The AIDS Orphans of Andhra Pradesh:

A Study of the Current Provisions for the Care and Support for Children Orphaned by AIDS

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The work for this report was funded by the World Bank. We thank our World Bank Task Manager, Maj-Lis A. Vos for her timely inputs.

Cover Illustration
A child-headed family of AIDS orphans. The children are currently homeless and are living in a roadside tent. They have had to stop their schooling in order to support themselves through petty enterprise (coconut selling) and must learn to cook and care for themselves.

C O N T E N T S

PROLOGUE

The number of AIDS orphans in India is fast approaching epidemic proportions. In order to plan and implement an immediate and forward-looking response to the emerging crisis, we have conducted a study to assess the situation facing HIV/AIDS orphans in India. This study is the first of its kind for India. Having been given a four-week time frame from start to completion, the study is necessarily exploratory in nature and represents only the tip of the proverbial ice-berg.

Before we become lost in statistics and proposals for programs and policies in India, however, we invite you to enter into the life of Mohan, a typical Indian child orphaned by AIDS. Mohan's story lies at the intersection of multiple issues arising from the HIV/AIDS epidemic in India. It shows how the AIDS-related death of a CAA's (Children affected by HIV/AIDS) parents impacts on the internal life of the child, and provides a micro-cosmic example of the likely socio-economic ramifications when the millions of India's children who are currently on the brink of orphanhood lose their infected parents to the HIV/AIDS epidemic.

Mohan's Story

Mohan, 14, who is the eldest in a family of 4 sons, lost both parents to HIV/AIDS. Mohan's father and mother died within a year of each other at ages 45 and 38 respectively. His father was a tractor driver, and his mother, a cotton laborer in a village near Hyderabad. Mohan studied up to 6th class. At the age of 10, his father became sick and could not work. Mohan was forced to stop school to take care of his bedridden father. The family took him to many hospitals but to no avail. Due to repeated misdiagnoses and lack of treatment, Mohan's father survived for only one year. Mohan's mother was never told directly that her husband had HIV/AIDS. Instead, the heath care workers divulged his father's status to Mohan's uncle, whose fatalistic attitude deprived Mohan's father of further trained medical care:

> Apparently, they told our uncles that my father had AIDS. But they did not tell us […]. We were trying hard to get some money to take him to Hyderabad for treatment when my uncle came and advised us not to go. "He will die anyhow," he told us quietly.

After his father's death, Mohan's family was burdened with debt. To repay those debts, Mohan worked as a bonded laborer, tending buffaloes. Just as Mohan's family was trying to nullify the debts and to recover from the loss of a father and husband, Mohan's mother fell ill. Her sister and her parents took them in. They tried valiantly to seek effective treatment for her, taking her to private hospitals and incurring more than 20,000 INR of additional debts for misdiagnoses and ineffective treatments. When she was finally diagnosed with HIV/AIDS, the doctors provided the family with no information on the disease or how to care for her. Rather, as Mohan recounts, they advised the family to stop seeking treatment: "She will not live, take her away." Again, Mohan was deprived of information:

> I don't know much about how one gets AIDS. The doctor did not tell me. He told my uncle who did not tell me anything. I also did not ask anybody at that time and didn't even know about it through television and newspapers.

Mohan remains haunted by his parent's death:

> Both died the same way. My father became very thin, like a broomstick before his death. My mother had frequent fever […] for the last eight months of her life she was bed-ridden. She could not eat rice or even fruits. In her last 15 days, she ate virtually nothing […] She vomited everything out.

No one told Mohan's mother that she had HIV/AIDS. However, after her death, somehow everyone in the village knew. The word spread through the village gossip like wildfire, "Then it was all out in the papers [and] we were ostracized." Mohan's family has not even been granted the right to mourn their loss with dignity. They are constantly plagued by probing questions: "People keep coming. They visit us and ask us for details."

After his mother's death, the crippling economic impact of HIV/AIDS on Mohan's family has widened to his siblings and grandparents. Now, Mohan's 11-year old brother has also been pulled out of school to try to repay the family debts and to help them eke out a bare subsistence.

> Mother herself arranged that my brother would work […] He has to look after buffaloes. He does not like it. He wants to stop working and cries. Like me, he wants to study.

Although Mohan's aunt had helped them care for his mother, this is as far as she is willing or able to go. Like many women in her socio-economic stratum, Mohan's aunt is burdened by a husband who "drink[s] too much and [*doesn't*] look after [*his*] own family properly, leave alone us." Harsh necessity has forced her to choose between her sister's children and her own. "Can my aunt become my mother?" is Mohan's plaintive question. He is perceptive enough to know that this question is almost reflexively rhetorical as he acknowledges, "She does not care about us any more."

The burden of caring for the orphans has shifted to Mohan's grandparents and to the siblings themselves. Although life is difficult even with the help of his grandparents, Mohan is sensitive to his elders' own struggles and needs.

> Our grandfather is a watchman. He is very old, but he still works very hard. My grandparents […] have no house or property. They are also surviving through work and we should not depend on them.

The children live with their grandparents in a rented house that costs 240 INR per month. They are responsible for all the household chores -- cooking, washing, cleaning etc. and have managed thus far, but now the owner is asking them to vacate. Mohan is anxious to relieve his grandparents of their added burden and is seeking alternative means of support, despite the fragmentation it would cause between himself and his siblings.

> After the newspapers carried the story […] people from the government came and said they would do something. Yesterday, the Member of the Legislative Assembly (MLA) came and told us that they would admit us in some hostel. […] I do not know much about hostels. […] Even if we (my siblings) get separated going to different hostels, it is okay. At least we can get some education. We can go and see each other once in a while.

At just 14, Mohan faces a life of complexity and of great uncertainty. Shouldering the responsibilities of a father and mother while grieving their loss, supporting his two younger siblings' schooling while postponing this dream for himself, enduring the verbal slings of village neighbors who misunderstood both his parents and himself; Mohan is a child walking a tightrope of stoicism above a chasm of despair.

> Looking back, I think our early childhood was happy. […] We played a lot then. We cannot do that anymore […] now there is no happiness in our lives. […] I do not know about my future. […] It's not our

> fault is it? But what can we do? I do not share my feelings even with my relatives, because they too will feel bad. […] Sometimes outsiders say unkind things. But what can we do? I feel offended […] but what happened is also true. I cannot deny the deaths. […] I should adjust myself to the circumstances. […] Even if I get angry, what can I do? Just one or two of us cannot do anything. There have to be so many of us making the effort.
>
> […] The government should try to stop the spread of this illness and admit children like us in some hostel. I wish the community would treat infected persons with affection and help educate affected children.

Mohan's situation is tragic. But the most frightening thing about his story is that it is ordinary, for there are 39 million more like him[1]. Mohan's voice, and face, and life, are a variation on a theme – the grim theme of the HIV/AIDS epidemic, its beat sounded by the drums of fatalism, ignorance, apathy, and insensitivity.

If Mohan's parents had been diagnosed early and treated properly, if the message of HIV/AIDS prevention and care had reached Mohan's parents, his family or their village community, then maybe they might still be alive and living stably as PLHAs. If Mohan's mother had been told about her husband's infection once he fell ill, then maybe she would not have become infected herself. If there was capacity to care for HIV/AIDS orphans such as Mohan maybe he would not have to worry about where he and his siblings will be living next month. If life were fair, then maybe Mohan would have graduated 9th class.

But life is not fair, and some may consider Mohan just another statistic. But the truth is the inverse of this idea. Each statistic is a Mohan, or a Shivani, or a Prakash. Each is a person, a child with feelings, hopes, a mind and a heart, in whose collection of experiences loneliness, anger, and pain outweighs happiness. Each one of these children is entitled to be hugged, and protected, and loved. Each one has the right to have their minds sparked by knowledge, and their futures opened, not closed by forces beyond their control.

Mohan is right. It is not their fault. We owe it to them to ensure that children like him are not crushed under the advance of the HIV/AIDS epidemic.

[1] World Bank statistics on the world's current population of AIDS orphans (2003)

INTRODUCTION

As the worldwide HIV/AIDS pandemic/epidemic enters its 20th year, there is a growing concern about the impact of the epidemic on children. In current field terminology, a child who is touched by the HIV/AIDS crisis is classed as "a Child Affected by HIV/AIDS" (CAA). CAAs may have HIV seropositive family members (most frequently a parent). Additionally, they may or may not be HIV positive themselves. The HIV/AIDS epidemic has made its most severe impact on the sexually active young adults (19-35 years) demographic. This age group represents a society's most economically productive members, and it is a well-known fact that the rapid spread of HIV/AIDS threatens to destabilize economies due to depletion of the workforce. However, the implications of HIV/AIDS are increasing recognition that because people in this age-bracket are in their most fertile years, another one of the major ways in which HIV/AIDS attacking society is through the mass-creation of HIV/AIDS orphans and HIV/AIDS infected children.

The current number of AIDS orphans, including paternal orphans and the children belonging to the 15-18 year group, is estimated at 39.6 million. It is predicted that this will double by 2010, to 79.2 million. UNAIDS has cautioned that "this unprecedented crisis will require radically scaled-up national, regional and community responses in decades to come".

Asia has the largest number of AIDS orphans - the spread of HIV in this region has been recent and swift. India has the second largest population of HIV infected people in the world. The official Indian estimate puts the figure at 3.5 million (Jan, 2000); however, this is believed to be a gross underestimate (Aegis, 2000). Within the country, Maharashtra has the highest number of AIDS cases (NACO, 2000), with micro-level studies highlighting the growing incidence of HIV seropositivity among married, monogamous women, housewives and women attending ante-natal clinics (Gangakhedkar, Bentley, Divekar, Gadkari, Mehendale, Shepherd, Bollinger & Quinn, 1997; Gogate, 1998; Solomon, Kumaraswamy, Ganesh & Amalraj, 1998). There is thus a strong basis for inferring a high and increasing rate of pediatric HIV/AIDS cases. In addition, India's total number of new infections is currently expected to double every 14 months. This alarming statistic foreshadows a countrywide explosion of the HIV/AIDS problem with shock waves that are certain to hit India's children even if they are HIV seronegative.

The experiences of India's CAAs, and the interventions required to support them have been the subject of growing discussions. However to date, little has been done in the realm of research, documentation, program planning and policymaking. As the understanding of the dynamics and complexities of HIV/AIDS deepens, a more comprehensive view of children's interface with the pandemic is emerging.

The aim of this report is to analyze the impact of HIV/AIDS on children in India and to identify the existing services geared to addressing their concerns. Through this analysis we hope to identify gaps in services that need to be filled, and to propose effective initiatives, policies, and best-practices for dealing with the particular issues that CAAs face.

This study draws conclusions about the situation of CAAs in India based on the situation that we have observed in AP. Our organization, Vasavya Mahila Mandali (VMM), has worked on HIV/AIDS issues in AP for more than six years. Currently, we have an HIV/AIDS care and support network with seven partner NGOs that work in 5 of the 23 districts throughout

the state. Although there may be some differences arising from variation in social, cultural, and economic circumstances between states and communities across a country as diverse as India, we believe that universal lessons can be gleaned from what we have learned in AP.

BACKDROP: THE CURRENT SITUATION IN ANDHRA PRADESH

State Statistics for HIV/AIDS

HIV/AIDS epidemic is spreading rapidly in AP. At present AP contributes about 10% of India's HIV-infected population (.35 million people) and is among the country's leaders in India's adult infections with 2.02% of HIV positives among its ante-natal cases and 26.9% HIV positives among its STD clinic attendees. A conservative projection of 5% infection level in India by 2007 would result in nearly 2 million people being infected in AP alone.

Recently, one of the largest behavioral surveys carried out in the general population by the National AIDS Control Organization (NACO) reported that the median age at the first sexual encounter was 16 years for females and 19 years for males while the minimum age was 12 years for both sexes. 13.3% respondents reported having sex with non-regular sex partners within a one-year recall period. It is reported that 19% of the male and 7% of the female population in AP have multiple partners in AP. This is the highest reported rate in the entire country.

Information from government VCTCs (Volunteer Counseling and Testing Centers) about HIV/AIDS incidence in adolescents and young adults visiting these centers between April 2002 to March 2003 hint at a disturbingly high incidence of HIV in AP's youth, with 17% of children below 14, and 5% of teenagers between 15-19 years of age, exhibiting HIV seropositivity.[2]

Even more alarming is the level of HIV-infection of pregnant mothers. Out of the 100, 000 women visiting 14 of the state's 37 PMTCT centers during the same sample period of April2002-March2003, the incidence of HIV is 2.2%. The mothers were divided equally between rural and urban populations. 58% of them were in their first pregnancies, and 30-35% in their second pregnancies. The average age of the HIV positive mothers was 22.5-23 years. 70% of these women's partners also came in for testing, and of these 83% of them is HIV positive.

In sum, these statistics indicate both high percentages and high absolute numbers of current and future CAAs, as well as high percentages and absolute numbers of future AIDS orphans in AP.

VMM Statistics on CAAs and AIDS Orphans

These state-level statistics are echoed by the results that VMM has received in this study on the current situation of CAAs and AIDS orphans in AP. For the purposes of this report, we conducted a survey of 1977 CAAs in 5 of the state's coastal districts. The coastal districts of AP are among its most heavily populated, and are also the areas where HIV incidence is highest.

Of the 1977 CAAs surveyed, the majority of children were below 10 years of age, while a significant proportion was between the ages of 11-15 years (Table 1). Of these, 37% had already lost both their parents to AIDS, while 36% were semi-orphans (with parental loss

[2] 17% out of a total of 3238, and 5% out of a total of 9446. Data provided by AP State Aids Control Society (APSACS)

being equally divided between the mother and father) (Table 2). Among the semi-orphans, 23% of the surviving mothers and 35% of the surviving fathers were HIV positive. Of the CAAs whose parents were both still alive, a shocking 59% of these had both parents who were HIV-seropositive (Table 3). Of the remaining CAAs with both parents still alive, the percentage of infected fathers was more than that for infected mothers (Tables 4 &5). This may either indicate the dominant phenomenology of the spread of HIV observed in India's heterosexual population – i.e. from husband-to-wife or may be a result of the fact that married mothers who are aware of their husband's HIV status are often unwilling to have themselves tested[3].

Although our sample size was small compared to the entire population of AP, and to the state's HIV-infected population, our results indicate the tender ages of present CAAs, and the tremendously high percentages of present and future AIDS orphans. Given the disturbing proportions that the HIV/AIDS epidemic has assumed in AP, these figures bode ill for the future of AP's children.

[3] Observations from VMM's fieldwork has shown that because social stigma against HIV/AIDs threatens their livelihood options, and may result in forced separation, harassment and depression, mothers who know that their husbands are HIV-positive are resist testing either themselves or their children for HIV seropositivity. As one woman said: " I know my husband's status but I don't want to go for testing although I am sick. If I know my status as positive, I will be thrown out of my rented house, I won't get work. I am much worried about children. If I find out that my child is HIV-positive, I will die."

Table 1.

