# ORPHANS AND VULNERABLE CHILDREN IN INDIA:
## Understanding the Context and the Response

**Report on Town Hall Meeting**

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**Abbreviations and Acronyms**

| | |
|---|---|
| AIDS | acquired immunodeficiency syndrome |
| ARV | antiretroviral |
| CABA | children affected by AIDS |
| CASP | Community Aid and Sponsorship Program |
| CHANGE | Center for Health and Gender Equality |
| CHES | Community Health Education Society |
| CHINAR | Child Nurture and Relief |
| FHI | Family Health International |
| FXB | Francois-Xavier Bagnoud |
| HIV | human immunodeficiency virus |
| IDTG | Informal Donor Technical Working Group |
| INSA | International Services Association |
| NACO | National AIDS Control Organization |
| NGO | nongovernmental organization |
| PLWHA | people living with HIV/AIDS |
| PMTCT | prevention of mother-to-child-transmission |
| PWDS | Palmyrah Workers Development Society |
| SAATHII | Solidarity and Action Against the HIV Infection in India |
| SOMARC | Social Marketing for Change Project |
| USAID | United States Agency for International Development |
| UNAIDS | The Joint United Nations Programme on HIV/AIDS |
| UNICEF | United Nations Children's Fund |

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## I. Background, Purpose, and Objectives

The Informal Donor Technical Working Group (IDTG) on Orphans and Vulnerable Children, in conjunction with the Orphans and Vulnerable Children Task Force and Plan USA, convened the fourth in a series of town hall meetings on June 2, 2003, in Washington, DC.

The IDTG, comprising representatives from USAID, the United Nations Children Fund (UNICEF), and other international organizations, meets three to four times a year, continuously adapting its purpose on the basis of the emerging needs of orphans and vulnerable children. The town hall meetings are a forum for exchange and learning in technical areas identified by IDTG participants. Previous town halls have focused on community mobilization and microenterprise as they related to children and adolescents affected by AIDS (CABA) and on responding to the educational needs of children affected by AIDS in sub-Saharan Africa.

Much of the IDTG's work has focused on orphans and vulnerable children in Africa. Participants were not as familiar with the needs of orphans and vulnerable children in Asia; India was identified as a starting point for familiarization. The objective was to begin a dialogue between people doing the day-to-day work with orphans and vulnerable children on the ground in India and people addressing these issues in Washington, D.C. The goals were to exchange information, share lessons learned, and continue the dialogue with those working in India who were unable to attend the meeting.

More than 60 people from the United States, Europe, and India gathered to exchange information and increase their understanding of the context and response in India. The meeting focused on understanding the needs of India, on sharing examples of successful programming approaches, and on the challenges, with a view toward defining a holistic approach to orphans and vulnerable children issues in India. Key speakers were from Francois-Xavier Bagnoud, Palmyrah Workers Development Society, Columbia University and Harlem Hospital, Family Health International/India, International HIV/AIDS Alliance, and Step Forward for Children Initiative.

## II. Welcome and Introduction

*Marie-Christine Anastasi*, AIDS Technical Officer from Plan USA, welcomed participants, thanked the planning committee, and briefly reviewed the history of past IDTG town hall meetings. She noted that many IDTG participants work on orphans and vulnerable children programs in Africa, where the AIDS pandemic has taken the greatest toll, and that several had expressed interest in learning more about similarities and differences in orphans and vulnerable children programming approaches in Asia, particularly India. The group saw this discussion as a learning exchange and a potential window of opportunity to "get ahead of the curve" by addressing increasing HIV infection rates and numbers of orphans in Asia. The ultimate hope is that, with earlier interventions, Asia will never see the number of children orphaned by AIDS that is currently seen in Africa. Ms. Anastasi thanked the presenters, several of whom traveled from India, for sharing their expertise with participants and expressed the intent that this meeting be just one of many dialogues that would continue in India and with additional in-country experts working with orphans and vulnerable children. She thanked Ambassador Princeton Lyman and the Aspen Institute for donating the meeting space and introduced Ambassador Lyman, who in turn welcomed the participants.

*Ambassador Princeton Lyman*, currently Executive Director of the Aspen Institute's Global Interdependence Initiative, explained that the institute is more than 50 years old. It originally convened corporate leaders to work on behalf of the betterment of society but has since broadened its reach to include young and emerging leaders around the world to deal with various issues from AIDS to global capitalism.

Policy programs are directed from headquarters in Washington. Many are domestic and deal with community issues.

HIV/AIDS is one of the greatest and most serious issues threatening the well-being of the world today. We are just beginning to understand and to acknowledge its implications and how to deal with it. The issue of children affected by AIDS is just now gaining the recognition and understanding it deserves. The Aspen staff is looking at how they can contribute to the battle against HIV/AIDS, as it cuts across almost every area of the institute's work.

*Maja Cubarrubia,* Chief Operating Officer of Plan USA/Childreach, welcomed the participants on behalf of the Orphans and Vulnerable Children Task Force planning committee. Ms. Cubarrubia described the twofold focus of the meeting: sharing of best practices and education of policy makers and donors. The hope is to define a holistic approach to orphans and vulnerable children issues.

Plan USA reaffirmed its commitment to advance orphans and vulnerable children issues so that they become priorities on national and international agendas. The ultimate goal of Plan is a world where all children will reach their full potential. Obstacles to that goal are the targets of Plan interventions worldwide as they work with local and national government agencies. The field is wide and the work is big, but working together can make it easier. The hope is that others will be inspired by what Plan USA does and says.

Ms. Cubarrubia briefly described some of Plan's work in India, Sri Lanka, and Africa. Plan works in Mysore on child survival and safe motherhood. Plan USA has reproductive child health projects in Delhi and works with the Social Marketing for Change Project (SOMARC) for young girls in Mumbai. In conjunction with the Community Aid and Sponsorship Program (CASP), Plan provides education and services to young street boys and restaurant workers. In partnership with Samascar, Plan supports children's assemblies and parliaments in which children shape policies that will benefit them. It works with RapidEd in Sri Lanka, serves as a core partner in the Hope for African Children Initiative, and operates child-focused, community-centered development programs in more than 40 countries.

*Gretchen Bachman,* Senior Technical Officer of Family Health International, reviewed the schedule and announced that after lunch there would be an open sharing session for participants, moderated by Jeff Richardson from Abbott Laboratories Fund-Step Forward for Children Initiative.

## III. Keynote Speech

*Anil Purohit,* Executive Director of Francois-Xavier Bagnoud (FXB) U.S. Foundation, delivered the keynote address, and welcomed the participants, especially those who had traveled from India, London, and Boston. He has worked with FXB since 1998.

Hopefully this meeting is just a beginning. India has the highest number of orphans in the world for many reasons, not just because of HIV/AIDS, and we can no longer afford to ignore that fact. Women and children do not always come first in the global world. Orphans often do not have value.

