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Children and young people affected by HIV/AIDS in India

Challenges and emerging issues

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According to the latest statistics released by the National AIDS Control Organisation (NACO) and UNAIDS, India has an estimated 2.5 to 3.1 million people living with HIV (PLWH) including children under 15 years and those aged 50 and beyond.¹ The adult HIV prevalence is 0.36% and the majority of HIV infections are in men aged 15 to 44 years. Nearly 40% of PLWH in India are women. It is estimated that some 70,000 children below the age of 15 are infected with HIV and 21,000 children are infected every year through mother-to-child transmission (Updated NACO estimates 2007). The country has an increasing population of children living with HIV and those who have lost either one or both parents to an AIDS-related illness. However, there are no official estimates available on children affected and orphaned by HIV and AIDS in India. Some of the HIV high prevalence states in India such as Karnataka, Tamil Nadu, Andhra Pradesh, Maharashtra, Manipur and Nagaland are grappling with increased numbers of children infected and affected by HIV and AIDS. There is an emerging trend of child-headed households and increasing number of children caring for sick parents and siblings. An increasing number of street and working children over the last decade could also be a reflection of the emerging AIDS crisis.

Often, children from families affected by AIDS drop out of school to care for sick parents or to earn a livelihood for their families. Lack of information on STIs and HIV, peer pressure and lack of access to clinical care increases their vulnerability and risk to HIV infection. Discrimination, combined with a failing public health system, leave many affected children without even the rudiments of healthcare. Girls are especially vulnerable to HIV infection if they are targeted for sexual abuse or have less access to information about HIV prevention and related issues. In addition, there are the direct effects of stigma and discrimination: the denial of health care, education, and family or institutional care.

What is being done in India?

A number of international and local organizations have been working on issues of prevention, care and support for children living with and

affected by HIV and AIDS. However, the current programming by these organizations, even though innovative, has had limited geographical coverage. There has been no long-term planning as funding has been time-bound and uncertain. The government has also not addressed this group with focused interventions and as a priority but that is slowly changing. There are also knowledge gaps due to lack of clear understanding of the magnitude of the problem, proven approaches that work, and limited availability of standardized programming tools to enable scaling up.

Programme highlights from one organization and one PLWH network in India working with children infected and affected by HIV and AIDS are given below. These two examples illustrate two different approaches: a) a comprehensive intervention for children in a high HIV prevalence district and b) the efforts of a network of positive women advocating for children.

St. Paul's Trust is an organization based in the HIV high prevalence district of East Godavari in Andhra Pradesh. They work with orphans, children infected and affected by HIV and AIDS and their families. The initiative is comprehensive and includes HIV prevention, care and support programmes within an enabling environment. The

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project has adopted a broad community-based approach to cover all households in the community and reduce stigma and discrimination. The emphasis has been on providing a basic package of services including medical care, nutritional, educational, psychological, legal and livelihood support. The programme also builds linkages between government services and PLWH networks. The approach has helped to lower stigma and discrimination.²

Positive Women Network (PWN+), based in Chennai, Tamil Nadu, is an affiliated organization of the Indian Network for People Living with HIV/AIDS (INP+) and works exclusively for women and children infected and affected by HIV in India. The objective of their work with children is to ensure access to quality education, health and safety for children living with and affected by HIV and AIDS in an environment without bias. Some of the key activities include establishing services for children of women living with HIV including crèches; advocating with the Department of Education, schools, parents, teachers associations and youth groups to protect children against discrimination in educational institutions and sexual abuse; advocating for access to medication and pediatric formulations specific for children living with HIV; and child counselling services and life skills education for all children irrespective of their HIV status.³

Challenges and emerging issues

Two emerging challenges are the issues of child-headed households and understanding the effectiveness of community foster care in the Indian context. In the Indian context, community foster care means that a child is placed in a family to which it is not biologically related. Adoption and fostering of such children has not been a traditional practice in the country. However, this is gradually changing. Most orphaned children are still in institutional foster care (orphanages). The India HIV/AIDS Alliance in collaboration with the Tata Institute of Social Science conducted a research in 2006 to develop greater understanding of the problems, needs and challenges of children heading households and children in community foster care in India.⁴ The study shows that especially children who head households face tremendous challenges and are vulnerable to exploitation. Though inadequately prepared, they have to move into adult roles. It also brings to the attention the advantages and disadvantages of community foster care. The fact that the community is coming forward to take care of the needs of orphaned children is definitely a positive sign. The findings accentuate the need for immediate responses at all levels in order to protect children from abuse and exploitation. The report concludes that there is a need to strengthen the support systems for PLWH and children affected by AIDS. Also, the physical and mental health

needs of PLWH and their children need to be identified and addressed.

A lot needs to be done in a country as vast and diverse as India with high levels of stigma and discrimination. Government policies are gradually being formulated and the issue of children infected and affected by HIV and AIDS is being recognized as critical. For the first time, through the third phase of the National AIDS Control Programme (NACP-III) launched in July 2007, the national and state governments are planning to increase their commitment to strengthen HIV treatment, care and support for children infected and affected by HIV and AIDS and their family members by expanding policy initiatives and committing resources more than ever before. For instance, 39,000 children living with HIV will be able to access ARVs for free. The Ministry of Women and Child Development will be the focal point for children affected by AIDS bringing them within the child protection umbrella. Also, minimum standards of care and protection will be established for institutional and community-based foster care systems.

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1. UNAIDS website: http://www.unaids.org/en/MediaCentre/PressMaterials/FeatureStory/20070704_India_new_data.asp
2. More information about St. Paul's Trust: Dr. K.I. Jacob, St. Paul's Trust, Opp. MRO Office, Samalkot-533 440, East Godavari District, Andhra Pradesh, India. Tel: +91 884 2327634, fax: +91 884 2329699, e-mail: stpacfi@rediffmail.com / drkijacob@rediffmail.com, web: <http://aidscontrol.org>.
3. More information about PWN+: P. Kousalya, Positive Women Network (PWN+), 9/5, Shanthi Apartments, Avenue Road, Nungambakkam, Chennai-34, Tamil Nadu, India. Tel: +91 44 28270204, 28203959, e-mail: poswonet@hotmail.com.
4. *A situational analysis of child-headed households and community foster care in Tamil Nadu and Andhra Pradesh States, India. A study conducted by India HIV/AIDS Alliance and Tata Institute of Social Science, 2006:* <http://www.aidsalliance.org/sw41834.asp>

Resources

on children affected by HIV and AIDS

Information sources:

- International HIV/AIDS Alliance's support toolkit on orphans and other vulnerable children: <http://www.ovcsupport.net> (also available on CD-ROM, order online or via publications@aidsalliance.org)
- AIDSPortal page on children affected by HIV and AIDS: http://www.aidsportal.org/overlay_details.aspx?nex=2
- Bernard van Leer Foundation: http://www.bernardvanleer.org/publications/browse_by_topics
- Ccaba – The Coalition on Children affected by AIDS: <http://www.ccaba.org>
- Avert: <http://www.avert.org/children.htm>
- UNICEF: <http://www.unicef.org/aids/>
- Eldis Resource Guide: <http://www.eldis.org/go/topics/resource-guides/hiv-and-aids/children-and-young-people>