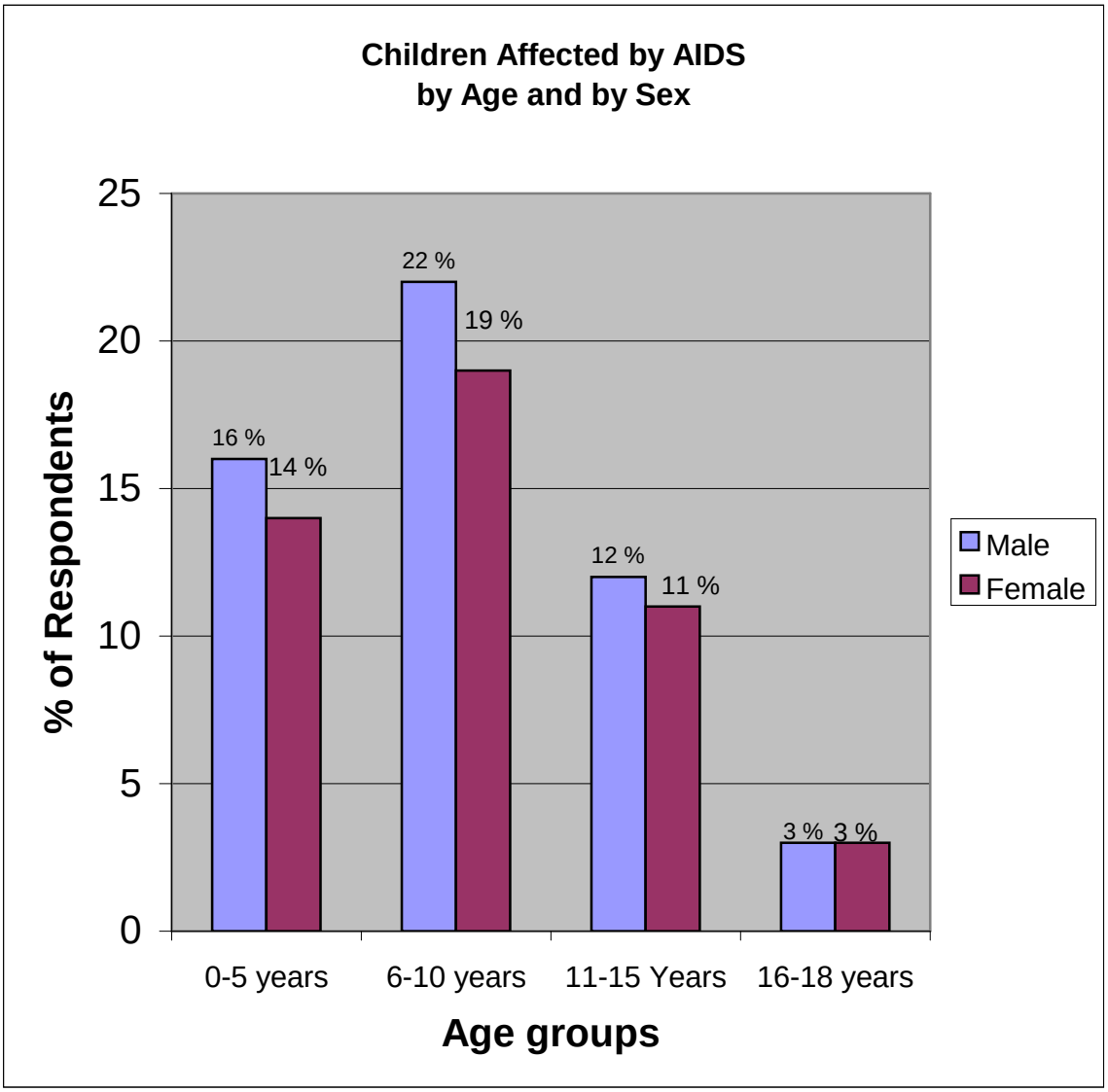

Children Affected by AIDS
by Age and by Sex
% of Respondents
25
20
15
10
5
0
22 %
19 %
16 %
14 %
12 %
11 %
3 %
3 %
0-5 years
6-10 years
11-15 Years
16-18 years
Age groups
Male
Female

Table 2.

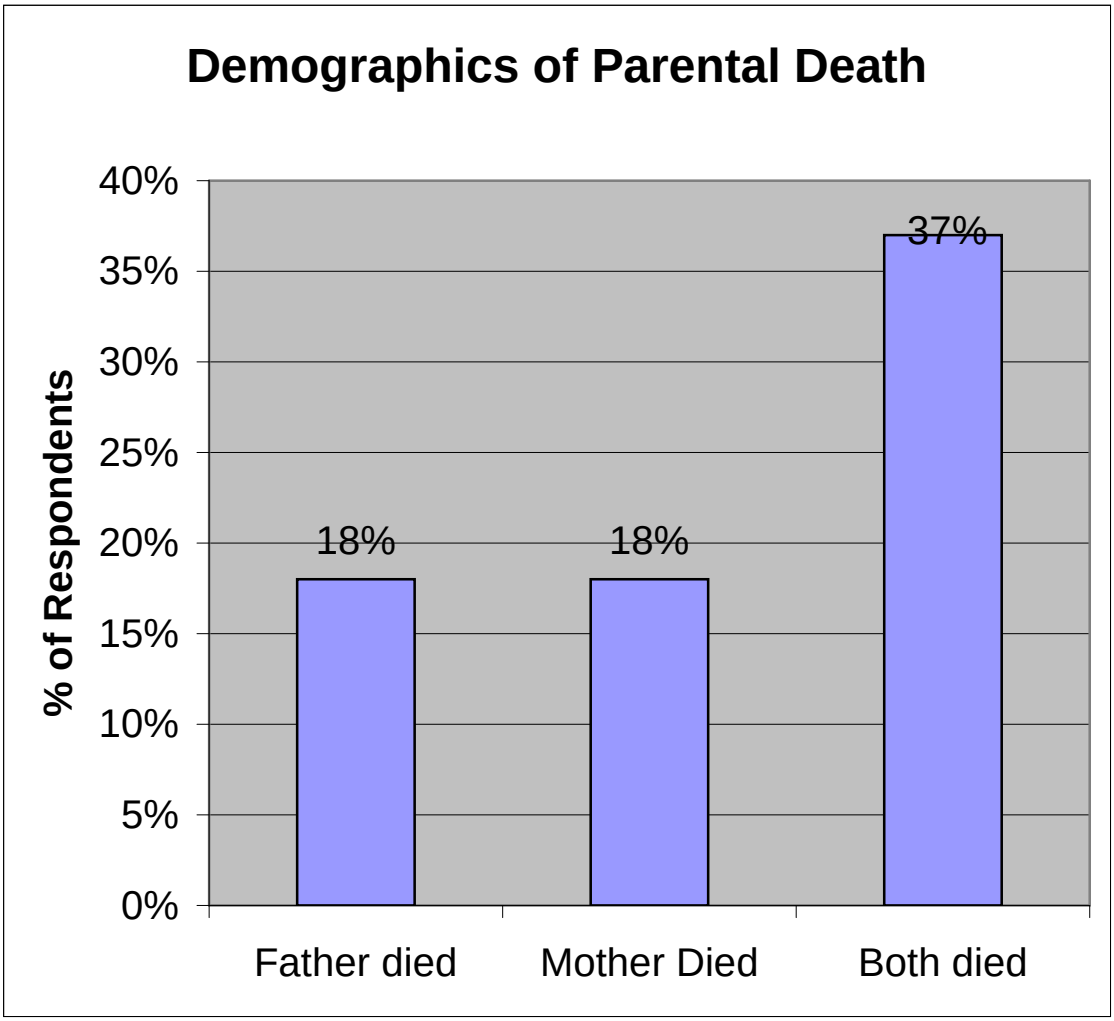

Demographics of Parental Death
% of Respondents
40%
35%
30%
25%
20%
15%
10%
5%
0%
18%
18%
37%
Father died
Mother Died
Both died

Table 3.

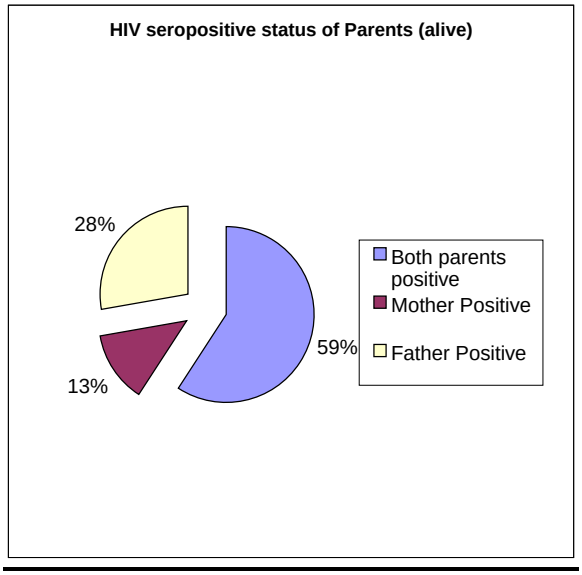

HIV seropositive status of Parents (alive)
28%
59%
13%
Both parents positive
Mother Positive
Father Positive

Table 4.

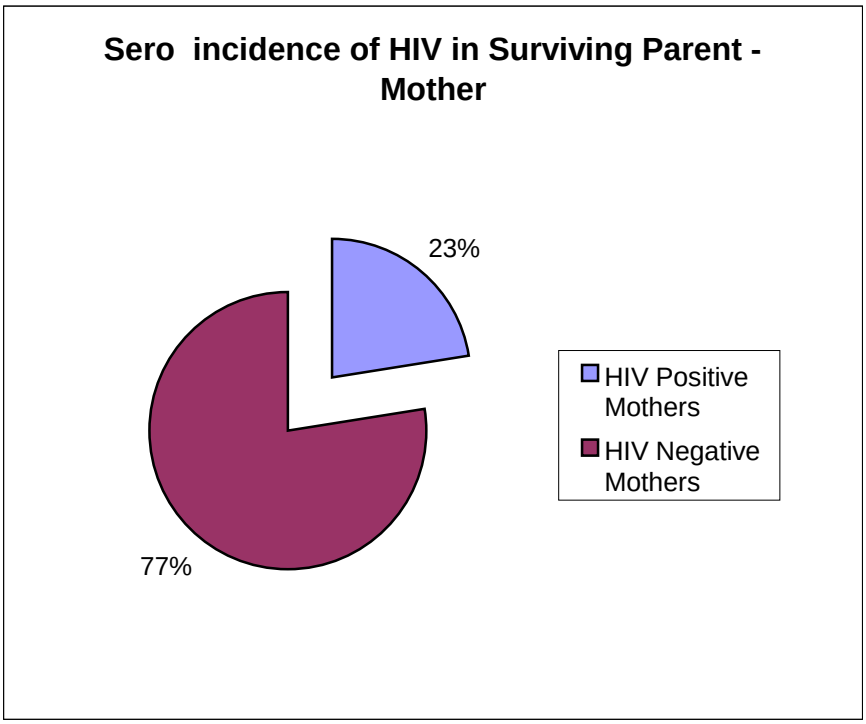
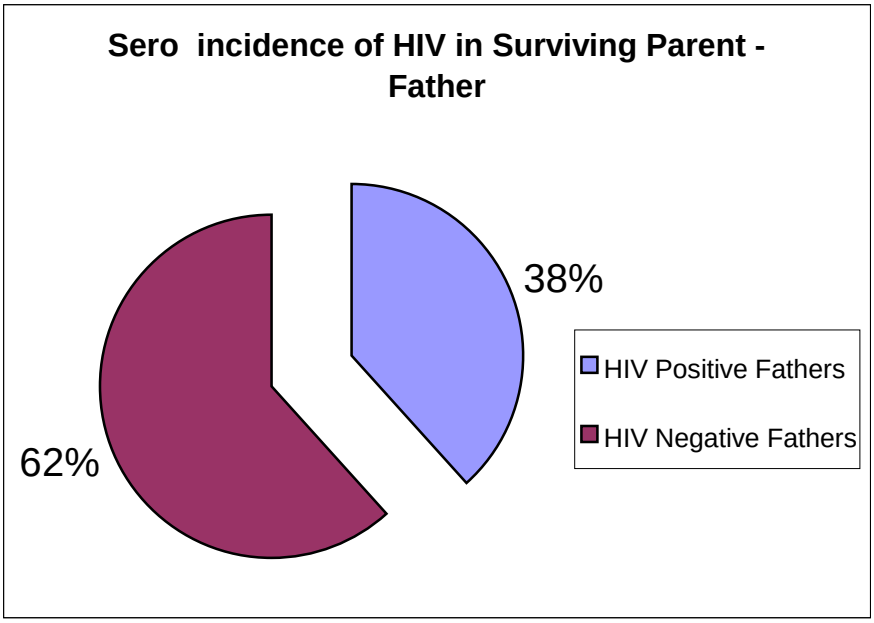


Table 5.



Government Initiatives on CAAs

By and large, the focus of Government, bilateral agencies and local NGOs with regard to children and HIV/AIDS is on prevention. The specific government initiatives in AP aim to reduce transmission in high-risk groups, between pregnant mothers to their babies, and toward increasing awareness among school children.

In the area of Care and Support, the Andhra Pradesh State AIDS Control Society (APSACS) services PLHAs under component IV of phase – II of the National AIDS Control Program. At present APSACS provides 14 service centers. Out of these, 12 are "Community Care Centers" and the remaining two are "Drop-in Centers" which provide care for PLHAs in the terminal stages of illness and who are afflicted by severe opportunistic infections.

All of the state centers essentially address adults and there is no focus on children. Just recently, APSACS submitted a proposal for funding to initiate 33 Community Care Centers in the whole state. The Community Care Centers for CAAs would be distributed through AP's 23 districts, with two centers in each of the 10 districts categorized as having high HIV/AIDS prevalence, and one center in each of the 13 low prevalence districts.[4] Although this is an indication of the AP government's increasing awareness about the needs of CAAs, it is important to remember that the project is still very much in its conceptual stages.

In the area of policies and services, the state and national government again lacks any specific provisions for HIV/AIDS orphans. The state and national government departments of Women and Child Welfare, of Social Justice and Empowerment, and of Health and Family Welfare have a few programs focusing on "Orphans and Vulnerable Children" which offer short-stay homes providing food, health care, and educational and psychosocial support while the state policy on orphans is limited to the Central Adoption Resource Agency's guidelines on adoption.

Government Medical Services for CAAs

In general, there is a large disparity between needs and public health service provision for those with HIV/AIDS. As of March 2003, fifteen physicians from 10 districts and the teaching hospitals in Andhra Pradesh are being trained in the management of HIV/AIDS. These physicians are distinguished from other medical practitioners by the designation of "Physician Responsible for AIDS Management" (PRAM). There is no specific training for the nursing staff with regard to HIV/AIDS beyond increasing their general awareness about the disease. In addition, there are no special wards and staff for the care of the infected persons. In fact, the present law demands that these persons should be managed in the same wards while maintaining the confidentiality. Moreover, although universal precautions have been advised to reduce HIV/AIDS transmission during surgeries, deliveries, and other medical procedures, the availability of facilities to enable these precautions to be observed is negligent to non-existent.

