for its hardworking lifestyle, is now ravaged by a cureless malady.” The article accused officials of doing nothing. The remaining residents confessed that they knew nothing about the “dreaded disease”. They do not know how it transmits or what precautions will protect them.

Cherlopalem is a microcosm of the ability of AIDS to unravel the social fabric of entire communities. It is clear that a failure to address the looming crisis in India will have dire consequences for the country, its children and the world for generations to come. A childhood cannot wait for the AIDS epidemic to subside, for poverty to be eradicated, for adults and governments to act, for the world to notice them.

(Shelley Seale is a freelance writer based in Austin, Texas. She is researching a book titled The Weight of Silence: Invisible Children of India on India's 12 million orphans).

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