Countess Albina, founder of FXB, wanted to use her resources to rescue children in forgotten places. Thus, FXB lobbies for full implementation of the United Nations Declaration of the Rights of the Child. It is difficult to be registered as a nongovernmental organization (NGO) in India, but FXB finally managed to do so in 2001, and now FXB works with UNICEF and other organizations as partners in all states and territories of the country. With the support of many local mayors, FXB managed to declare an 'AIDS Orphans Day' to raise awareness of the situation of children affected by AIDS in India

FXB has worked in Rajasthan on rural awareness projects that aimed to alleviate the stigma attached to orphans whose parents had died from HIV/AIDS. Often, even close relatives would not take them in. One project involved migrant workers that go to the cities and bring the disease home**.** A typical story involves a 72-year-old man suffering from tuberculosis who came into the clinic with his seven-year-old granddaughter. Her parents had died from AIDS. She had two brothers. The thirteen-year-old brother worked in Mumbai and the nine-year-old was a carpenter. Thanks to the grandfather, the girl was going to school, but he was worried about what would happen to her when he died. He wanted to live until she could marry and thus secure her future.

Lack of education and awareness are the biggest issues. If field workers do not talk to local governments, the governments will not face problems. The World Bank is meeting on AIDS in Delhi, India, on June 8 of this year. There should be a push to look into including orphans and vulnerable children on the agenda at that time. We should also concentrate on the validity of our development objectives, evaluate institutional arrangements, and identify future directions of AIDS programs. Currently, some programs define orphans as children up to the age 15; that should be extended to age 18.

Street children are an especially vulnerable group in India. Their lack of parental support means they are all orphans. They often abuse drugs and alcohol and are vulnerable to sexual abuse and recruitment as criminals. They are highly mobile and are difficult to reach with public health programs. Children of sex workers, both boys and girls, are another highly vulnerable group often recruited into sex work or crime.

India also has the phenomena of *de facto* orphans. Children of sick parents have to drop out of school to take over their parents' roles. "Maternal" orphans have to take responsibility for household tasks and child rearing. "Paternal" orphans may have to find jobs, including migrant work. If the widow goes to work, the children become maternal and paternal orphans. Children are also often placed in orphanages for reasons other than the death of parents. These include parental abuse of alcohol and drugs, mother's sex work, mental illness, or divorce.

## IV. Plenary Panel 1

### Orphans and Vulnerable Children Program Issues within the Context of the Overall Social Impact of HIV/AIDS

*Neil Monk,* Orphans and Vulnerable Children Advisor for FXB, worked in Uganda before India.

What is social impact? Society is dynamic. It evolves and adapts in response to the environment. War, revolution, and disasters command responses to changing circumstances. Those responses become social impact. Disease and public health issues are no exceptions, especially when they reach pandemic proportions. The response can be negative or positive. Preceding events also have an impact; for example, war, poverty, and labor and gender inequalities have had an impact on the spread of HIV. The initial impacts of HIV/AIDS are mortality and morbidity; these demographic impacts become social impacts as the number of adults who can act as caregivers decreases. The graph of the projected population structure with and without AIDS in Botswana in 2020 vividly illustrates this point.

Morbidity also has a social impact that is often forgotten. Seriously ill people cannot work. Productive labor is diverted to caring for them and to meeting growing medical expenses, which reduce family income. Children are then taken out of school to work. Loss of productive labor on farms increases the length of the workday, reduces crop yields, and negatively affects nutrition. In short, children of ill parents effectively become orphans.

Other factors or externalities have an impact on orphans and vulnerable children. Migrant labor is an integral part of AIDS in India, as it is a common source of income for rural families. Typically, fathers work outside the city for extended periods, during which time some engage in risky behavior (34.4 percent admitted to having sex with sex workers, according to the FXB Mumbai baseline survey) and return home with HIV. Widows may borrow money on the future labor of children, especially boys, which puts great pressure on them. Migrant labor is often their only possibility, and some start as young as age 12.

In Rajasthan in 2000, only 28.69 percent of females were literate, compared with 64.83 percent of males. Where female literacy is low, girls are less likely to go to school. Increased orphaning further undermines education programs aimed at girls because with little money for school, boys get priority. A case study illustrates this point. In a rural Rajasthani household in 1997, a husband, wife, and their five children lived on the 1,000 rupees a month the husband earned as a migrant worker. The oldest child was a seven-year-old girl. She and her five-year-old brother were in school. At home were a three-year-old girl, a one-year-old boy, and a newborn boy. In 1998, the husband died and household income was uncertain. The elder girl dropped out of school, but the eldest boy did not. In 1999, the family income was 500 rupees a month. The eldest boy was still in school, but neither of his sisters was. In 2001, the family income had not increased. The eldest boy was still in school and his younger brother had started, but it was uncertain if either could continue. There was no money for the youngest boy to start. The girls were working in the home so their mother could work outside.

Analysis of social impact shows what is happening and what needs to be done and can direct community-based programs. It demonstrates the root causes of problems and how communities are coping or failing to cope.

The impact of the AIDS crisis on sociocultural factors must also be assessed. Morbidity can have as great an impact as mortality. How does HIV/AIDS affect existing programs? HIV/AIDS has an impact on the entire framework for orphans and vulnerable children support. Orphan-focused programming is not enough. Cooperation with non-AIDS programs is essential.

**Orphans and Vulnerable Children: Community Responses and Emerging Future Options**

*D.T. Reji Chandra* is the Director of the Palmyrah Workers Development Society (PWDS), founded in 1977 as a development support organization for Palmyrah artisans in Tamil Nadu. PWDS works in agriculture, enterprise and marketing, microfinance, construction, child care, education, and health. PWDS does not specialize in HIV/AIDS, but the society has been working for two and a half years with orphans and vulnerable children in 13 southern districts of Tamil Nadu, in partnership with 20 NGOs.

Children affected by HIV/AIDS often do not attend school because of the stigma associated with HIV, because ailing parents cannot pay school fees, or because their parents migrate. These children face starvation, forced labor, prostitution, and abuse, and they are denied their property rights.

Community mobilization is essential. Rather than providing new services or infrastructure, PWDS aims to strengthen and mobilize existing ones. The self-help group is the basic unit. Community-based NGOs are integrated into ongoing programs. The constraints they face include rural poverty; illiteracy; cultural practices; a fatalistic attitude; project limitations; lack of resources, capacity, and services; and stigma associated with HIV and orphans (“cursed children”). Volunteers, including religious leaders, are keys to success.

PWDS has encountered several problems in its work with orphans and vulnerable children. One problem is assigning responsibility for orphans and vulnerable children. The community has a role, but so does the state. Overall, responsibility is a gray area. Another problem is using existing facilities. People with and affected by HIV/AIDS should not have to start their own schools and hospitals. If, however, parallel services must be offered, how long should they last before they feed into existing ones? Focusing help on HIV when there are street children in worse conditions also can be a problem. Rigid project approaches do not work, as villagers do not see their lives in sectors. A lack of supportive policies affects sustainability.

HIV aggravates all the existing problems of children, but there have been positive experiences. In Sathankulam, a seven-year-old child was sent out of school because of HIV in the family. PWDS worked long and hard to convince everyone in the community to let the child back in. This act set an example that has had far-reaching effects, as it has been frequently cited as a precedent. That same community has started a scholarship program for HIV-affected children. Another community mobilized to provide a daily handful of rice to orphans and vulnerable children. Again, it involved lots of persuasion, but the impact has been sustained.