Voluntary counseling and treatment centers (VCTCs) are now widely available in government hospitals. However, these are yet to effectively service existing needs due to lack of awareness about the service provision and of ignorance of its affordability. Counseling at VCTCs is available only during narrow time frames and the VCTCs frequently suffer from irregular supplies of testing kits. The general gaps HIV/AIDS-related

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services in the existing public health system affect children directly (as services are equally unavailable to children and adults), and indirectly as well (because the care available to their parents or other care-givers is poor.)

When the high and increasing need for HIV/AIDS-related pediatric care and support is considered, the government's public health efforts in HIV/AIDS is disproportionately focused on preventing the mother to child transmission (PMTCT). There are no specific policies or practices designed to manage pediatric AIDS cases, whether orphans or otherwise. HIV positive children are treated with the same procedures as adults, regardless of whether these procedures are truly appropriate for the child.

Initiatives by local and international NGOs

The initiatives currently being conducted by local and international NGOs to provide care and support to CAAs and to AIDS orphans in AP are listed below:

1. Since 2001, Vasavya Mahila Mandali (VMM) and its 7 partner organizations in coastal AP have been running a Home and Community -Based HIV / AIDS Care & Support Program (HCBCS) for PLHAs, CAAs, and FAAs, with the support of International HIV / AIDS Alliance.
2. Freedom Foundation has been running an institutional care & support center since February 2001. The center is located in Hyderabad and provides medical care for PLHA adults and HIV positive children suffering from opportunistic infections or who are in the terminal stages of AIDS. Since its inception, the center realized the need for long-term care of abandoned HIV positive or of HIV positive orphans. In response to this need, the Foundation created '"DIYA" ("light") - a residential home for HIV positive children – in November 2002. DIYA has a capacity of 20 beds, and admits HIV positive children from ages 0 to 15 years. Although it is located in Hyderabad, DIYA has been receiving orphans from all over AP. It is currently the only home for HIV positive children in the state of AP.
3. The Catholic Relief Services (CRS) funds six programs in Andhra Pradesh that have a specific component of support for CAAs in terms of education, medicines and recreation.
4. Prajwala, an NGO, works with the children of sex workers and provides them with emergency health care through financial support and referrals to the Freedom Foundation's care and support center.
5. Family Health International (FHI) supports five programs with specific focus on CAA. Psychosocial support, educational, medical and recreational supports are the main components of the program.
6. François Xavier Bagnoud (FXB) Society has a center in Vishakapatnam that provides counseling for high-risk groups and HIV positive individuals, PMTCT centers, and medical support for street children. Out of 125 PLHAs, there are 10 CAAs for whom FXB provides nutritious food, institutional and home-based counseling, and medical support for opportunistic infections.
7. Population Services International (PSI) is a port based comprehensive HIV/AIDS program with main focus on VCT, STI Treatment, Awareness generation and reducing the vulnerability of the people directly or indirectly dependent on the port.
8. World Vision Care and Support Program is in nine locations of Andhra Pradesh. Their focus is on Counseling, Nutritious food, medical services for PLHA and FAA.

Among the care and support NGO service-providers, the majority devote their resources to providing health care (specifically, treatment of CAAs for common illnesses and treatment of HIV positive children for common opportunisitic infections), support for education (school books, bags etc.) and recreational activities (Table 6). Very few provide or arrange shelter for CAAs. As more CAAs become AIDS orphans, this is an area in which care and support NGOs will certainly need to expand their activities. Finally, none of the NGOs provide clothing for the children that is unrelated to education – currently, the only clothing provided to the children is for school uniforms.

It appears that the NGOs currently operating in care and support divide their efforts almost equally between CAAs, PLHAs, and FAAs (Table 7). This is an encouraging statistic, as programs to address the emerging problems of CAAs should target not only the children, but also their parents and their extended families in its interventions.

Table 6.

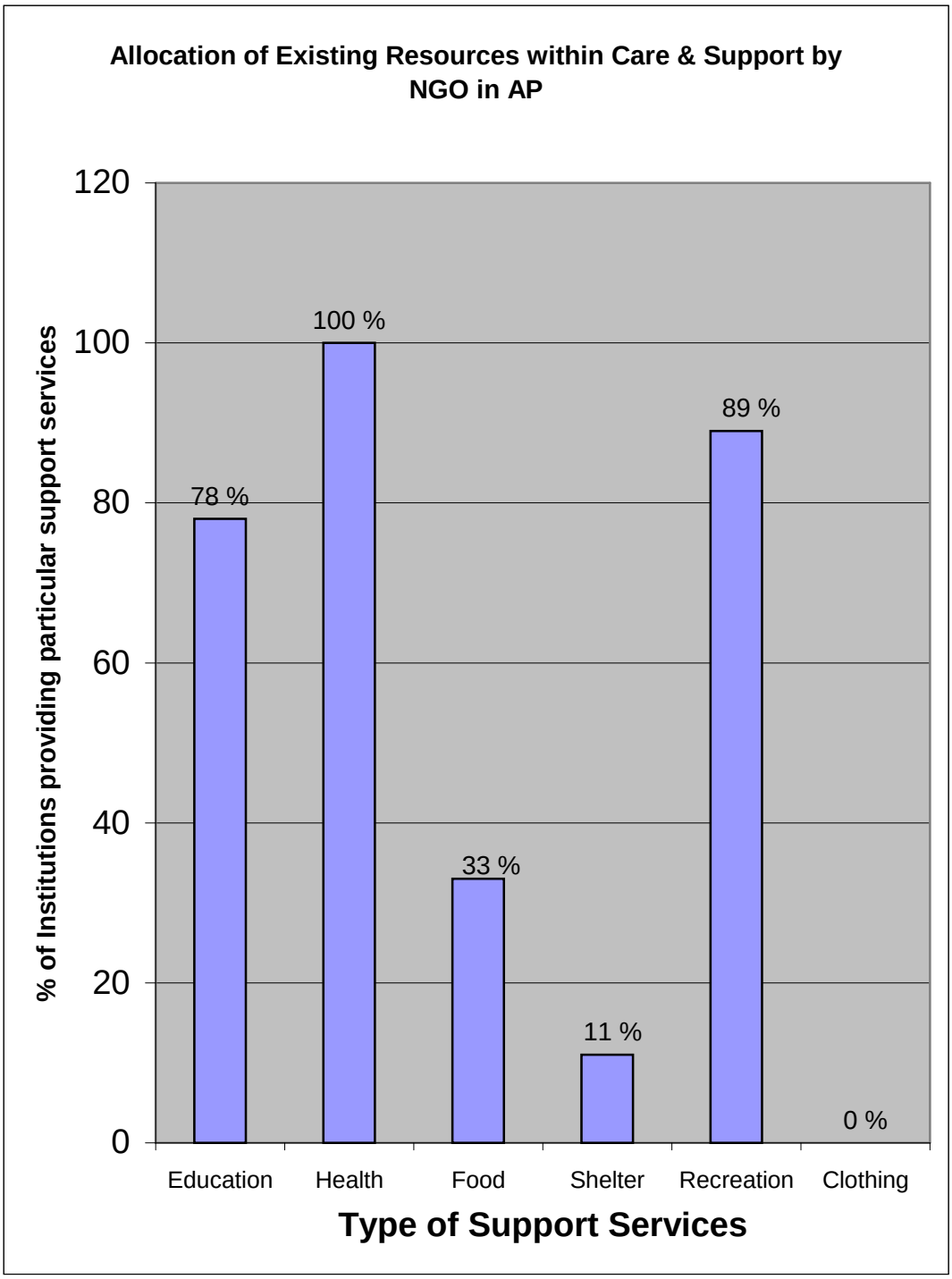
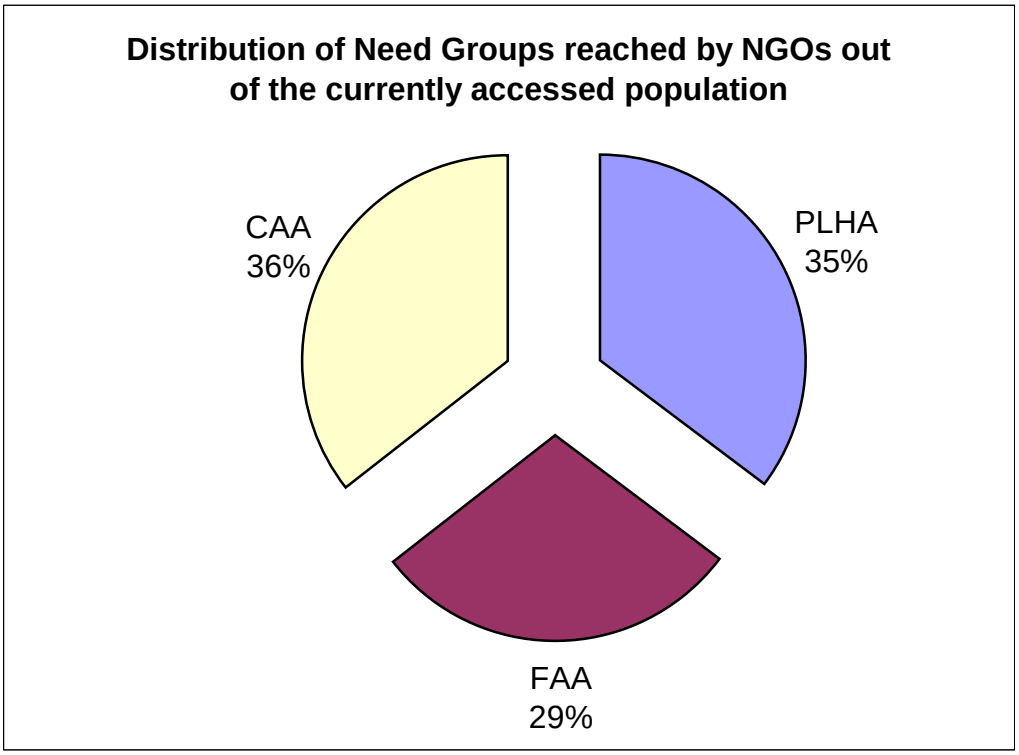

Allocation of Existing Resources within Care & Support by NGO in AP
% of Institutions providing particular support services
120
100
80
60
40
20
0
78 %
100 %
33 %
11 %
89 %
0 %
Education
Health
Food
Shelter
Recreation
Clothing
Type of Support Services

Table 7.


Distribution of Need Groups reached by NGOs out of the currently accessed population
CAA
36%
PLHA
35%
FAA
29%

FINDINGS: THE IMPACT OF HIV/AIDS ON CHILDREN

Social Impact

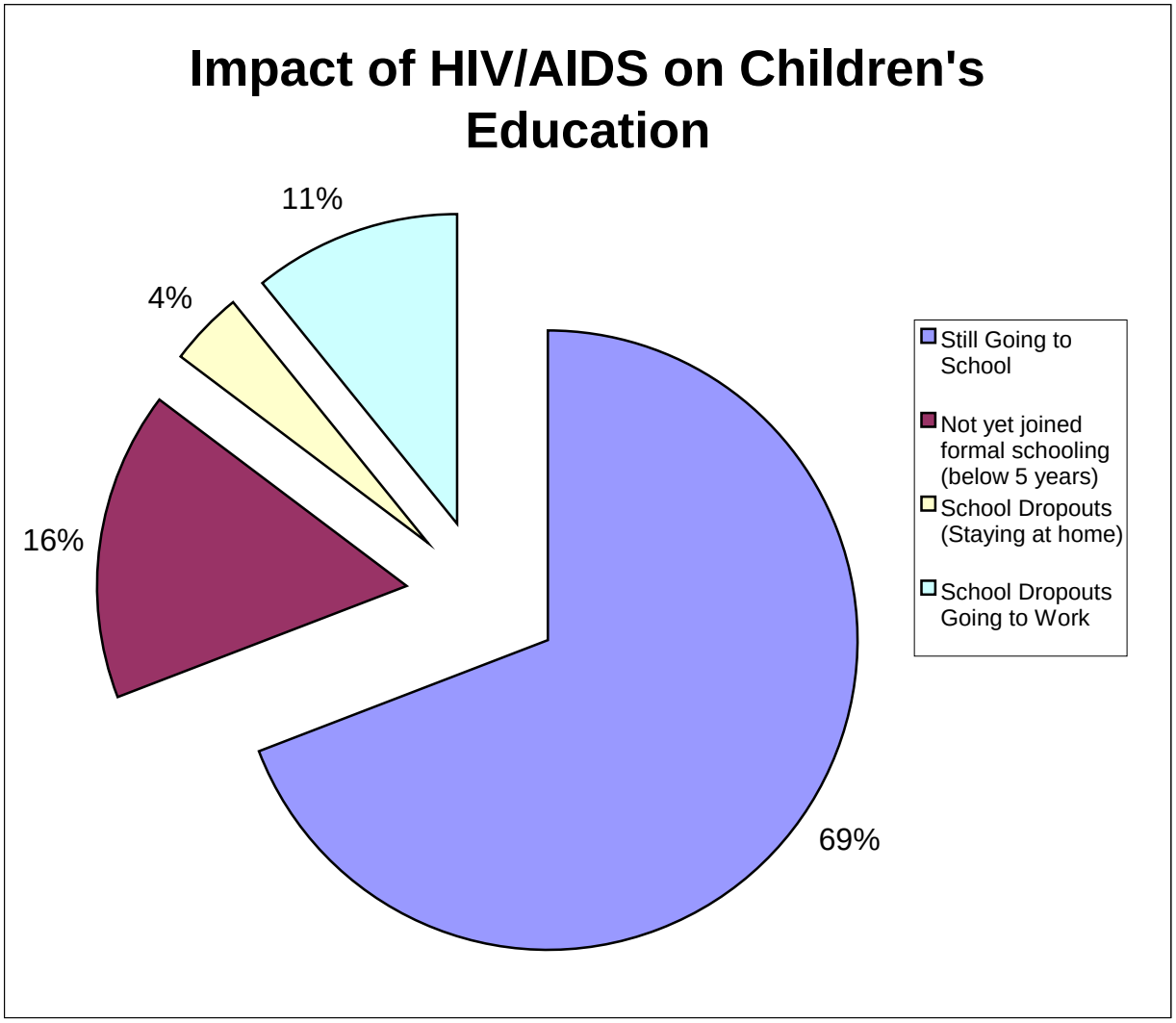
Children of HIV positive parents frequently suffer harassment and isolation from the community. A common misconception is that children of HIV positive parents are automatically HIV positive themselves. As a result, they may be denied access to schools and to other services. As their PLHA-parent progresses from HIV to AIDS, their children are forced to assume adult responsibilities. Often, CAAs are pulled out of school to shoulder the burden of supporting the family economically, while juggling care giving for their PLHA-parent with the demands of managing the household. In our survey, despite the support of NGOs that place heavy emphasis on providing educational assistance, 15% of our respondents have dropped out of school. 11% of the children have replaced study with work as the predominant consumer of their time (Table 8). The deprivation of educational opportunities that CAAs suffer has life-long negative impacts as it limits their future job-opportunities and hence lowers the ultimate standard of living that these children could possibly attain.

It is fairly obvious that the economic and social conditions worsen when the CAA loses one parent to AIDS. However, it is important to note that the way that the situation changes depends on which parent the semi-orphan loses. If, for example, the father dies, the semi-orphan and his widowed mother suffer intense discrimination as a widowed and fatherless family. Oftentimes, the semi-orphan's mother is blamed for the death of her husband. In some cases, once the husband dies, his parents turn the widow and the semi-orphans out of the house.

If the CAA is unfortunate enough to lose both parents to HIV/AIDS and to become a full-fledged orphan, the child experiences a significant change in family structure. If the orphan is HIV negative, the extended family commonly tries to assume responsibility for caring for them. In developing countries like India especially, the extended family is ill-equipped to deal with the responsibility of raising the AIDS orphans as aunts, uncles and grandparents, who may have little income themselves and who may have counted on the support of the HIV infected relative, must now be the ones to provide care and support. In fact, in many cases, the extended family may extend its help to the PLHA parents and their children once the parents are alive. However, after the parents pass away, the economic burden of caring for the AIDS orphans on a long-term basis is too much for the extended family to face. In such circumstances, the relatives may tell the AIDS orphans outright that they cannot provide for them. In addition, our survey indicates that in many cases, one or more members of the orphan's extended family may also be infected by HIV/AIDS.

Caption: Impoverished grandparents who now have to shoulder the responsibility of caring for their young grandchildren after the children were orphaned by AIDS.

Table 8.


Impact of HIV/AIDS on Children's Education
11%
4%
16%
69%
Still Going to School
Not yet joined formal schooling (below 5 years)
School Dropouts (Staying at home)
School Dropouts Going to Work

When the extended family is either unwilling or unable to care for the children orphaned by AIDS, the fate of the children tends to fall into institutional hands – be they governmental or non-governmental. Institutionalization of AIDS orphans raises new problems, regardless of the HIV serostatus of the AIDS orphans:

- Firstly, most of these agencies are not equipped with counseling services to help children deal with the trauma of having to watch their parents die.
- Secondly, the institutions tend to lack programs that equip children with skills that will help them survive in the real world.
- Thirdly, most of these institutions admit children on the basis of strict and exclusive classifications, for example, on the basis of age, gender etc. Because of these restrictions, AIDS orphans – like other orphaned children – often suffer separation from their siblings.

One of the biggest problems that AIDS orphans face is discrimination on the basis of their HIV status. For example, if relatives find that one child is HIV positive while his brothers and sisters are not, they will adopt the HIV negative siblings and abandon the HIV positive child to institutional care. Essentially, the HIV positive orphan's fate is left to the wind, as institutions themselves are unwilling to admit HIV positive children. In fact, it is not unusual for these institutions to inquire about the HIV serostatus of prospective entrants. The lucky HIV positive orphan is referred by these institutions to the small number of organizations willing to accept HIV positive children. However, the number of organizations who are accepting HIV positive children is already insufficient to service the burgeoning numbers of HIV orphans (as well as the increasing number of HIV positive children who are being abandoned by their parents). As a result, the accepting institutions are currently suffering under the strain of extreme overload. These institutions also suffer from lack of funding, as the current donor mentality is not yet focused on caring for HIV orphans.

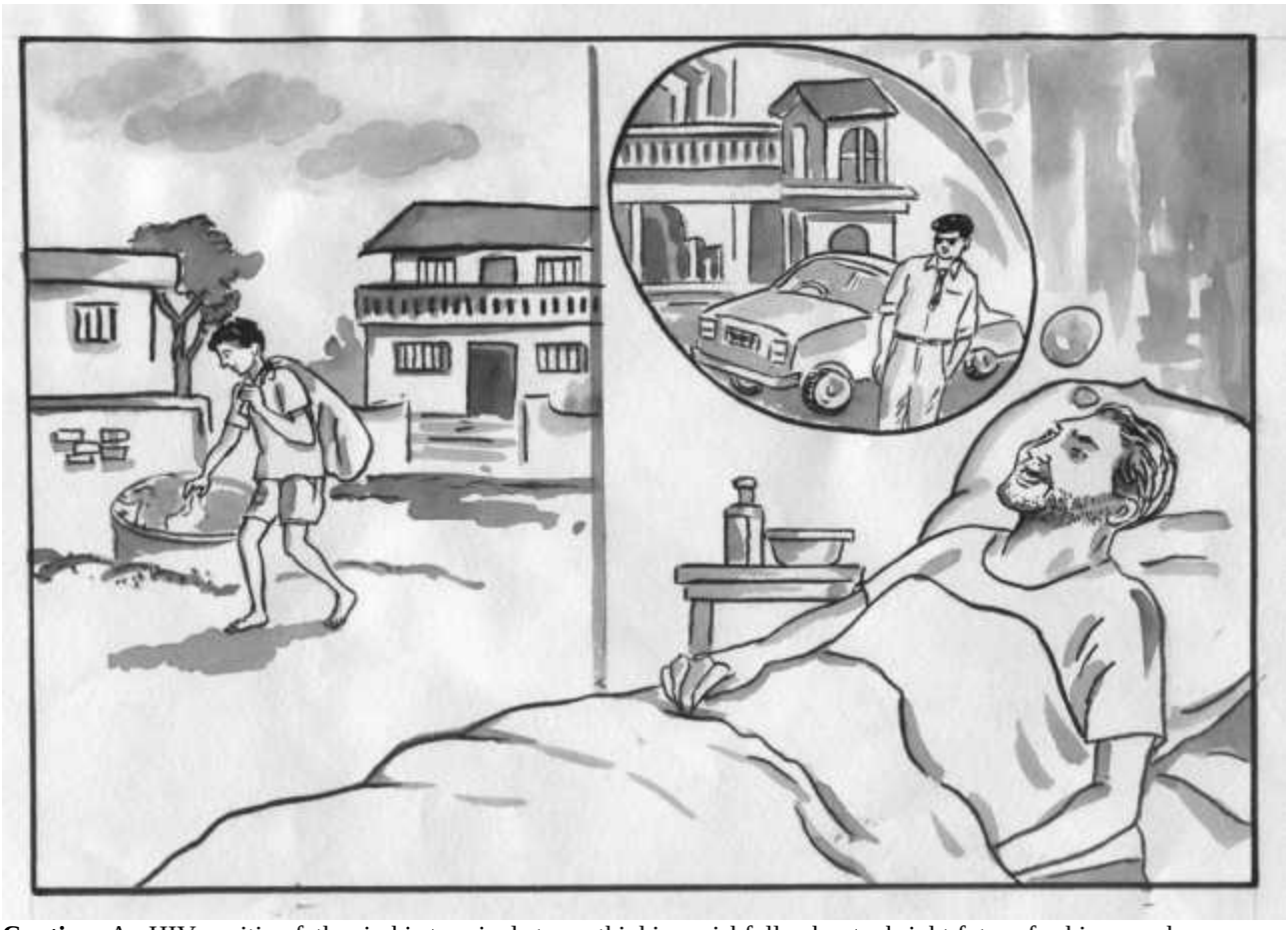
When relatives abandon them, and when institutions refuse to take them, the HIV positive AIDS orphans have no choice but to fend for themselves. This has created a growing population of child-led households comprising AIDS-orphaned siblings who try to stay together. Such children -- especially the older ones who are in-charge of the household -- generally drop out of school and find unskilled employment (UNAIDS, 1999). Clearly, these children's ignorance about care giving, nutrition, health, their legal rights, and other social and economic issues makes them vulnerable to disease and to exploitation. Moreover, these children experience the added psychological and emotional strain of having to mother- and father- themselves.

The home of last resort for some AIDS orphans find is the street. Because of AP's especially well-developed rail network, it is common for AIDS orphans in rural areas to migrate to urban areas in search of a better life. Life on the streets is harsh, and the children are susceptible to violence and sexual exploitation. The frustration and mental turmoil that these children have experienced increases their vulnerability to the lure of drugs.

Economic Impact

Even before an HIV positive parent dies, household resources dwindle due to medical expenses and parents' inability to work. Because parents may be dismissed from work due to their HIV status, parental income may be lost completely even before they progress to AIDS. After their parents die, AIDS orphans and semi-orphans tend to suffer loss of property and deprivation of their entitled inheritance, either because of laws that disenfranchise widows and/or because of the acquisitiveness and deceit of the extended family or other opportunists.

As we have already observed, AIDS orphans and semi-orphans are almost always forced to work and are pulled out of school. The educational deprivation that these children suffer has both micro-and macro-level implications. At the micro-level, because the children lack training and skills, they typically find work in the petty-service sector where salaries are low. In the short term, therefore, the AIDS orphans' existence is one of bare subsistence. In the long term, the lack of education reduces the children's chances for future income earning and effectively locks them into a life of enduring poverty. At the macro-level, because the vast and growing number of poorly educated CAAs is shrinking India's skilled human resource pool for the future, the impact of the AIDS orphan crisis on the Indian economy will be enormous.



Caption: An HIV positive father in his terminal stages thinking wishfully about a bright future for his son who in reality has become a homeless rag picker.

Psychological / Emotional Impact

CAAs experience intense psychological and emotional distress, which arise from combinations of several factors including:

1. *Discrimination* that CAAs and their parents suffer in the home, in schools and in the wider community either because of their HIV positive status, or because of their association with an HIV positive relative.
2. *The premature burden of multiple, adult responsibilities* that a CAA must shoulder causes them psychological distress
3. The harrowing, extended ordeal of caring for their sick parents, siblings or other HIV positive relatives, and of *watching people whom they love suffer and die*.
4. *Loss of Individual Identity* is a major problem that AIDS orphans face. This is especially relevant to very young AIDS orphans.
5. Because there is no well-established system in place for the care and support of AIDS orphans, AIDS orphans suffer under *the strain of uncertain futures.*

These experiences fill CAAs with feelings of powerlessness, pain, and anger. In the case of discrimination, many CAAs are unable to understand why they are being singled out or treated differently from other children. They long to be included in the activities of "normal" children. The feeling of exclusion that CAAs often experience contributes to loss of self-esteem.

Because parents and relatives are reluctant to disclose their HIV positive status and to discuss their condition with the children, many CAAs also experience intense confusion and trauma as they witness their parents, siblings or other relatives growing inexplicably weaker. CAAs who are aware of the illness have to grapple with the realization that they are also losing one or both parents. As the future AIDS orphan tries to come to terms with this expected loss, behavioral and emotional disturbances are possible (King, 1993).

The family is an essential unit in the formation of individual identity. Within the family, children are given a sense of place and belonging. In addition, the family teaches children how to relate to the larger society. When CAAs and AIDS orphans become separated from their families, memories of home life quickly fade and intra-familial relationships that essential to their identities are broken or lost. As they grow older, AIDS orphans yearn for answers to some of the most basic questions about themselves like, "Who am I?" "What were my parents like?" and "Where do I belong?". Truthful answers to these questions are essential for all children, however, in the Indian context where individual identity is strongly based on heredity and family lines, the need for these answers is especially strong.

Finally, CAAs and AIDS orphans are subjected to constant worry about their future. These children are often shuttled from one family member, or one institution to another. These concerns added to all of the other problems that a CAA or an AIDS orphan must face add further burden to children who are already under significant strain.

Medical Impact

1. *Because parents are positive, regardless of whether the child is positive:*

   Direct:

   Children with HIV+ parents are also exposed to medical risks through their roles as care givers. Due to either the absence or unwillingness of other adults in the household to take care of the HIV+ parent, the children must often take on the responsibility for caring for their parents themselves, increasing their risk of contracting infections from their sick parents. Moreover, because of widespread ignorance about HIV/AIDS, children of HIV positive parents are at greater risk of dying of preventable diseases and infections whether or not they are HIV positive themselves. This results from their parents' mistaken belief that when the children become ill it is necessarily due to AIDS. Because many PLHAs have a fatalistic attitude towards HIV/AIDS and believe that there is no point in seeking medical help for AIDS-related opportunistic infections, their children are automatically denied access to otherwise treatable diseases.

Caption: A child-caregiver feeding her HIV positive mother is now bedridden after severe opportunistic infections.

Indirect:

Because AIDS renders PLHAs unable to work, and because its management demands medications that are of relatively high cost to most PLHAs, it severely depletes an FAA's economic resources. In these resource-poor settings, capacity of parent to care for the child is reduced. For example, children often suffer from nutritional problems because of lack of food.

2. *Children who are HIV positive:*

HIV positive children undergo considerable physical suffering as the infection plays out its course. The progression from HIV infection to AIDS and death is faster in children as compared to adults. The situation for HIV+ children who live in developing countries such as India is complicated by the inaccessibility of health services and the unavailability of even basic medicines. HIV infected children in developing countries are also at higher risk of contracting opportunistic infections because of poor nutrition, poor sanitation, over crowded housing, poor immunity, not having congenal environment etc. Drugs for rarer HIV associated illnesses have not been included in programs that supply the world's poorest hospitals and clinics. Clinical guidelines for pediatric AIDS are less clear than those for adults. The difficulties that pediatric AIDS cases face are complicated by the fact that the follow up of HIV positive children born to HIV/AIDS parents is very poor. In addition, since the infections that HIV positive children die of are similar to those that commonly kill other children and since parents do not like to test their children's HIV serostatus, the HIV serostatus of many positive children is unknown, making it difficult for health workers to distinguish between HIV positive and HIV negative children. As a result, children may not receive the special, HIV/AIDS-specific care that they may need (UNAIDS, 1999).

Table 8. MEDICAL PROBLEMS OF CAAs

Medical problems on par with other children	*Medical problems specific to CAAs*
➢ Nutritional deficiency ➢ Respiratory infections ➢ Diarrhea ➢ Warm infestations ➢ Pyogenic meningitis ➢ Oral sepsis ➢ Ear infections ➢ Scabies	➢ Skin diseases like fungal and bacterial infections contracted from HIV seropositive parents ➢ Respiratory infections ➢ Infective arthritis ➢ Staphylococcal meningitis ➢ Tuberculosis ➢ Psychological problems ➢ Risk of transmission through breast milk.

At the countrywide level, HIV/AIDS in both adults and children has become a burden on the Indian government's medical budget. Feticide has increased in HIV positive mothers. The Infant Mortality Rate has increased due to opportunistic infections. There has been a significant, HIV/AIDS-related increase in the incidence of delayed milestones, retarded growth, and under-weight infants. Children are experiencing increased morbidity due to opportunistic infections, most noticeably pyogenic meningitis, bacterial pneumonias, and skin diseases. Psychological insecurity and depression in CAAs are on the increase while nutritional status has declined.

COMPLICATING FACTORS: GENDER

In the international arena, India is almost reflexively associated with societally ingrained gender inequalities. As it does with almost all other social issues, gender complications the problems of CAAs and of AIDS orphans at multiple levels. For example,

1. *Economic: Caste & Gender-Specific Roles in Employment*

In many traditional communities, the family livelihood is determined by a caste system that has operated for generations. In such communities, a single family would have followed the same occupation or "trade" (such as fishing, pottery, weaving etc.) -- for generations. Within these families, tasks are assigned along gender lines: men are the breadwinners while women play a supporting role as homemakers. When the breadwinner of the family succumbs to HIV/AIDS and can no longer perform his job, the gender-based employment system is so rigid that women are rarely permitted to replace the breadwinner in the family trade. This system effectively robs families of their income. In situations where there are no males to assume the breadwinner role, their dependents (female: widows and girl children, and possibly males who are too young to work) are relegated to lives of poverty.