PWDS believes that building on positive experiences, however small they may be, is the right approach. The way forward involves initiating integrated interventions, promoting collective functioning, mobilizing community participation, and enabling mainstream linkages for sustainability.

**Prevention of Mother-to-Child Transmission of HIV:**
**Program Highlights from India**

*Dr. Sai Subhasree Raghavan* is Assistant Professor in Clinical Nutrition Medicine at Columbia University, Program Director of the HIV Nutrition Program at the Harlem Hospital Center, and Director of SAATHII (Solidarity and Action Against the HIV Infection in India). She is also a faculty member in the Department of Epidemiology in the Joseph Mailman School of Public Health at Columbia. She coordinates prevention of mother-to-child-transmission (PMTCT) programs funded by the Elizabeth Glazer Pediatric AIDS Foundation in India.

India has the second highest number of AIDS cases in the world (3.86 million); only South Africa has more. This number represents 10 percent of the global burden and 68 percent of the total burden for South Asia. The prevalence in the 15–49 age group is 0.8 percent. AIDS is no longer restricted to high-risk populations; instead, it is spreading rapidly in the general population.

In a landmark decision for PMTCT in India, the Global Fund for AIDS, Tuberculosis, and Malaria awarded the project $100.8 million to scale up interventions at 444 public and private institutions by 2008. Of those, 365 are in the high-prevalence states (Maharashtra, Andhra Pradesh, Karnataka, Tamil Nadu, Manipur and Nagaland). The Elizabeth Glazer Pediatric AIDS Foundation awarded $1.2 million to advance programs at 25 private institutions in the same states. Together these states account for 90 percent of all HIV/AIDS infections in the country. Each state has at least one district where prevalence exceeds 2 percent among antenatal women (in some it exceeds 5 percent), and 90 percent of them are unaware they are infected.

One of every four people infected with HIV in India is female. Most are married and monogamous. The epidemic is fueled by illiteracy, ignorance, poverty, migration, lack of openness and myths about sex, inadequate health facilities, lack of STD treatment, drug use, lack of anonymous testing, and inadequate support programs for vulnerable groups (sex workers, men who have sex with men, IV drug users, truck drivers, housewives). Gender inequalities that overlap with poverty, illiteracy and social inequalities are the driving forces behind the HIV epidemic in Indian women.

Of the 27 million annual pregnancies in India, 65.4 percent of women receive some antenatal care, 33.6 percent deliver in institutions, and 42.3 percent deliver with skilled birth attendants. The National AIDS Control Organization (NACO) estimated that, of the 27 million pregnancies in 2001, at least 100,000 occurred in HIV positive women, creating a potential cohort of 30,000 infected babies and 70,000 uninfected future orphans per year. In the same year, UNAIDS estimated that approximately 170,000 children in India, under age 15, were already living with HIV/AIDS. The Global Fund grant will be used to provide women of child-bearing age and their families with a package of primary prevention, including family planning, voluntary counseling and testing, antiretroviral (ARV) prophylaxis, and counseling on infant feeding. Programs will begin in 125 institutions in 2003 and will be in all 444 by 2008. The breakdown is as follows: 81 medical colleges in high-prevalence states; 155 district hospitals in high-prevalence states; 129 maternity and private hospitals in high-prevalence states; and 70 medical colleges in low-prevalence states.

The PMTCT program will offer HIV prevention counseling and testing to 7 million pregnant women and their families every year. Nearly 350,000 HIV-positive pregnant women will be identified to receive ARVs and to link their families to HIV/AIDS care. Unfortunately, of the 350,000 HIV-positive women identified, only 4,500 will initially receive ARV treatment from four NGOs. In the absence of therapy, 345,500 of these women will die in five to ten years, leaving behind 345,500 to 500,000 orphans and vulnerable children. The Global Fund money will provide 2,200 health care workers and will fund 1,300 NGOs to train workers in AIDS care. But can they care for 350,000 HIV-positive pregnant women and their families? How long and what kind of care can they provide? And what about the HIV, medical and psychosocial care for these families after PMTCT interventions are completed? Who will continue the work when the Global Fund grant is finished? Annually, 100,000 HIV-positive women give birth in India. In the absence of ARV therapy, there will be more than one million orphans and vulnerable children to care for in five to ten years.

## V. Question and Answer Session

**Q:** Is there a comprehensive policy on orphans and vulnerable children in India?
**A:** No. Orphans are often even denied property inheritance, and courts are slow to act to uphold their rights. Different states and villages have different responses.

**Q:** Is birth registration an issue?
**A:** Yes. Everyone does try to register births, but it is not easy. Migration is tracked by ration cards that also serve as ID cards. Without one, a person has no rights. A problem with sex workers' children is that they have no fathers. Without fathers, they cannot get birth certificates, and without birth certificates, they cannot get into school.

**Q:** Can there be state-level policies? Do any states have them?
**A:** Most HIV policies are formulated at the macro level, but implementation is at the state level. There has to be tying up (integration). The biggest problem is the lack of a national orphans and vulnerable children policy. Because of that, states cannot make policies on children affected by AIDS, so there are no state programs. There is a need to start something at the national level.

**Q:** Who will take over projects with time limits?
**A:** States do have a responsibility. For basic services currently provided by NGOs, there is a need to push states to take them on. It might be beneficial to bring NGO representatives to provincial committee meetings to advocate from the start. There is a mainstreaming approach identifying existing institutions to take over.

**Q:** There are many resources going into PMTCT, but we do not see many results. What are you doing to generate desirable numbers? What are your strategies?

**A:** The latest strategy in India is to provide services at antenatal clinics. Participation has been good, but we are struggling with the fact that women do not come back for AZT and breastfeeding advice. We advocate integrating government and NGO services to bring women back. PMTCT offers psychosocial care in the 444 national hospitals covered. Four NGOs offer care to 15,000 HIV-positive families. Additional resources are needed.

**Q:** What is the faith-based response in India, and what is their role?
**A:** There is lots of movement toward it, mainly among Christians and Hindus. Thousands of missionary hospitals are addressing the problem by becoming more involved in care. They have not succeeded at a mass level, however. Family Health International (FHI) and Catholic Relief Services are funding programs on children affected by AIDS.

## VI. Plenary Panel 2

### Challenges and Strengths in Addressing the Needs of Orphans and Vulnerable Children in India: Lessons from a Child Participatory Methodology

*Dr. Bitra George* is Associate Director, Program and Technical, of FHI/India.

The needs of orphans and vulnerable children (including street children), the children of sex workers and rag pickers, and those infected and affected by AIDS in India are vast. The response to date has not minutely met them. There are different ways to reach out to the most vulnerable, especially street girls, substance users, and working children. They have a diversity of needs, as we learned from street children programs. A safe shelter, food, and clothing come first; HIV comes later.

There are different interpretations of the terms "children affected by AIDS" and "orphans and vulnerable children." USAID-funded projects were first children affected by AIDS projects. Now USAID and FHI look at orphans and vulnerable children within a larger definition, but general child development-child welfare models have no HIV/AIDS focus. Also, there are no reliable numbers. How does one measure coverage without a denominator? It is estimated that there are 3 million street children and after those come the children of sex workers and rag pickers.