2. *Reproductive health -- Female sexuality, adolescence:*

AIDS orphans need to be educated about their sexuality just as any other child does. Because parents are their children's primary role models, their "instruction" – however imperfect – is vital. AIDS orphans and semi-orphans are often deprived of male and female role models. This is particularly true for orphans who are not adopted by their extended families. Girls are especially affected. They need special attention during menstruation and need to be taught about the consequences of the changes their bodies are undergoing. These include their ability to become pregnant, and their changing nutritional needs (for iron, for example).

In addition to their special need for education on sexuality, girls orphaned by HIV also need special protection. Girls orphaned by HIV/AIDS are often impoverished and isolated. Many such girls are driven or tricked into prostitution, or become the victims of sexual abuse. Overall, ignorance about sexuality, safe sex practices, and their individual rights increases the risk that girls orphaned by HIV will contract HIV themselves (UNAIDS, 1999).

3. *General Deprivation*

Gender inequities manifest themselves in almost all aspects of Indian family life. In general, girls are less valued and cared for. They are considered burdens, are made to do physically demanding labor, and are often subjected to multiple forms of abuse. In the case of food, for example, the best food goes to the husband who eats first, followed by the male children, the girl children and finally, by the mother. This situation is paralleled in the case of education, medicines, and medical care[5]. The poorer a family is, the more severe these inequities tend to be. Once a family is affected by HIV/AIDS, the resource pool shrinks. The mother/wife suffers first, followed by the girls. As a result, CAA girls are at increased risk of nutritional and educational deprivation, and are more likely to suffer higher morbidity than their male counterparts. These problems extend to HIV

[5] In our field-work, we have observed several cases where husbands would buy medicines for themselves, hide them from their wives, and the wives would have to steal the medicine to treat her OI's.

positive women. In India, men live for an average of 5 years post HIV infection while women live for an average of only 2.5 to 3 years. This is because culturally embedded gender inequities reduce the Indian woman's physical, emotional, nutritional and mental health as compared to the Indian man.

The options available to male and female children also differ outside the familial framework. In our field work, we have observed that among street children it is much easier for boys to find petty jobs while girls are quickly snapped up by pimps and traffickers. This has implications for the way education, care, and support programs can target street boys and street girls. Because the street boys are outside hawking, begging, or rag picking, they constitute a "visible population" that can is reachable through proactive outreach efforts. In contrast, because the street girls are absorbed by "institutions" for sex-work and trafficking "networks", they are largely an "invisible population" that requires more sensitive and carefully-planned outreach efforts.

4. Discriminatory Foster Care

Because of families perceive girls to be burdens and boys to be assets, there have been instances where the extended family has blatantly refused to adopt an AIDS orphan specifically because it was a girl.

5. Child Widows

In the rural and semi-urban areas especially, girls are pulled out of school and married off at the onset of menses. The phenomenon of the Indian "child-bride" is well known. When the husbands of these "child-brides" succumb to HIV/AIDS, the "child-widows" are left to cope with the consequences. The child widow wrestles with the same issues that many HIV/AIDS orphans must deal with —debts, insecurity about the future, psychological trauma, and discrimination at being associated with HIV/AIDS. In addition, the child widow (often no more than 13 or 14 years old herself) may have the additional burden of looking after children. Because child-widows are prematurely taken out of school to enter into married life, they are ill equipped to provide for their children. Moreover, in many places widows are either still not entitled to their husband's property or are unaware of their rights. Hence, the widow frequently loses badly needed economic resources.

The problems that child widows face are complicated by the intense traditional discrimination that widows face in Indian society. In India, the widow is traditionally viewed with suspicion. She is shunned, ostracized and alienated. It is common for the widow to be blamed for the death of her husband. Following the death of her husband, the widow's in-laws may throw her out of the house. Widows often cannot even turn to their own families for protection and support. The widow's family considers itself relieved of a great burden once they marry off their young daughters. As far as they are concerned, their duties to their daughters do not extend beyond giving them a husband.

Traditionally, widows are not permitted to remarry. In addition, they are considered fair game for men's sexual advances. Here, the child widow is a particularly attractive target. Whether a widow wants this attention is usually irrelevant. Ironically, the beleaguered widow is blamed by the community for encouraging these advances even as she tries her best to fend off sexual predators. In such an environment, widows who experience sexual exploitation have few options for redress.

In sum, the child widow to HIV/AIDS is among the most unfortunate of all those affected by the HIV/AIDS crisis. The child widow suffers discrimination due to gender, to her status as a widow, and to her association with HIV (whether she is HIV positive or

not, although it is even worse if she is positive). The child widow is especially vulnerable because her youth, and her inexperience, and because she may be saddled with caring for a string of children, even though she is practically a child herself. Most child widows range between 14-18 years of age. Many child brides are widowed shortly after they are married, typically with just enough time for their husbands to infect them with HIV as well. Because of multiple stresses, the physical and mental health condition of the child widows – especially the HIV positive ones -- deteriorate rapidly. At present there are no programs in place to address the specific needs of the child widow. This is a grossly neglected area and a situation of great attention.

SPECIFIC ISSUES: ADOPTION AND FOSTER CARE

At present, there are few established institutions or programs that are prepared to provide care and support to AIDS orphans, or to other CAAs. The CAAs who are in need of care and support fall into two major groups: those who are HIV negative and those who are HIV positive.

As might be expected, the outlook is brighter for HIV negative AIDS orphans. The major problem that they face is being mistakenly classed as HIV positive and thus relegated to the second group. Once their HIV negative serostatus is established, relatives, community-members, and orphanages are much more willing to admit AIDS orphans. These social and institutional networks provide for the child's basic physical needs (food, shelter, clothing), and oftentimes for some form of education or skill training. However, by-and-large the family members and institutional care-givers lack the capacity to provide the emotional counseling, care, and support that the AIDS orphan needs in order to come to terms with the tragedy that they have experienced in their lives. There is a need not only to expand the *types* of support services provided for AIDS orphans (expanding from physical needs to psychosocial counseling, for example), but also to expand the *numbers* of actors or agents that are equipped to care for these children. Currently, capacity for the community-networks and for state and non-governmental institutions to absorb the growing numbers of AIDS orphans is limited.

Adoption for even HIV negative orphans is not a viable solution due to the socio-economic and cultural realities of the Indian situation. In general, childless Indian couples will not adopt a child who has no blood relation to them. Thus, at present, there is practically no adoption of AIDS orphans by un-related families. In addition, under the existing system, India cannot depend on adoption by relatives. Although such relatives may be willing to care for the AIDS orphans, harsh economic necessity forces many relatives to turn the orphans away. Currently, foreign families are experiencing a small and growing interest in adopting HIV negative orphans from India. However, even if the demand for HIV negative AIDS orphans grows in foreign countries, the absorptive capacity of foreign couples will still be miniscule compared to the number of orphans that the epidemic is certain to generate in India.

Another popular proposed solution to the AIDS orphan problem is through state- and non-governmental institutionalization. This is not a viable strategy in the long run as the expected number of AIDS orphans is certain to be well beyond the numbers that the government and other institutions can afford to provide holistic, 24-hour care.

The situation for HIV negative AIDS orphans is difficult, and the projected outlook for the growing population of these orphans is grim if extensive measures are not taken now to increase institutional and community capacity to absorb them. That said, the forecast for HIV positive AIDS orphans is much grimmer if the current situation does not change.

As mentioned above, HIV positive AIDS orphans face extensive and extreme discrimination. Family members abandon these children to institutions that are unwilling to accept them. Today, the lucky HIV positive children are referred to the one or two over-burdened, and under-funded organizations that have geared themselves towards providing for these most unfortunate victims of the HIV/AIDS epidemic. The dearth of organizations that are willing

to take care of HIV positive orphans is readily illustrated by the situation in AP. At present, there is only one institution in the entire state that fill this need – the Freedom Foundation (with a capacity of 20).

If adoption is not a viable option for the HIV negative orphan, it is exponentially less so for the HIV positive child. Prima face, it is unlikely that non-related couples (be they Indian or foreign) will willingly adopt an HIV positive child. Even if these couples are sensitized to HIV/AIDS, the HIV positive orphan comes with two major disadvantages – the requirement for extensive and expensive medical care and psychosocial support, and the practical certainty that the child is unlikely to survive to adulthood. Adopting parents are human also, and it is therefore unrealistic to expect that they will choose to become emotionally invested in a child that is doomed to die.

In contrast to the limited options for adoption by non-related couples, there is a possibility for establishing adoption by relatives and community foster care for HIV positive orphans. The viability of these alternatives will be contingent on the government and the non-governmental community to sensitize the population so that people are willing to accept HIV positive orphans into their homes, and to mobilize the desperately needed funds for their care.

As is the case for HIV negative orphans, there is a need to expand not only the *number* but also the *nature* or *types* of care and support services available to them. HIV positive children are both similar to and different from HIV negative children. Initiatives designed to care for HIV positive children must keep this in mind and must constantly balance their services to ensure that the unique medical, nutritional, and psychosocial needs of the HIV positive child or HIV positive orphan are met without making the child feel alienated or that he or she is "abnormal".

BEST PRACTICES: LESSONS FROM THE FIELD

The best practices we present have been drawn from lessons that we have learned in the field. At present, initiatives for providing care and support to PLHAS, CAAs, and FAAs can be divided into two major groups based on their approach to the problem – home and community-based initiatives, and institutional initiatives. Home and Community-Based Care and Support (HCBCS) initiatives aim to mobilize community resources to deal with the expanding impact of HIV/AIDS. HCBCS programs use advocacy at the community level to increase awareness and to sensitize the people about HIV/AIDS and its related problems. The solutions that HCBCS has used in response to the varying manifestations of the HIV/AIDS epidemic are typically devised and implemented by community-members themselves. In contrast to the HCBCS initiatives, organizations that take an institutionalized approach provide care and support by drawing purely on the organization's own human and monetary resources.

Home and Community-Based Care and Support (HCBCS) Initiatives

To date, most of the funding for the HCBCS has been coming from international donor institutions. Nevertheless, our HCBCS efforts have already begun to tap community resources. It is our goal to further expand the mobilization of community, local, and national governmental donor resources toward the cause of the HIV/AIDS affected community in AP. The services that HCBCS NGO's have been providing to CAAs fall into two major categories:

1. Philanthropic Donations:
   These are drawn from community members and are used to provide clothes, educational support (provision of school books, fees, uniforms, books, bags etc), nutritional support, medications for HIV positive children.

2. Increasing community capacity to respond to CAAs and to the wider epidemic through:

   - *Advocacy:* Awareness and sensitization campaigns are used to remove the stigma of HIV/AIDS and to inform the public about the condition of PLHAs, CAAs, and FAAs. Often, these campaigns target either high-risk groups (like sex workers, PLHAs, street children) as well as influential groups (local government leaders, teachers etc).
   - *Training of community volunteers:* Training of volunteers multiplies the capacity for advocacy. In addition, training is used to broaden the communities' capacities to respond to the diverse aspects of the HIV/AIDS situation (for example, training of counselors for CAAs, training on the nutritional needs of PLHAs and CAAs etc.) Finally, volunteers are often able to provide helping hands in valuable but simple ways to families or institutions caring for CAAs (for example, by taking CAAs on recreational outings etc.)
   - *Developing support groups of PLHAs, CAAs etc*: Support groups allow affected individuals the space to share their concerns with others facing similar problems. Moreover, the support groups have allowed affected

individuals a chance to pool their efforts toward evincing the changes that they feel need to be made in their community.

The most inspiring and humbling lessons that VMM and the HCBCS network have come through the diverse ways in which communities – once sensitized – have been able to come together to alleviate HIV/AIDS related suffering of CAAs and to devise solutions to the problems that these children face. To illustrate some of the best practices that we have learned from these communitarian efforts, we have provided a number of summarized case studies below.

Case studies Illustrating Best Practices in the HCBCS Network

1. Mobilizing Existing Community Advocates - Women's self help groups

In the villages of AP, especially in coastal AP, women self-help groups or government-initiated "DWCRA groups" (Development of Women and Children in Rural Areas) are actively involved in saving and micro-credit schemes to assist families affected by HIV/AIDS to start small income-generating projects. In addition, the women's self-help groups (10-15 women per group) have started "Sarvodaya Patra" ("Bowl for Holistic Development"). Each member contributes one handful of rice every day. The rice is stored in a group-owned vessel and every month, collected rice is divided among families with CAAs and young women widowed by AIDS. The self-help groups recognized the need to support young widows as widows are not generally allowed to work and are not permitted to leave the house for one month after their husband's death. In the interim, the widow's family often starves. This practice has been taken up as a model by VMM's HCBCS program and is being replicated in other communities where these restrictions apply.

2. Supported Child-headed Households

Due to the stigma of HIV/AIDS, many PLHAs migrate from their original communities and relocate their families in places where their HIV status and their identities are unknown. This creates a difficult situation for the AIDS orphan. Because the extended family lives far away, the orphans find themselves without familial support. Oftentimes, the orphans are so young that they do not even know the identities of their relatives and are unable to contact them for help.

One of our implementing partner organization, "Needs Servicing Society" (or "Needs") was informed of 3 orphaned siblings (aged 11, 8, and 5) who were thrown out of their rented house following their parents' death. Needs spoke to community leaders and sensitized them about the issue. Through collaboration with the community and Needs, a small thatched hut was built for the three children. Needs is providing clothing and psychosocial support for the children while the community is providing the children with food and other support.

3. Creating Student/Youth Volunteers

Every year universities and colleges across India involve their students in two-week long government-mandated service schemes as part of the National Service Scheme (NSS) program. Through the advocacy of VMM and our partner organization, "AIRTDS" (Action for Integrated Rural and Tribal Development Social Service Society) in Tenali in the Guntur

District we encouraged two colleges to make PLHAs and CAAs the focus of their 2003 NSS program.

In Vijayawada, 35 college students adopted two urban slums and conducted a 15-day children's camp for 83 CAAs. During the camp, the children were given an opportunity to showcase their talents through activities like drawing, painting, song, and role-play. All of the children were awarded with gifts to encourage them. The experience at the CAA camp inspired four of these student volunteers to devote 7-8 hours every week to providing supplementary education all 83 CAAs. The volunteers are currently collecting the necessary books and stationary from students at their college and distributing these to the children.

In Tenali, 35 students made surveys of the HIV related health status of high-risk groups in the city of Tenali and in 5 of its surrounding rural villages. Thanks to this initiative, 12 students have volunteered to conduct continuous house visits and to provide psychosocial support to PLHA parents and their children.

4. Utilizing the Media for Advocacy

CAAs Speak

Our organization visited the homes of 30 CAAs with a recording team from All India Radio, one of the nation's biggest governmental agencies for information and broadcasting. The children were drawn from 5 locations (both rural and urban) in 2 coastal districts of AP. The children were asked to convey their feelings, experiences and needs as CAAs. The voices of these children were broadcast across 9 districts in coastal AP.

The CAA's Ballet

Every year, All India Radio conducts program highlighting particular issues relevant to children on the eve of Children's Day (November 14th). In 2001, All India Radio approached VMM with the idea of focusing on the needs and concerns of CAAs and AIDS orphans. Through this collaboration 9 CAAs from Vijayawada performed a sensitization ballet " Goranta Deepam" (Tiny Lamp) to a live audience of more than 2000 people from all levels of Vijayawada society. The ballet was also recorded and broadcasted to 9 districts of coastal AP.

Reaching National and International Audiences through Television and Print Media

Over the last 3 years, 4 television channels (MAA TV, E TV, Star Plus, SITI Cable) and one newspaper (the Indian Express) have approached VMM expressing their desire to increase public understanding of the situations that CAAs and AIDS orphans face. At the children's consent, each news agency conducted a group interview with 8-10 children drawn from the street-children in VMM's care and support program for CAAs. These children were either AIDS orphans or were CAAs who had been forced out of school and unto the streets in order to support themselves or to help support their HIV/AIDS-affected families. The children (mostly boys) were asked to explain why they were on the street and to describe their current sexual behavior. The CAAs were also asked questions aimed at assessing their knowledge levels on AIDS and on safe sex practices. Finally, the children were invited to describe their present occupations in which they were engaged to support themselves,

and what they would prefer to be doing. These interviews have been broadcasted locally and internationally and have helped to sensitize audiences to some of the problems of CAAs (such as deprivation of educational opportunities) and needs of CAAs (such as skill training for better employment and more comprehensive education on sexuality and HIV/AIDS). In addition, the programs increased public awareness of the fact that many CAAs are engaged in high-risk behavior (sexual activity etc).

Overall, our efforts to sensitize and mobilize the public through media-facilitated advocacy have been well received – the letters received by All-India Radio in response to these programs number in the thousands.

5. Community-wide Acceptance and Integration of PLHAs and CAAs through Local Government Structures

Discrimination is one of the major hurdles for PLHAs, CAAs and families affected by HIV/AIDS. Sometimes, the stigma against HIV/AIDS is so strong that HIV/AIDS affected individuals are robbed of their dignity and deprived of their livelihoods. Children's inherent simplicity render them especially emotionally susceptible to discrimination. They are severely affected by ostracism, particularly in public places and social spaces like the playground, the village well or standpipe, the school, and at community cultural events.

One of our partner organizations, "SHADOWS" has been conducting community-wide efforts geared toward de-stigmatizing HIV/AIDS. As part of its community capacity-building efforts, SHADOWS educated and sensitized a number of PLHAs and FAAs in Solomon Village, Prakasam District, AP who have now become volunteer-advocates themselves. In response to the discrimination that the PLHAs and CAAs were facing in the community, the volunteers sensitized the secretary about the issue. The secretary joined with the volunteers and in turn took the issue to the entire gram panchayat. After more than a month of sensitization, education, and advocacy efforts, the volunteers convinced the gram panchayat about the seriousness of HIV/AIDS discrimination, and of the necessity that the situation be changed. The Soloman Gram Panchayat responded to the cause by discussing this issue in its regular meetings. As a result, the whole village has been sensitized. In addition, in November 2002 the Soloman Gram Panchayat passed an HIV/AIDS anti-discrimination resolution.

At this point, we feel that it is important to note that the volunteers from Solomon Village exhibited a strong sense of community and a powerful co-operative ethic. The commitment and communitarian passion of these volunteers were invaluable in catalyzing the change in Solomon Village. The story of community empowerment and mobilization in Solomon Village has become a great source of inspiration for VMM and for our other partner NGOs. The experience indicates the immense resources available at the community-level to combat HIV/AIDS stigma. Until now, these resources have remained largely untapped. We are in the process of replicating this example of community-based advocacy that the Solomon Village volunteers have provided, and we hope to expand its impact to the state-level.

6. Linkages with Existing Government Programs

Young HIV/AIDS Widows & the Apadbanbhava Program

The government of AP runs a scheme called "Apadbanbhava" ("Helping Those in Need"). This scheme gives one-time grant of 10,000 INR to widows to help them meet their families' immediate financial needs following the death of the family breadwinner. AIDS widows often find themselves in severe debt as a result of having spent much of the family's monetary resources on their deceased husbands. In addition, due to the stigma attached to HIV/AIDS, the AIDS widow often has difficulty accessing the already limited livelihood options that might otherwise be available to her.

Unfortunately, the Apadbanbhava program is under-utilized because many widows are completely unaware of its existence. VMM has recognized this gap between needs and services. Since August 2001, VMM has initiated efforts to satisfy the needs of AIDS widows by linking them to the existing Apadbanbhava scheme. As a result, our partner NGOs, Mahia Mandali in Chirala and St. Paul's Trust in Samalkot have been referring AIDS widows to the AP government's Apadbanbhava program. The bridge funds provided by the Apadbanbhava program have helped the AIDS widows maintain at least a minimum standard of living for themselves and for their children without losing their dignity. In addition, it has given them the space and resources to save for their children and to invest in income-generating self-employment schemes.

For example, after the death of her husband, Gouri, a young, 24-year old AIDS widow was faced with a debt of 4000 INR and the need to support herself and her 5- and 7- year old daughters. Thanks to the funds from the Apadbanbhava scheme, Gouri was able to pay off her debts. She divided the remaining 6000 INR equally between herself and her children, and opened fixed-deposit accounts in their names. Gouri now has a financial safety net for her two girls. In addition, Gouri plans to invest her share in a sewing machine, which she will use to support herself and her girls in the future.

Tapping Old-Aged Pensions

Many senior citizens do not draw the government pensions to which they are entitled because the process of application for the pension is bureaucratic and cumbersome. As the HIV/AIDS continues to decimate parents and to create orphans, senior citizens are now being forced to assume breadwinner roles, this time, on behalf of their grandchildren. For these senior citizens, the pension represents another source of badly needed funds. VMM and our partners have helped these AIDS-affected senior citizens access these funds by helping them with the arduous application process.

Utilizing State-Run Hostels for Vulnerable Children:

The government of AP runs hostels that provide food, clothing, shelter, and education to "vulnerable" children (these include the poor, and children belonging to scheduled castes and scheduled tribes). We have been helping to channel financially strapped AIDS orphans into these hostels. Most of these orphans are actually still in

contact with their extended families. If these orphans were to reside with their families, most of them would be forced to drop out of school to help the family support them. By linking these children with the government's hostel services, the children are able to continue their education while maintaining contact with their relatives.

The success of these initiatives has encouraged us to expand VMM's linking initiatives between the government and those affected by HIV/AIDS. At present, VMM and our partner Mahila Mandali are researching, documenting, and cataloguing existing governmental services in AP and are mapping these services to the emerging needs of PLHAs, FAAs, and CAAs.

7. Adopting Innovative Strategies to Circumvent Gender-Specified Roles

11-year old Lakshmi lives in a Vadarevu, a small coastal village in Chirala, AP. Her family belongs to the Pallakarlu caste in the Jalari community. For generations, the Jalaris have earned their livelihoods through fishing. Two years ago, Lakshmi's father died of AIDS. He left the family a humble thatched hut on the banks of Bay of Bengal, a small vacant plot of land valued at about 200,000 INR and a fishing net which he had used to support the family. Lakshmi's family consisted of her herself, her mother, her four sisters (ages 15, 13, 9, and 7), and her grandmother.

Lakshmi's family was caught in a web of restrictive cultural norms: after her father's death, Lakshmi's family was unable to support itself because traditional rules prevent women from assuming the breadwinner role. In the Jalari community, girls are married off almost as soon as they enter puberty. At ages 15 and 13, Laksmi's two older sisters have reached the marriageable age, and the costs and the burdens of expectation to have the girls married is a constant worry for Lakshmi's mother.

The family's already pinched economic situation has been exacerbated by the tragic discovery that Lakshmi's mother is also HIV positive. Currently, she is in the terminal stages of AIDS and a large percentage of the family's limited funds are being spent on her medical care. To make matters worse, Lakshmi's uncle (her father's younger brother) robbed her family of the land, depriving Lakshmi's family of their inheritance rights and of monetary resources that are of critical need to the family at this time. The combined pressures have forced Lakshmi and her two older sisters to drop out of school.

Until the intervention of SHADOWS, one of VMM's partners in the Care and Support Program for PLHAs and CAAs, Laskmi's family could barely survive. As Lakshmi recounts, "We didn't have food to eat or money to get medicines for my sick mother." A team of workers and volunteers from SHADOWS brought the plight of Laksmi's family to the attention of Devudaiah, the community leader. Devudaiah became committed to finding a solution to the family's problems. He immediately approached Lakshmi's father's former employer who donated 10,000 INR to cover Lakshmi's mother's medical expenses and the family's daily needs. Although the donation was a great help, Lakshmi's family, the SHADOWS team, and Devudaiah were convinced that a long-term, sustainable solution would be necessary to solve the family's problems. Through several discussions between themselves and members of the Jalari community, they were able to devise an innovative

solution: Laskhmi's family would be allowed to rent its fishing net out to community members at a cost of 100 INR per day.

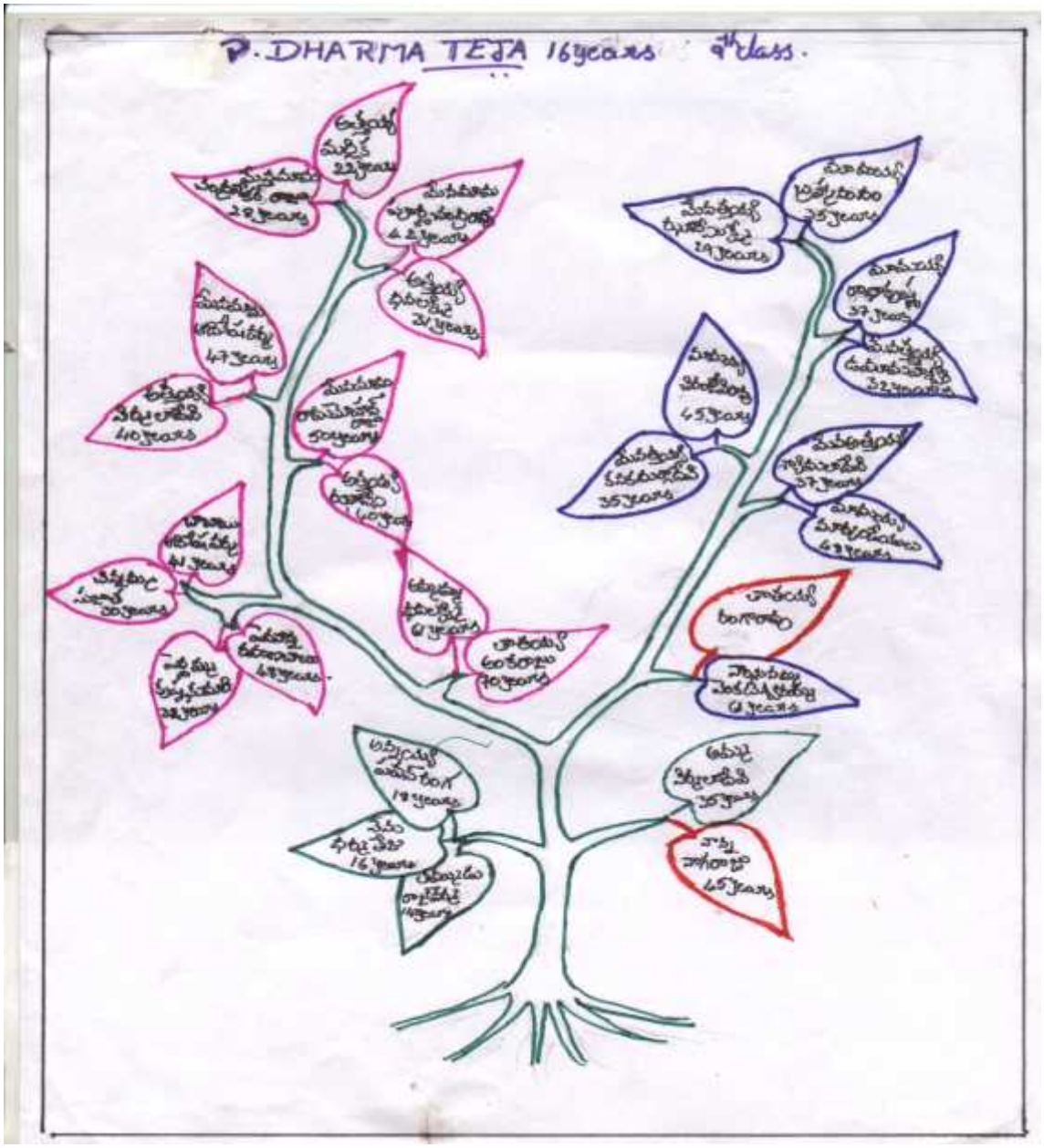
To those who have grown up in societies where gender inequities are less rigid, this solution may seem unsatisfactory, as it does not change the underlying gender-based restrictions that are embedded in the Jalari community. However, it is important to realize that change often occurs in small steps, and that Lakshmi's family cannot wait for the day when gender is no longer a determining factor in Indian life. Renting the fishing net is therefore a practical and strategic solution that works within the existing societal structure to circumvent the culturally embedded restrictions that were depriving Lakshmi and her family of a means to support itself. In the short term, it is solutions such as these -- which are sensitive to the fact change occurs in incremental steps -- that will help those in current need and that will provide the building blocks that will eventually form the basis for a more egalitarian societal framework.

Caption: A widowed family of 5 young girls and one old grandmother who are unable to work because of gender-based employment restrictions. The house is bare, and the sick mother is HIV positive.

8. Protecting the Sense of Identity of the Future AIDS Orphan

As previously mentioned in this report, AIDS orphans typically experience identity crises after becoming separated from their parents and their extended families. In response to this need, VMM encouraged PLHA parents in our HCBCS program to make family trees with their children. It was our hope that the 'Family Tree Activity' would help the future AIDS orphans build memories and sustain their connection to their families. During the Family Tree Activity, parents would also inform the children about family traditions, and about ways to contact their extended families (addresses etc).

PLHA parents have lauded the Family Tree Activity. They say that it is not only useful to their children, but it has also been psychologically helpful to them as it encouraged them to remember their happier times. The Family Tree Activity has had even more benefits - once the children get involved in helping their parents create the family tree, parents find it easier to start discussing their future deaths and the changes ahead with their children. These discussions have prompted parents to start making plans with friends and relatives for their children's care after their demise. The PLHA parents say that the concrete preparations they have made for their children's future have made them feel both physically and emotionally stronger. In many cases, parents said the Family Tree Activity has helped them to talk to their families for the first time about HIV/AIDS. As they are no longer hiding the truth from the children, PLHA parents say that the discussions have filled them with an immense sense of peace.



Caption: A Family Tree Drawn by a PLHA parent and child (The writing is in Telugu, the local language of AP.)