Community-based care for children affected by AIDS is relatively new. Institutional care is the traditional approach, with tuberculosis and leprosy programs as models for delivery, but it is difficult to sustain and replicate and is not community owned. Most care for children affected by AIDS and for adults is still through institutions and is based on service delivery. NGO responses are limited more to vulnerable children.

Government response is limited. The Ministry of Social Justice and Empowerment funds some interventions that include street children and runs programs for children in difficult circumstances. Juvenile offenders are sent to remand homes. The National AIDS Control Organization does not have a policy on children affected by AIDS, though there is a program for prevention among street children. India also has a Ministry of Education, Ministry of Woman and Child Welfare, and Ministry of Health. All run their own programs; there is no integration.

In 1999–2000, FHI started with six programs for children affected by AIDS. We now have 13 children affected by AIDS projects with 20 NGO partners spread all over the country, and that number will double next year. We are currently working with 7,000 vulnerable children, as well as those affected, infected, and orphaned by HIV/AIDS. We can now share positive examples of community-level impact, despite early skepticism.

FHI's strategy has evolved from work with street children and sex workers' children according to the pattern of the epidemic. Key elements of the strategies include building community-based support and accessing community resources to address the needs of all children in a geographic area. We are looking at projects that are community owned and that are different from service delivery. The emphasis is on home-based care rather than care in institutions and medical centers. We cannot just look at children; we must look at the family as the unit for care. For example, the Community Health Education Society (CHES) in Chennai was a traditional, institution-based project that had come to be viewed as a dumping ground for orphans and HIV-affected children. It was turned into a community-based program linking prevention and care. We address stigma and discrimination, strengthen linkages and referrals, provide psychosocial support, and ensure that children participate in project planning and implementation.

What are our program entry points? We use existing programs for adults to reach children. Capacity building is a critical area for development. We must strengthen the capacity of families to cope and must increase the availability of foster care. We need sustainable, replicable, community-owned approaches to orphans and vulnerable children issues.

There are many problems to address. Discrimination is still very widespread. For example, Kerala is a very literate state; nonetheless, two children were denied entrance to school because they were HIV positive. The government forced their entrance, but everyone else in the community withdrew their children. Another problem is that India does not have a system for talking about death, and palliative care is much neglected. Furthermore, 99 percent of parents will not tell their children they are ill, and children do not know their own status. Testing and disclosure are needed.

We have found that child participation in programs that affect them builds esteem, solidarity, and confidence and is an effective empowerment strategy despite limitations, risks, and cultural implications. No child questions an adult in India, yet we want children to decide for themselves. The approach needs to be carefully handled and children need to know what is involved. It is best to start with small steps and add on activities. Most of all, it is important to spend adequate time preparing the adult staff.

Children can be members of monitoring committees that meet once a month. Bal Sabha are collectives of children making decisions on how shelters function. They even open bank accounts. Older children can be peer educators, researchers, and evaluators, though there are ethical considerations in research. Interestingly, most of the problems with child participation are with the adults, not the children. Children's rights are not recognized. Many adults consider them empty vessels, ignorant, irresponsible, and incapable. Thus, there is lots of tokenism; real partnerships are still a dream.

FHI is developing the following: a life skills manual for children; protocols for counseling, HIV testing and disclosure, child participatory methods in programs, and guidelines for formative research to develop behavior change communication strategies for partner children affected by AIDS projects.

Many challenges remain. High levels of stigma and discrimination are still present in most places in India. Children affected by AIDS have low visibility in communities. Referral services and linkages are poor, and children's needs are diverse within HIV programs. Sustainability is problematic, and there is a lack of community ownership and collective action.

There are bright spots as well. There are innovative NGO programs, such as Dancing Feat, **SBT**, Sharan/Support, and Alliance Partners, which can reach out to huge numbers of orphans and vulnerable children. Many child development organizations can take on HIV prevention and care activities, and the interest among donors and government agencies to address orphans and vulnerable children issues is increasing. India also has a great deal of technical expertise available to address the problem.

**Catalyzing Community Action for Children Affected by AIDS in India: The Alliance Experience**

*Sujit Ghosh* is responsible for the International HIV/AIDS Alliance South Asia Program and has helped develop the India program on care and support for children affected by AIDS and for people living with HIV/AIDS (PLWHA).

The Alliance started an integrated, comprehensive, community-based HIV/AIDS program on family and home care that has orphans and vulnerable children and prevention components. The Alliance provides care and support services in Andhra Pradesh, Delhi, and Tamil Nadu to 16,000 children affected by AIDS and their families. It further supports 40 community projects for children affected by AIDS, seven in cities and 33 in rural or semiurban settings.

There were many challenges to setting up care for HIV patients, especially children. The Alliance diverged from established practices by widening the response from cities to rural and semirural areas, and selected three lead partners (one in each state) relatively new to care and support for capacity building and technical support. These partners, in turn, established 30 community projects in six to nine months where little or nothing had been happening previously. Simultaneously, Alliance had to establish a country office. Several factors helped this move from tradition; flexible funding, trust, and a lack of indicator constraints and "straight jackets" were among them.

The setting is very different in each state, so we could not take one standard approach; instead, we listened to our partners. We shifted the approach from including children in the services provided for infected parents to establishing integrated, child-centered projects that respected children's rights and included them in project review and redesign. We are still in that process and are learning how to go about it. It has required much technical support from outside and inside India. The turning point was including children in project review and redesign and ensuring children were equal partners in the process.

The challenge continues; we want to push even more. Definition was a hurdle. Who was to be included—HIV-positive children or children whose parents were ill or dead? We started with children that had a parent either HIV positive or dead from AIDS because resources were limited. We need approaches that address children at different developmental stages. The need for material support is endless. Who is responsible for these future citizens: the state, the community, the family? There need to be links among all involved parties.

We try to make sure there are safeguards for children to protect their rights. Linkages with NGOs are very important in that regard. It is better to assist existing agencies rather than set up a new structure. Accessing the strong NGO sector in India has been helpful, as they have a range of experiences—from best avoided to best practices. Our own experience with the 40 integrated community projects in three states has helped us ensure quality and focus technical input.

At present, we are scaling up community action. We are at a crossroad. We want to document our approach with research so we can influence policy to give children affected by AIDS priority. This must be done in conjunction with other agencies. Organizations must start talking to each other, and influential figures must speak out on children affected by AIDS.

## VII. Question and Answer Session

**Q:** When implementing community-based programs, what safeguards are there to ensure that they are not labeling and stigma producing?
**A:** In Tamil Nadu, we worked with self-help groups of women that had access to credit. They are quite influential now. Bringing in the children affected by AIDS program through these established, influential bodies avoids stigma and labels.

**Q:** Children aged 0–4 comprise 15–20 percent of the orphans UNICEF identified in sub-Saharan Africa. What is there for children under age 5 in India?
**A:** Traditionally, most programs look at children aged 5–18. Only recently have we started using the family as the unit for care. We are now looking at how to address children under age 5 in life skills programs and are trying to adapt existing programs to India. We are learning from other programs and from NGOs already doing the work.