By helping PLHA parents to cope with their disease and to take a proactive approach to protecting and providing for their children after their deaths, the Family Tree Activity helps to lessen the pain of the child's entire experience with HIV/AIDS both before and after the parent's deaths. In addition, the activity has been able to increase children's awareness about HIV/AIDS, and to thus reduce their risk of contracting HIV/AIDS later on.

9. Creating Child Change Agents

Arjun is from the Chebrolu village in the Guntur district, Andhra Pradesh. His life was like that of any other boy until the unexpected demise of his father due to AIDS in May 2002. His father left a wife, Arjun, and two younger sons.

When illness struck Arjun's father, a mason, in 2000, the family was forced to spend the 0.3 millions INR they had saved, as well as borrow 70, 000 INR for his treatment. As soon as his illness became identified as AIDS, relatives and neighbors kept away from them. The children stigmatized as untouchables because of their father's disease.

Arjun's grandfather, a retired employee of the Health Department in the Government of Andhra Pradesh, was aware of the causes and spread of HIV/ AIDS. He got Arjun's mother tested as well, and it was discovered that she was also HIV positive. Arjun's mother, once a housewife, had been working in the fields to earn money for food and to clear the debts left when her husband died. As her health deteriorated, she became unable to continue working.

It was at this point that Arjun, a 16-year old boy studying in the 10^{th} standard, had to quit school in order to take over all of the family responsibilities. He set up a coconut shop with the 2000 INR he borrowed from a moneylender. Although he wanted to continue his schooling, Arjun realized that he could only clear the family debt of 20, 000 INR by maintaining his petty business, which earned just 50/- INR per day. It was then that he learned about the HCBCS program being conducted by AIRTDS, a local NGO that is operating under the support of Vasavya Mahila Mandali / HIV/AIDS Alliance.

Since Arjun's family first contacted the HCBCS program, his mother's condition has improved considerably. The counseling and medicines provided to the family have helped them gain confidence. Arjun's mother – who had been bedridden – is now able to move around and help her son in the shop. Besides receiving the necessary medicines from the HCBCS program, the family has also been promised educational support for Arjun's two younger brothers and financial support for the coconut shop, if needed.

Arjun, who unexpectedly became the family caretaker, has now become an agent of change. He is spreading awareness about HIV/ AIDS, and is trying to erase the misconceptions about the disease. He feels that no other family should have to live with the bitter experiences he has had – communities felt that the air his family breath out and the bathing water comes out of their house from the drain will pollute the whole village – and because of this he readily introduces people suffering with HIV/ AIDS to the HCBCS program. The Whereas he was once deprived of friendship due to the stigmatization of the disease, Arjun's relatives and neighbors are slowly changing their attitudes about HIV/ AIDS, and have renewed their friendships with Arjun's family. Arjun's family eagerly promotes the HCBCS program, stating that it is a boon not only to their family, but also to all PLHAs, FAAs and CAAs.

10. Increasing the Participation of CAAs

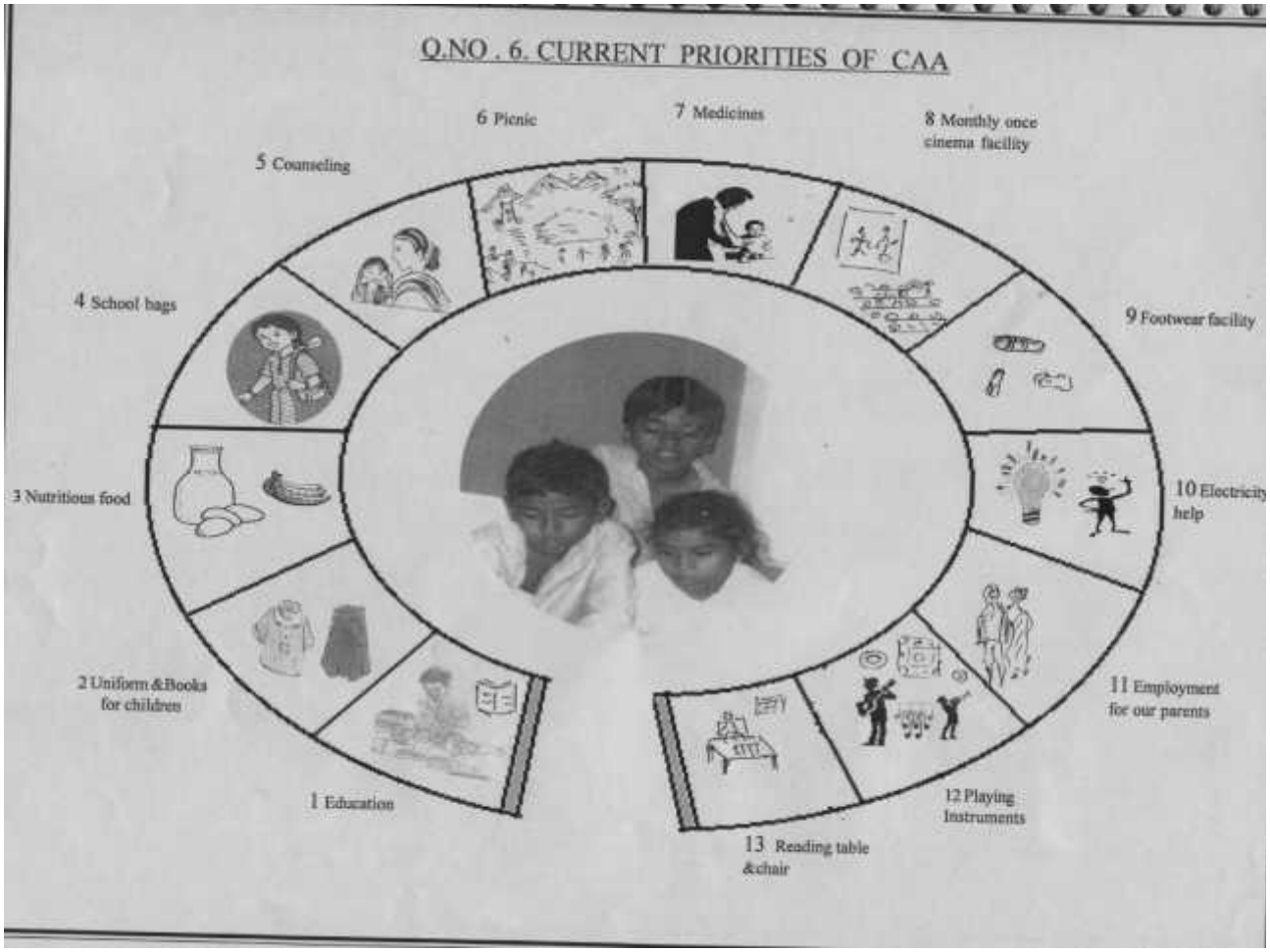
Most adults tend to dismiss the idea that children should be actively involved in making decisions about their lives. This is because the predominant societal model for the child is as a *tabula rasa* or "blank slate" that needs to be taught and guided by adults. However, when adults begin to listen to what children know about their lives and to find out the children's views, they are usually surprised to discover how insightful children actually are.

Through our work VMM and our partners in the HIV/AIDS Alliance network have come to recognize both the importance and the benefits of making children active participants in the formation of policy and in the implementation of programs aimed at promoting their interests. This belief is manifested in almost all levels of child-centered efforts in our HCBCS program.

CAA Contributions to Participatory Community Review

Because VMM is committed to effectively serving the needs of the community in our HIV/AIDS HCBCS program, we conduct semi-annual Participatory Community Reviews (PCRs) so that community feedback can be used to modify existing programs so that they are better aligned with community needs. When VMM decided to start the HCBCS program in 2001, we conducted a Participatory Community Assessment (PCA) to determine what services our communities felt that they needed. The PCA took its information only from adult PLHAs and adult members of FAAs.

One year later, at our first PCR, we also gave the CAAs (predominantly 11 years and above) an opportunity to voice their views. Interestingly, the needs that the adults had identified for the children during the PCA were different from the needs that the children expressed for themselves during the PCR. For example, parents – especially the PLHA mothers – stressed their concerns for their children's education and future security. The children, in contrast, stressed their need for acceptance despite their association with HIV/AIDS and their need for integration into community-level social activities through outings and other recreational events. In addition, the children expressed their concern for their parents, identifying medicines for parents and food for the whole family as some of their most pressing concerns. The disparity between the needs expressed by the adults and the CAAs shows that adults alone cannot represent the needs of CAAs. Moreover, the selfless concern of the CAAs for their parents and their families shows that in order to help CAAs, it is vital that care and support efforts be geared towards maintaining the health of their parents and the happiness of their homes.



Caption: A summary of the needs expressed by CAAs at VMM's Participatory Community Review.

The PCR also highlighted the strong desire that the CAAs have to become change agents and active participants in the policy-making. During the first PCR, the children noted that during the PCA when VMM volunteers visited their families, that they would typically direct their discussions to the parents. The CAAs proposed that instead of being ignored or asked to leave that they included in the process, and that a regular forum be provided for them to voice their opinions and concerns.

In light of these responses, we have developed CAA-centered initiatives like CAA-support groups, CAA peer counseling and CAA training on HIV/AIDS. These initiatives have enabled the CAAs to express their feelings and have empowered them to reach out to the community and to other children through murals, poetry, and role plays which they themselves have created and introduced into their local communities or through one-to-one discussions between themselves and their peers, and even their elders. Overall, the lessons we have learned from the CAAs have been invaluable. As one volunteer commented at a meet organized to showcase the CAAs' opinions on HIV/AIDS related issues:

> We began by simply helping the orphans and other vulnerable children in the neighbourhood. We gave them food and school fees, uniforms, bags and books apart form psychosocial support and advised to them how to keep safe from AIDS. Then we decided to invite the children to take active part in the program. Children led the meet. […] The community has [been] surprised at the involvement and ability of the children.

12. *Networking between NGOs, GOs, and Bi-Lateral Agencies*

VMM has been working in HIV/AIDS since 1997. Since 1999, more than 100 intervention projects designed to combat the HIV/AIDS epidemic have been conducted in AP by various donors, numerous government departments, and by the corporate sector. Despite these efforts, the prevalence of HIV/AIDS in AP is still skyrocketing. This situation impressed us with the urgent need to open dialogue with other players working in HIV/AIDS in AP. As a result, we organized a one-day regional workshop on March 16th, 2003.

The workshop brought together representatives from multiple donor agencies (like Plan International, World Vision, Lepra India, and International AIDS Vaccine Initiative), government agencies (APSACS, TRU, District Leprosy Officers), networks of HIV positive individuals (INP+, TNP+) and 96 NGOs working in HIV/AIDS in the areas of prevention and of care and support in coastal Andhra Pradesh.

The purpose of the workshop was to:

1. Learn about the government's initiatives towards prevention, control, care & support of HIV/AIDS.
2. Discuss the role of NGOs in prevention, control, care & support of HIV/AIDS.
3. Document and present the challenges in their endeavors in the respective HIV/AIDS programs and to propose possible solutions
4. Propose strategies for a coordinated effort.
5. Understand the existing situation in the coastal districts of Andhra Pradesh and thereby attempt to identify the areas of improvement in existing programs

Through group discussions, workshop participants came to learn that there are huge lack of care and support services for PLHAs, CAAs, and FAAs. The majority of the programs being conducted in AP are currently focused on prevention rather than on care and support. Furthermore, they predominantly target high-risk groups like street children, sex workers, truckers and slum dwellers and are not canvassing the general population. The care and support efforts that are actually taking place have been highly localized, piecemeal, and are unconnected to a larger plan. We have included the recommendations from this meeting as an annexure to this report.

The dialogue between different NGOs, the government, and bi-lateral agencies at our March 16th meeting enabled us to share best practices, and to start designing more comprehensive and coordinated initiatives for PLHAs, CAAs, and FAAs. The inter-organizational communication will also prevent wastage of resources through redundant efforts and will help us form linkages for referral services. Finally, it has served as a platform for proposing much-needed policy changes to the government.

Case study Illustrating Best Practices Outside of the HCBCS Network in Utilizing Institutional Strategy

Freedom Foundation

As described earlier, the Hyderabad-based Freedom Foundation has been running full-time residential institutional care & support center, called 'DIYA', for HIV positive children since November 2002. DIYA has a capacity of 20 beds, and admits HIV positive children from ages 0 to 15 years. Since DIYA is the only home for HIV positive children in the entire state it has been receiving orphans from all over AP. It is currently the only home for HIV positive children from all over AP.

At present, the Freedom Foundation provides a holistic care package for the children – food, clothing, educational materials, toys for the children and appliances for the center (such as stove, washing machine etc) have either been provided by the Foundation or through individual private donors. Because the local schools will not accept HIV positive children due to the fears expressed by the parents of their HIV negative students, the children are occupied during the day through institution-bound educational and recreational activities conducted by a single counselor who works from 9am-6pm. To reduce the children's feelings of exclusion at not being admitted to school, DIYA created "school uniforms" for the children and provided them with schoolbooks and bags. The daily activities are scheduled to mimic a normal school routine.

In addition to grappling with feelings of exclusion and abandonment, the major emotional difficulty that the children face are coming to terms with death: both their own and those of the other children in DIYA. When we spoke to her, Gita, a young, kind-faced, and soft-hearted girl who works as the counselor who cares for the children during the day said that a 15-day old baby had died in the home just 2 weeks before: "The children kept asking questions … about why a child so young could die while other people had grown so old and were still not sick."

The counselor provides psychosocial and emotional support for the children; she tries to encourage them to believe that their lives, though brief, are still worth living. Two female workers (one, herself an HIV positive mother of one of DIYA's children) provide the children with 24-hour care. None of DIYA's children are on ARV treatment. DIYA cannot afford it. However, the children's health status is constantly monitored and they are treated for opportunistic infections.

DIYA was created out of funds, which the Freedom Foundation scraped together in its commitment to responding to the needs of the helpless HIV positive children who were referred to their general HIV/AIDS care and support home. At present, DIYA continues to operate on a shoestring, without governmental, community, or other institutional support. Although some community volunteers come in to play with the children, or to take them on outings, the children who still have families do not go on family visits, as their families do not want them. Not even the volunteers are willing to invite them into their homes for fear of what their neighbors might say.

Gita says that she needs more staff support. Ideally, she says, there should be about 6 children to one counselor. Currently, the ratio is 15 children to one.

When asked what was the most difficult part of her job, Gita paused reflectively and said, "When you working with these children, you develop an emotional attachment to them. We know that these children are going to die, but we try to give them everything that they need, including our love. When a child dies, we feel really depressed. It is as if we have lost a member of our own family."

Looking at the statewide statistics on the incidence of HIV/AIDS, it is obvious that the Freedom Foundation alone cannot fill the existing needs of all of AP's abandoned or orphaned HIV positive children. The replication of Freedom Foundation's model for institutional care and support for these HIV positive children is mandatory. It is crucial that more funds be provided to replicate the DIYA model. Initiatives must be taken to train more counselors like Gita, and to provide emotional support to caregivers in homes like DIYA. In addition, efforts must be made to mobilize the community to assist institutions like DIYA through volunteer work and through programs that integrate the HIV positive children into the community.

Within the context of human rights, these proposals for care of the HIV positive child are not just the expression of existing needs, but constitute a moral mandate.