**Q:** What techniques do you use to mobilize communities?
**A:** It has been only six months since FHI changed to a community approach. We first identified partners with long-established work records that were already active in the community and then integrated HIV into what they were doing. That made it easier for us to mobilize. Many tools are being developed to deal with the problems of vulnerable children who have no family support.

We listen to the children. An example of change of focus and results involved deciding whether to take a girl from her elderly grandmother who needed care herself and move her in with extended family members who lived far away. She did not want to leave, so the community pitched in to help so she could stay.

A network of partners is very important. FHI currently supports treatment of opportunistic infections, but there is no provision of ARVs, so FHI wants to support other agencies that can work with them. Some partners have collected funds from private agencies to work with ARVs. At present, the projects are too small and too widespread to have an impact on morbidity and mortality levels. Eventually, research and evaluation will have to be done.

It took a long time to build a national network of well-established NGOs from various sectors. The goal was capacity building, with lead NGOs supporting smaller CBOs. Six are now recognized as national NGOs by the government of India. We both tap and strengthen this network for quick disbursement of funds and support at the district level from the government service delivery network. Services are lacking, but they still have infrastructure and a level of support. The multidimensional needs of children require broadening the base of support.

## VIII. Summary of the Morning Session

*Jeff Richardson,* Abbott Laboratories Fund-Step Forward for Children Initiative.

I hope that having conversations like this will be timely in staving off approaching disaster. In discussions on policy, the focus is often on the social service side. To advance the cause, we need to address policy and those who shape and influence it. Progress can be made even if a government has not fully embraced the issue. Remember that it took President Reagan seven years to say the word "AIDS." Statistics can overwhelm people. The fact that there are 25–40 million orphans due to AIDS can leave one feeling that there is no hope and so no reason to invest. We must make the situation understandable even if data used are anecdotal.

Noteworthy comments from the morning session include the following:

*Neil*: Social impact is dynamic so programs must be flexible and forward looking and should include not only AIDS-service organizations but also non-AIDS organizations too, building on their access to community resources. We must look at the big picture and not just focus on orphans and vulnerable children.

*Reji:* PWDS decided to follow two paths: (1) access solid, well-respected, existing organizations and mainstream AIDS into its existing work; and (2) coordinate to effect change. Coordination and mainstreaming are key.

*Subha:* The statistics were very helpful; in fact, they are essential for setting realistic, measurable program goals. It is critical to get started and to link up with sources like the Global Fund.

*Bitra:* Coordination is the key; it is true everywhere. Appropriately engage children by listening to them. Child participation is imperative.

*Sujit:* There was uncertainty and skepticism when Alliance got started, but now they have success stories to share. Take risks, trust partners, and get started; then adjust the program as needed. That is the basis on which to get things moving forward.

## IX. Open Sharing of Program Highlights from Participants

*Jadgish Harsh, Director of Francois-Xavier Bagnoud /India*
Francois-Xavier Bagnoud (FXB) works in 35 states in India. Its mission is to provide a voice for infants and children in the wake of the AIDS pandemic. Originally, FXB provided day care centers and houses for orphans in Thailand, and then moved to community-based work and renovation of schools in Africa. An overview of our work in India includes many voices. We have a community-based approach to programs for orphans and vulnerable children that includes education, health care, and nutritional support. We provide medical and nutritional support and treatment for sexually transmitted infections and opportunistic infections. There is no model program for orphans and vulnerable children. We have to be flexible. Currently, numbers are misleading and cannot be used to set policy. FXB is working to improve them. Sensitized and enabled communities could provide better care to orphans and vulnerable children. FXB is working toward sustainable smiles.

*G. Rashm, Executive Director, Vasavya Mahila Mandali*
Since 1969, the program has focused on women and children. In 1995, we got involved with HIV/AIDS sensitization. In 1999, we established partnerships to work with street children to bring them into the mainstream. In 2000, we started working in coastal districts of Andhra Pradesh in home and community-based care and support.

Children asked to be involved in reviews to make their priorities heard. One example involves a seven-year-old who begged from house to house to feed her two younger siblings and her grandmother. The care and support program helped, and now she is going to school and an NGO is supporting the family. We also support income-generating programs. A widow with three teenage girls was given funds to buy a sewing machine. She now has a small business making blouses, and the family is sustained. The community has received her, and her girls are going to school and helping her with handwork.

*Avni Amin, Center for Health and Gender Equality (CHANGE)*
CHANGE works in the United States and India. It is nonprofit and takes its mandate from the international conference on population and development. CHANGE promotes reproductive health and rights through policy analysis and research. In India, we work in gender-based violence, health sector reform, and expanded choice in reproductive health, prevention of sexually transmitted infections and HIV prevention,

and analysis of national AIDS policies from a gender and rights perspective. We interview stakeholders about their priorities and how they are being implemented.

Many aspects of the morning presentations are unique to orphans and vulnerable children, but some are also relevant to women. One is the vulnerability of girls. We must try to understand how the national AIDS prevention program can address girls. Another is PMTCT and linking it to family units to address women's needs. How can the program address gender and rights issues? Third, we share policy constraints. CHANGE works in advocacy in Washington. We spearheaded a coalition of NGOs for the recently signed AIDS bill to promote needs of women and girls in that legislation and to do away with clauses that would have harmed them**.**

*Seemin Qadiri, Child Nurture and Relief (CHINAR)*
CHINAR works with orphans in conflict-ridden areas. It is apolitical and secular. The focus is on Kashmir. There is one orphan there for every 34 adults, and two out of three orphans do not receive support. There are 24 orphanages to take care of 1,500 children. CHINAR will address this by starting a home. We have a building already donated and will start with 20 children from acutely affected areas. Nurturing will be done by trained "mothers." Many orphans have seen their parents and relatives killed and raped. The emphasis will be on the children's psychological health and well-being and on reintegrating them into society, making them part of the community. We also plan to teach them religious tolerance and the value of world peace.

*Edwina Pereira, International Services Association (INSA) India*
INSA offers training on how to establish community-based health and development programs. We work with organizations that do not have budgets for staff development. Training is participatory from the beginning, as trainees make their own programs. We are now training workers to take care of children affected by HIV/AIDS and to mainstream HIV/AIDS prevention education into health and education programs, linking them to government structures and other agencies. We also work with organizations that implement vertical HIV/AIDS programs.

## X. Questions, Answers, and Comments

**Q:** How do you get wealthy people involved in Vasavya Mahila Mandali?
**A:** Mobilize the community and make it their program. Local industrialists help.

*John Williamson*: In a review of the program in Zimbabwe, a major issue was language. Community workers talked about "CABA" children using the acronym to label and identify them and, as a result, this stigmatizes them. We should be aware of such pitfalls.

## XI. Key Questions and Opinions Expressed from Break-out sessions

### Theme 1: Advocacy and Key Messaging to Increase Awareness of the Situation of Orphans and Vulnerable Children

**Questions:**

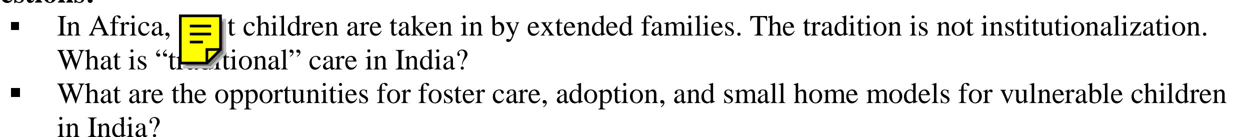
- How can we involve state and local policy makers in national policy making?
- Who should advocate for changes in the national policy?

**Opinions Expressed Included:**

- Encouraging state governments and government stakeholders to become involved in local experiences and in work with community-based organizations.
- Communities encouraging local, state, and national governments to do all that they can for orphans and vulnerable children in India.
- Fostering a relationship of trust and encourage government and NGO's to work together as equal partners to promote meaningful advocacy.
- Positioning NGOs as extensions of and resources to state agencies, with increased access and ability for action and advocacy – "your success is ours and ours is yours".
- Encouraging NGOs to work together with government officials in other ways than asking for funding.
- Including the needs of orphans and vulnerable children and addressing children affected by AIDS in national policy.
- Gathering input from people experienced in capacity building to include in advocacy efforts.
- Encouraging donors to advocate for inclusion of orphans and vulnerable children in policies.
- Encouraging the UN (UNICEF) to lead in advocating for increased awareness and resources for orphans and vulnerable children in India.
- Encouraging the World Bank to work with governments to take up orphans and vulnerable children issues.
- Promoting focused advocacy at all levels through various means.
- Communities bringing larger numbers of people into the advocacy arena.
- Involving religious leaders in advocating for orphans and vulnerable children.
- Ensuring that people have information and are aware of opportunities for advocacy at the community and NGO levels.
- Positioning NGOs as a source of information for state governments to rely upon
- Setting up stakeholder groups at the state level that include civil society and government institutions (i.e., state task forces).

**Theme 2: Moving from the Context of Institutionalization to Community-Based Care for Orphans and Vulnerable Children**

**Questions:**



- In Africa, [illegible]t children are taken in by extended families. The tradition is not institutionalization. What is "t[illegible]tional" care in India?
- What are the opportunities for foster care, adoption, and small home models for vulnerable children in India?

**Opinions Expressed Included:**

- Finding alternative forms of care for orphans and vulnerable children rather than institutions. Institutional care is not the best resource.
- Recognizing that institutions are more expensive than community care models. A World Bank study found that institutional care could be six times as expensive as other alternatives.
- Recognizing that children have different developmental problems at different stages of life, and without a family identity, older children have problems integrating into society as adults.
- Recognizing that institutions can be stigmatizing and seen as outlets for poverty.
- Recognizing that existence of orphanages may undermine community resolve to take on responsibility.
- Accessing and tapping into strong, grass-roots movements, especially women's groups for orphans and vulnerable children care.

- Exploring the range of alternative forms of care for orphans and vulnerable children, including adoption, boarding schools for older children, day care centers, night shelters, and drop-in centers.
- Learning from other countries' experiences (i.e., short-term residential programs in South Africa).
- Working with communities and community-based organizations to identify vulnerable families and assist them before children enter institutions or are abandoned.
- Acknowledging that institutions are often the response from HIV/ AIDS organizations, but they are not the social or cultural tradition in India.
- Recognizing that education may be the best prospect for the long term and scholarships or work-study programs can provide future opportunities for orphans and vulnerable children. Encouraging scholarship candidates to "give back" a percentage of what they earn for future scholarships and agree to educate their children to perpetuate the movement.

**Theme 3: The Effects of Stigma and Discrimination on Orphans and Vulnerable Children**

**Questions:**

- How do we address and work around the issue of stigmatization of children affected by AIDS?

**Opinions Expressed Included:**

- Acknowledging that we do not know how widespread discrimination is or how deeply stigma runs, and that there is still a lot of denial at all levels. There are examples of rejection from school, but few formal studies (UNAIDS in 2001).
- Acknowledging that India is a country of one billion people and varied cultures, so a single approach will not work.
- Researching how to deal with discrimination and stigma in India.
- Acknowledging and addressing misconceptions: Many educated people still believe HIV/AIDS is associated with homosexuals, prostitutes, and intravenous drug users. Many people would not rent office space for AIDS treatment clinics.
- Being precise when discussing risk factors so as not to perpetuate misinformation.
- Working with and through Indian society to empower Indian women. In rural areas a man's infection may be blamed on the woman, and her children may be taken from her. Women must bear children to be an accepted part of society, even if they know their children might be infected with HIV.
- Increasing awareness by working with local governments and religious leaders. In Uganda and South Africa, the church was helpful in establishing that the immorality was not in contracting HIV/AIDS, but in letting people die from it.
- Encouraging government, cultural, and religious leaders to be proactive to change perceptions.
- Getting people to speak out at all levels is essential.
- Recognizing that if people feel they can get care and support, they might be willing to speak out.
- Recognizing that when the stigma of AIDS can be addressed, addressing the stigma of being orphans and vulnerable children will follow.
- Recognizing that labeling promotes stigma and discrimination. Terms and acronyms make life easier for donors, but their use can have negative effects. If you go into a community and ask for the "most vulnerable" children, you will get AIDS patients without stigmatizing them because the word "vulnerable" was used. We must get professionals in tune with this philosophy.
- Recognizing that mass media prevention messages might exacerbate stigma (e.g., which is the "bad egg" in the basket ad). Fifteen years of sustained negative images have done a lot of harm.
- Involving famous people, such as actors and actresses from Bollywood, may help reduce stigma. In Mysore, a famous pediatrician got involved with HIV patients with very positive results.

- Integrating orphans and vulnerable children /children affected by AIDS programs into existing programs to avoid stigma.
- Recognizing that stigma and discrimination are two separate issues. Discrimination is an act; stigma is a perception.
- Recognizing that religious leaders play a major role in defining community responses to disease.

**Theme 4: Integrating the Needs of Children Affected by Aids into Other Program Areas (i.e., Street Children, Care and Support, etc.)**

**Questions:**
- How do we integrate the needs of children affected by AIDS into other program areas?

**Opinions Expressed Included:**
- Efforts to link AIDS education with the situation of orphans and vulnerable children.
- Involving young people in home-based care can be part of teaching HIV prevention.
- Strengthening the quality of HIV education in schools and including life skills training.
- Training teachers to be advisors and a source of support to students.
- Building informal education centers for children living both in and out of slum areas. An informal education center for children living in and out of slums was started in Delhi. Getting the children who live in slums admitted was the first problem. Then these children were reluctant to attend because their classmates would not visit them after school. A library and a gym were established in the slum area that everyone used, which helped integrate outsiders so the children living in the slum were more willing to attend school.

## XII. Closing Remarks and Future Actions

The World Bank will be in Delhi on June 8, 2003, to work on Phase 3 of the National AIDS Control Plan. It would be highly desirable if the groups represented here could form a task force and get orphans and vulnerable children issues on that agenda, as the plan will cover the next five years. The group agreed to pose questions on SAATHI (Solidarity and Action Against the HIV Infection in India) and send them to the World Bank, as the listserv is impartial and unbiased. Several speakers and participants from the town hall expressed interest in holding a similar one-day forum for discussion on the situation of orphans and vulnerable children in India at the 4th International Conference on AIDS India in Chennai, India, in November 2003. The purpose would be to broaden the discussion and to have organizations working with orphans and vulnerable children in India set the agenda and share their experiences.

## XIII. Appendices

### Appendix A: Agenda

**ORPHANS AND VULNERABLE CHILDREN IN INDIA:**
**UNDERSTANDING THE CONTEXT AND THE RESPONSE**

**Monday June 2, 2003**
**9:00 a.m.–5:00 p.m.**

**Meeting facilities donated by The Aspen Institute**
**1 Dupont Circle, NW/ Washington DC, NCHE Conference Center Floor 1B**

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9:00 – 9:15 **Welcome and Introduction**
Princeton Lyman, Aspen Institute
Maja Cubarrubia, Plan/Childreach

9:15 – 9:30 **Background, Purpose, and Objectives of the Town Hall –** Marie-Christine Anastasi, Plan USA

**Purpose of the Town Hall:** To Provide a Forum for Discussion and Information Exchange Regarding Children Affected by AIDS and Other Vulnerable Children in India

**Overview of Objectives**: To Discuss and Raise Awareness of Selected Thematic Issues around Orphans and Vulnerable Children in India, including:

- The Impact of HIV/AIDS on Orphans and Vulnerable Children in India
- Types of Responses Being Implemented
- Challenges and Successes in Responding to the Needs of Orphans and Vulnerable Children in India

**Review of the Day's Schedule –** Gretchen Bachman, Family Health International (FHI)

9:30 – 9:45 **Keynote**: **Overview of the Situation of Orphans and Vulnerable Children in India –** Anil Purohit, Francois Xavier-Bagnoud (FXB)

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9:45 – 10:50 **Plenary Panel 1:** Moderator – Linda Sussman, USAID Bureau of Global Health, Office of HIV/AIDS

**Orphans and Vulnerable Children Program Issues Within the Context of the Overall Social Impact of HIV/AIDS in India** – Neil Monk, FXB

**Orphans and Vulnerable Children**: **Community Responses and Emerging Opportunities/Future Options –** Reji Chandra, PWDS

**Prevention of Mother-to-Child Transmission of HIV: Program Highlights from India** – Sai Subhasree Raghavan, Columbia University and Harlem Hospital

**Questions and Answers**

10:50- 11:05 **Break** – Sponsored by Plan USA and FHI

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11:05 – 12:00 **Plenary Panel 2:** Moderator – Paurvi Bhatt, Step Forward for Children Initiative

**Challenges and Strengths in Addressing the needs of Orphans and Vulnerable Children in India: Lessons from a Child Participatory Methodology -** Bitra George, FHI India

**Catalysing Community Action for Children Affected by AIDS in India: The Alliance Experience –** Sujit Ghosh, The International HIV/AIDS Alliance

**Questions and Answers**

12:00 – 1:00 **Lunch and Videos ("Dancing Feat" and other videos) –** Sponsored by Step Forward for Children Initiative – Abbott Laboratories Fund

1:00 - 1:45 **Summary of Morning session – Issues and Challenges Raised and Open Sharing of Program Highlights from Participants –** Jeff Richardson, Step Forward for Children Initiative

1:45 – 2:00 **Explanation of Small Group Exercise and Break into Small Groups** – Renee DeMarco, The Synergy Project

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2:00 - 3:00 **Break-out Sessions – Small Groups around Emerging Themes**

**Theme Group 1: Advocacy and Key Messaging to Increase Awareness of the Situation of Orphans and Vulnerable Children in India** – Discussion Leaders: Koki Agarwal, The Policy Project, and Regi Chandra, PWDS

**Theme Group 2: Moving from the Context of Institutionalization to Community-Based Care for Orphans and Vulnerable Children in India** – Discussion Leaders: Neil Monk, FXB, and Sujit Ghosh, The International HIV/AIDS Alliance

**Theme Group 3: The effects of Stigma and Discrimination on Orphans and Vulnerable Children in India –** Discussion Leaders: Anil Purohit, FXB, and Camilo Mora, FXB

**Theme Group 4: Integrating Needs of Children Affected by AIDS into Other Program Areas (i.e. street children, care and support, etc.) –** Discussion Leaders: Jagdish Harsh, FXB, Sai (Subha) Subharasee Raghavan, Columbia University and Harlem Hospital, and Bitra George, FHI

3:00 – 3:15 **Break –** Sponsored by FXB

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3:15 – 4:00 **Panel of Speakers – Q & A from Break-out sessions –** Moderator: Sai Subharasee Raghavan

4:00 – 4:35 **Closing Remarks and Wrap Up – Next Steps and Future Actions –** Sujit Ghosh, Jagdish Harsh, Linda Sussman

***Note:*** The objectives of the planned Town Hall Meeting have been significantly modified in response to feedback from technical experts and other stakeholders working with children affected by HIV/AIDS in India

## Appendix B: Participants

### Planning Committee

| Name | Organization |
| --- | --- |
| Renee DeMarco | Synergy Project |
| Marie-Christine Anastasi | Plan USA |
| Braeden Rogers | OVC TF/Plan USA |
| Linda Sussman | USAID |
| Gretchen Bachman | FHI |
| Anil Purohit | FXB |
| Camilo Mora | FXB |
| Jagdish Harsh | FXB |
| Paurvi Bhatt | Abbott Laboratories |
| Kate Harrison | HIV/AIDS Alliance |
| Sujit Ghosh | HIV/AIDS Alliance |
| Neil Monk | FXB |
| Reji Chandra | PWDS |
| Bitra George | FHI/India |
| Subha Raghavan | Columbia U/SAATHII |

### Participants

| Name | Organization |
| --- | --- |
| Koki Agarwal | Futures Group |
| Mandy Fick | World Vision |
| Elizabeth Berard | GHDS/Synergy |
| Joan Parker | DAI |
| Tracy Dolan | CCF |
| Jaya Koilpillai | consulting |
| Jeff Richardson | Step Forward |
| Nicolette Borek | NIDA/NIH |
| Rose Amolo | CEDPA |
| Seemin Qadiri | CHINAR |
| Vathani Amrthanayagan | USAID |
| Andrew Rlaber | UNICEF |
| Dawne Walker | AED |
| Sarah K. Dastur | AED |
| Ruth Kattumuri | LSE |
| Monika Kalre | RFK Memorial |
| Laelia Gilborn | Horizons/Pop.Council |
| Atia Byll Cataria | UNF |
| Mit Patel | Community Reach,Pact |
| Edwina Periera | INSA India |
| Irfan Shahmiri | Child Nurture Relief |
| Rashmi | Vasavya Mahila Mandali |
| Shalini Kapoor | CIRA |
| Navin Vij | CSIS |
| Florence Nyangard | PHNI |
| Laurette Cucuzza | Synergy |
| Kathrin Gegenfeldt | CEDPA |
| Avni Amin | CHANGE |
| Ann Matz | Step Forward |

| Name | Organization |
| --- | --- |
| Chloe O'Gara | AED |
| Brian Wagner | VOA |
| Rhoi Kaima | AFA |
| Chalya Lar | World Vision |
| Jamie Cooper-Hohn | CI Fund Foundation |
| Chris Cooper-Hohn | CI Fund Foundation |
| Maj-Lis Voss | World Bank |
| David Stevenson | World Vision |
| Carol Clark | World Vision |
| Ed Willett | FOI |
| Irene Richter | World Vision |
| Frank Manfredi | Plan USA |
| Maja Cubarrubia | Childreach/Plan USA |
| Lisa Bowen | Plan USA |
| Carl Henn | Plan USA |
| Don Cohen | Plan USA |
| John Williamson | DCOF/USAID |

## Appendix C: Biographical Data of Speakers

*Princeton Lyman* is currently Executive Director of the Aspen Institute's Global Interdependence Initiative. In January 2003, he was appointed the first Ralph Bunche Chair in Africa Policy Studies at the Council on Foreign Relations, a full-time appointment as of July 2003. At that time, Ambassador Lyman will join the Initiative's senior advisory council. He is concurrently Adjunct Professor at Georgetown University. He is a member of the boards of the Fund for Peace, Childreach, the U.S.-South Africa Business Council, the Amy Biehl Foundation, Africare, and the Balkan Development Initiative, and is a member of the Task Force on HIV/AIDS, co-chaired by Senators John Kerry and Bill Frist. He currently serves as a member of the international supervisory panel overseeing the evaluation of the UNAIDS program. Ambassador Lyman's government career included appointments as Assistant Secretary of State for International Organization Affairs, U.S. Ambassador to South Africa, U.S. Ambassador to Nigeria, and Director of the State Department's Refugee Programs Bureau. He received his B.A. from the University of California at Berkeley and his Ph.D. in Political Science from Harvard University. He is the author of *Partner to History: The United States' Role in South Africa's Transition to Democracy* and co-author of *Korean Development: The Interplay of Politics and Economics*. He has published articles on Africa, economic development, United Nations Security Council reform, United Nations peacekeeping, U.S. foreign policy, and the AIDS crisis. He was co-chair of the Council on Foreign Relations/Milbank Memorial Fund study in 2001 "Why Health is Important to U.S. Foreign Policy."

*Maja Cubarrubia* is Chief Operating Officer of Plan USA. Prior to her assignment in Plan USA, Maja worked in Plan Asia. In her previous life, Maja was the Training Director and an Associate Director of Peace Corps Philippines. She holds a master's degree in International Development from Tulane University.

*Anil Purohit* joined the humanitarian advocacy and HIV/AIDS efforts of Francois-Xavier Bagnoud (FXB) in 1998. He currently maintains the roles of President of FXB/India and AIDS Program Director worldwide and Executive Director of the FXB/USA Foundation. He has been instrumental in establishing programs in all 35 states and union territories in India under the leadership of Countess Albina du Boisrouvray. The FXB/India Society employs more than 150 persons from grass-roots levels to physicians and lawyers and has 17 members on the board of directors from different states in India.

*Neil Monk* graduated from the University of East Anglia with a B.A. in development and an M.A. in rural development. He did project work on sustainable agriculture and appropriate technology in support of orphans in Uganda in 1995 and 1997. He did field research with FXB on orphans and vulnerable children and HIV/AIDS in Uganda in 2000 and in India in 2000 and 2001. He has been the Orphans and Vulnerable Children Advisor for FXB since January 2002.

*D.T. Reji Chandra* is the Director of the Palmyrah Workers Development Society, a development organization founded in 1977 in Tamil Nadu, India. He has 16 years of experience in development project management. He has a post graduate degree in humanities and social science with development documentation and project management specialization.

*Dr. Bitra George* is a clinical specialist in skin, sexually transmitted diseases, and leprosy, and has worked in the field of HIV for the past 10 years. He was associated with Salaam Baalak Trust before joining FHI in March 2002, first as program manager and now as Associate Director, Program and Technical. His areas of interest include integrating prevention and care and counseling, testing and disclosure in children affected by AIDS programs.

*Dr. Sai Subhasree Raghavan* is Assistant Professor in Clinical Nutrition Medicine at Columbia University, Program Director of the HIV Nutrition Program in the Harlem Hospital Center, and Director of SAATHII. Her ongoing research includes studies of wasting and long-term side effects of ARVs among HIV-positive individuals in the United States. She is currently chairing a multisite, national clinical trial on the side effects of ARVs, funded by the National Institutes of Health. She is a faculty member at the Division of Epidemiology in the Joseph Mailman School of Public Health at Columbia University. Her work in India involves HIV prevention, education, and treatment, with specific emphasis on PMTCT. She currently coordinates PMTCT programs funded by Elizabeth Glazer Pediatric AIDS Foundation in India. She is also involved with the dissemination of research, funding, and training information at the country level, with advocacy, and with networking of health care providers working on HIV/ AIDS issues. She is working on the development of guidelines for the treatment of nutritional complications and on clinician and nonclinician training in India through SAATHII and Columbia. Dr. Raghavan's other international work involves nutritional complications (wasting) among HIV-positive adults and children, the impact of breastfeeding on mother to child transmission, and long-term metabolic toxicity due to antiretroviral use in poor settings.

## Appendix D: List of Presentations, Handouts and Materials, and Websites and Resources

*(Presentations are available in electronic form at www.synergyaids.com)*

Neil Monk, FXB. "OVC Program Issues and the Social Impact of HIV/AIDS in India."
Reji Chandra, PWDS. "OVC: Community Responses Emerging Future Options."
Sai Subhasree Raghavan, Harlem Hospital Center/Columbia University and SAATHII. "Prevention of Mother to Child Transmission in India: A National Scenario."
Bitra George, FHI/India. "Challenges and Strengths in addressing Needs of OVC in India: Lessons from a Child Participatory Methodology."
Dr.Sujit Ghosh, International HIV/AIDS Alliance and Step Forward. "Catalyzing Community Action for Children Affected by HIV/AIDS in India-the Alliance Experience."

### List of Handouts

Abbott Laboratories Fund/Step Forward. A Global Care Initiative from Abbott for Orphans and Vulnerable Children.
www.stepforwardforchildren.org
International HIV/AIDS Alliance and Step Forward. Responding to the Needs of Children Affected by HIV/AIDS in India.
Childreach/Plan. India 2002 Annual Program Report.
www.childreach.org; www.plan-international.org
Child Nurture and Relief(CHINAR).
www.chinar.org

### Websites and Resources

www.aidsalliance.org
aids-india@yahoogroups.com
www.apcdproject.org
www.childreach.org / www.plan-international.org
www.fhi.org
Life Skills Manual for Youth
www.fxb.org
www.synergyaids.com
www.usaid.gov
www.saathii.org
**SAATHI** is a centralized mechanism for dissemination of information in India that will reach 90 percent of those working on HIV/AIDS in the country. SAATHII (Solidarity and Action Against the HIV Infection in India). The e-mail address is SAATHII@yahoogroups.com. Their web site is www.saathii.org.

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Hand in Hand: Issues and Innovations in Caring for AIDS-Affected Children – Aarti Kumar and Arabinda K. Pani