RECOMMENDATIONS

Interventions before the death of the PLHA Parent:

Interventions on behalf of the CAA or AIDS orphan can begin even before death of the child's parent(s). Because of ignorance about HIV/AIDS many HIV infected or affected individuals hold the mistaken belief that an HIV positive status is an immediate death sentence. As a result, they often do not treat opportunistic infections and fail to take proactive, preventative measures that can help prolong the life of the HIV positive individual. Interventions that teach PLHAs and the wider community that it is possible to prolong life for many years after infection with HIV will increase the lifespan of many parents and thus reduce the rate of generation of AIDS orphans and the severity of the crisis.

Efforts to combat PLHA parents' depression and fatalistic attitudes are essential to the well being of future AIDS orphans. Assisting parents to come to terms with their HIV status is an important first step to initiating this process. Parents should be motivated to disclose their serostatus and its implications to their children, contingent on the children's cognitive stage. This would help the children understand the changes taking place in the household following the onset of the symptomatic stage. Teaching HIV positive parents and their children how to be caregivers for PLHAs Within this context, the relevance of adopting precautions could be brought home to the child. In addition, children should be taught self-care (e.g. the importance of good nutrition, hygiene etc).

In addition to helping PLHA parents and their children to cope with HIV/AIDS while the parent is still alive, it is equally important to show HIV positive parents the importance of creating a safety net for their children after they die. This includes encouraging parents to save for their children's economic support and education, empowering the children with skills to make them self-reliant, and making arrangements for their foster care. In addition, parents can pre-empt the identity crisis and sense of rootlessness that many AIDS orphans face by, for example, making family trees and making messages and objects which the child may keep to remember their parent by. Concomitant with this, support for the child to deal with the news of the diagnosis is imperative. A part of this would involve preparing children for the death of parents.

Interventions after the death of the PLHA parent(s)

1. Economic issues

To counteract the economic disempowerment of AIDS orphans after their parents die, future AIDS orphans and future AIDS widows should be educated about their property rights with respect to inheritance. Advocacy and monitoring is needed to ensure that AIDS orphans and widows that their legal rights are expected, and to identify whether further changes in the existing legal system are necessary.

2. Care models, Sponsorship Programs & Community Mobilization

Guardianship for the AIDS orphan is a central issue. Some proposed models include:

1. Intra-family adoption - foster care for the AIDS orphan by the extended family
2. Inter-family and intra-community adoption – foster care by supportive members of the orphan's community
3. Intra-country adoption – foster care by non-related families who may not be from the orphan's community but who reside in India
4. Inter-country adoption – foster care by families who reside outside of India.
5. Orphan-headed households – essentially the children conduct their own self-care
6. Community-based orphanages/care institutions – institutions run by concerned community members when AIDS orphans cannot be adopted into individual homes.
7. Orphanages or care-institutions that are not community based - these may be purely government-run or run by state, country or international-level non-governmental organizations. In general, this is the least desirable solution, as orphanages naturally remove children from the family environment.

It is widely recognized that a familial environment that is similar to the orphan's original socio-cultural milieu is the most favorable for the orphan. As a result, intra-family adoption, and adoption of the AIDS orphans by carefully chosen community members would be ideal. Unfortunately, rampant poverty and scarcity of economic resources makes it very difficult for relatives and members of the community to adopt AIDS orphans despite their willingness to do so. Sponsorship programs where adopting families are given monthly assistance for child-support would be a powerful way to empower relatives and community members to care for AIDS orphans and to ensure that the orphans remain connected to their families and integrated into their communities and culture.

Sponsorship programs would also be of vital assistance for orphan-headed households and can be of extreme help to future AIDS orphans as well. As we have previously described, the HIV positive serostatus of a family member squeezes families of already scarce resources. Sponsorship programs that help children stay in school or that enable future orphans to acquire skills for self-reliance, and that help pay for the PLHA's medical needs could be of great help. The idea of sponsorships would even be useful for children who are institutionalized in either community or non-community-based care institutions, as the current pool of funds for such institutions is small. Funds for sponsorship could be mobilized from the community, government, the private sector and from local and international NGOs.

In addition to sponsorships, programs that support for income generating activities, small business co-operatives, vocational training and micro-credit schemes are powerful tools to help enable adopting families to adopt and care for AIDS orphans. The major benefit of these schemes is that they empower the adopting families and promote self-sustainability.

Although orphanages are the least ideal model for AIDS orphan care, linkages between foster families and child-care institutions could be a useful way to help provide support, guidance, and services to families who have adopted AIDS orphans.

Care models for HIV positive children and HIV positive orphans

It is critical to note that the situation and viable solutions is vastly different for HIV negative versus HIV positive orphans. All of the schemes mentioned above are feasible for the HIV negative child. The most dramatic difference between the HIV negative and HIV positive orphan is that intra-country and inter-country adoptions are not a realistic option for the HIV positive child. It is possible that the HIV positive orphan might willingly adopted by relatives or possibly even a concerned member of the child's community. Presently however, community-wide ignorance about HIV has made people unwilling to adopt HIV positive orphans. Consequently, effective sensitization programs are needed to combat the existing prejudice and to mobilize the dormant community resources for their care. Because the HIV positive child has special needs, institutions geared specifically toward their care are necessary. Again, sponsorship programs would be of great help to families and organizations that are willing to adopt and care for these children.

Policies about informed content and testing of children for HIV infection need to be formulated. In general, we believe that informing an HIV positive child of his/her status benefits the child. Informed children can understand the need for, and the value of, maintaining positive health, can be taught to adopt precautions in their daily lives, and can comprehend the changes in their health status as the disease progresses. Emotional support and counseling services to help HIV positive children them come to terms with their diagnosis need to be developed. Medical services appropriate for HIV infected children must be created. These should include pediatric AIDS facilities with trained specialists, and child-friendly testing centers which practice painless blood taking, and which provide AZT programs for neonates and infants.

Medical Issues

1. *Protecting CAAs from Opportunistic Infections:*
   As already mentioned, children of HIV infected parents are at increased risk of contracting opportunistic infections because of their constant interaction with sick parents. Moreover, PLHA parents' fatalistic attitudes and ignorance about AIDS often prevents them from ensuring that their children receive adequate medical care. Guidance to child caregivers and parents about the nature and course of HIV related opportunistic infections, precautions, and advice on how to deal with emergencies, would significantly reduce the CAA's risk of becoming ill.

2. *Child-appropriate VCTC Provisions and Policies*
   Pre- and post-test counseling adapted to the child's level of understanding should be provided for children at VCTCs.

Training and Capacity Building

Since HIV/AIDS the problem of AIDS orphans is a relatively recent phenomenon, and issues related to it emerge constantly, the training of personnel working with children in child welfare agencies, health services, schools, etc., is necessary to understand, anticipate, and adapt to emerging challenge with skills and sensitivity. Support for care giving staff is also necessary because of the intense emotional strain engendered by HIV related work.

Community-Based Care and Prevention Centers

Several experts working in the field of HIV/AIDS in AP have expressed interest in the utility and cost-effectiveness of a model of community-based care and prevention centers. These experts believe that a community-based approach that utilizes existing infrastructure constitutes the only way for AP to meet the immense need of its HIV/AIDS-affected population. According to one professional:

It is necessary that some care and prevention centers (drop in-centers) be established in high prevalence areas, which will be focal points for out reach with the families and the community in the initial stages.

These centers can be located in hired premises or in the houses of volunteers or in the houses of affected families if the prevailing conditions are conducive. Trained NGOs or volunteers with financial support can manage the centers initially. These prevention and care centers (PAC) will handle the tasks of counseling of the infected and affected families, extend immediate medical facilities for treating opportunistic infections, and follow-up with the nearest government/private schools, health facilities to extend their services to this needy group. This center will also be the focal point for community mobilization for care and support and rehabilitation work, which will be eventually handled by the community itself. Trained personnel from this center can also build the capacities of the families to plan for the future of the infected and affected members, which may include training in vocational skills, accessing government schemes of assistance, like credit, training, incentives for Micro enterprises etc. These PACs will be funded for a specific period of time and specific activities can be funded by different agencies if the scale of activities requires sufficiently large funding. However, at present given the scale of the demand for services in each location surveyed multiple funding sources may not be required. Capacity building in necessary technical skills of counseling, nutritional education and support and economic empowerment, psychosocial support should provided donors through the relevant nodal NGO.

Making the Process Participatory

Integrating the input of CAAs and AIDS orphans at the planning and policy-making levels is vital. Feedback from the children would provide an insider's view of the problem. Such a participatory approach would help to ensure that the solutions proposed will have the required impact and that current interventions are serving their desired purpose.

At a more general level, education programs on AIDS-related issues around reproduction, sexuality, HIV/AIDS, lifestyles, substance abuse, life skills, and legal rights targeting children at all levels and in all contexts are indispensable. These interventions should begin in schools at early stages, as the dropout rate is very high, and as many children who drop out at mid-school level do not get covered at all. Such programs must also be taken beyond the school set-up to street children, children in detention, refugee children and other such groups.

Looking Forward

1. The Need for Research

Current interventions are too often limited to those children who are already suffering AIDS related loss and trauma. We must intervene earlier to prevent children from finding themselves in situations that leave them exposed to the impact of AIDS. At this point, is important to stress the need for energetic and continuous research. Empirical evidence forms the backbone of effective program planning and policy formulation. There is a need to monitor the impact of HIV/AIDS on children and families, to estimate the number of orphans and examine their living conditions, to explore the experiences of positive children and of siblings of positive children, and finally, to evaluate interventions. These data would form the basis for further planning and intervention, and could also be used for advocacy and for building awareness about the social impact of AIDS and the rights of children. Finally, vigorous research activities and transparency of information will enable policy-making and implementing agencies involved in the AIDS-orphan initiative to foresee emerging problems and to design solutions to them before they reach crisis-point.

2. Networking

It is highly difficult to one service provider to meet the CAAs' multiple needs. Hence, linkages between organizations, the private sector, the government, and the local community will play a vital role in controlling the AIDS orphan crisis efficiently, effectively, and sustainably.

3. Attacking the Society-Wide HIV/AIDS problem

The most effective way to combat the AIDS orphan crisis is to be proactive. The AIDS orphan problem is inextricably linked to the larger problem of the HIV/AIDS epidemic itself. Short-term care solutions for AIDS-orphans like adoptions and sponsorships, and the provision of counseling, medical-care, and other support services to CAAs should be integrated with the aggressive pursuit of long-term prevention measures for that stop the creation of AIDS orphans and HIV positive children, and that stem the spread of HIV/AIDS in the first place. Interventions therefore cannot remain only at the level of children, but must touch all spheres of society.

Forthright commitment at India's highest political levels is critical for dealing effectively with both the AIDS orphan crisis and the larger HIV/AIDS crisis. Visible and influential leadership will go a long way in helping Indian society overcome the fear and stigma associated with HIV infection. Because the virus disproportionately affects the poorest and most disadvantaged in India, the need for funneling resources into poor communities threatened by HIV/AIDS cannot be over-emphasized. While the government needs to spend more philanthropically on these communities, it can also assist them by allocating higher percentages of existing resources towards promoting their economic development, and by providing basic social services such as education, primary health care, nutrition and low cost water and sanitation (UNICEF, 1999). In addition to promoting economic development, changes in the existing social order, in areas such as sub-ordination of women, exploitation of the lower income and caste groups, are also imperative, if a long-term and sustainable solution to the crisis is to be achieved.

CONCLUSIONS

The state statistics for HIV-incidence and the results of our own research efforts highlight the growing seriousness of the HIV/AIDS epidemic in Andhra Pradesh. AIDS has already reached AP's most vulnerable community – our children – on a large scale. Since it was first recognized as a major public health problem, HIV/AIDS has surprised and disturbed us by its capacity to destabilize communities at multiple levels. Our survey results and case studies show that HIV/AIDS is affecting the emotional, intellectual, and physical well-being of AP's children. It is robbing them of their parents, their childhoods and their futures. The individual assaults of HIV/AIDS on the families of AP are rapidly unraveling AP's societal fabric and destabilizing the state's present and future economy.

AP has the unfortunate distinction of being one if India's leaders in sobering state-level statistics on HIV/AIDS. As a result, the plight that Andhra's children are facing in the destructive and expanding wake of the HIV/AIDS epidemic is a warning signal to the rest of the country of what may come if immediate measures are not taken to stem the generation of CAAs and to deal appropriately with the needs of this fast-growing population.

AP's status as a red flag signaling the growing vulnerability of India's CAAs also makes it one of the country's most crucial battlegrounds against the HIV/AIDS epidemic. For if AP can succeed in mitigating the impact of HIV/AIDS on its children, then our victories can be used as models in the national war against HIV/AIDS.

VMM's assessment of the vulnerability and the current needs of AP's CAAs indicates that the majority of our child-focused efforts should be directed toward care and support. To date, the state and national government have done little to specifically address the problems of CAAs. At present, there is an acute absence of governmental policies and programs designed to provide a safety net for CAAs. The response of the NGO sector has been slightly more encouraging. Although most programs are still disproportionately focused on prevention and awareness, a small number of AP's NGOs have started providing much-needed care and support for CAAs. Overall, the response of GOs and NGOs has been relatively localized and piece-meal, and there is a dire need for increased networking, resource-sharing, and planning for initiatives that provide full and non-redundant coverage of CAAs, AIDS orphans and HIV-positive children.

Given the current and expected scale of the CAA problem, it is certain that neither government nor private philanthropy will be able to provide the resources necessary to manage the CAA problem in the long run. Lessons from the field indicate that the only sustainable way to attack the crisis is to increase the community's capacity to assist CAAs, FAAs, and PLHAs, and to empower these vulnerable groups to create innovative solutions for themselves.

GLOSSARY

CHILD

Age groups of 0-18 years
Both Female and male (Boys and Girls)
Child of PLHA

ORPHAN

A child, who lost one or both parents
Children whose parents died of AIDS
'Children affected by AIDS' – used broadly to mean children infected / affected by AIDS

HCBCS - Home/Community Based HIV/AIDS Care and Support Programme
NACO - National AIDS Control Organisation
NACP - National AIDS Control Programme
APSACS - Andhra Pradesh State AIDS Control Society
PLHA - People Living with HIV / AIDS
FAA - Families Affected by AIDS
CAA - Children Affected by AIDS
VCTC - Voluntary Counseling and Testing Centre
FHI - Family Health International
PSI - Population Services International
FXB - François Xavier Bagnoud
PMTCT - Prevention of Mother to Child Transmission
PCR - Participatory Community Review
PCA - Participatory Community Assessment
TRU - Technical Resource Unit
IAS - Indian Administrative Services
IES - Indian Economic Services

ACKNOWLEDGEMENTS

We are very grateful to the communities and staff associated with Green Vision (Vishakapatnam), St. Paul's Trust (Samalkot), Sanghamitra Service Society (Ibrahimpatnam and Chillakallu), AIRTDS (Tenali), Needs Serving Society (Chilakaluripet), Mahila Mandali (Chirala), SHADOWS (Chirala), and Sravanthi Organization (Rajahmundry) for their assistance in implementing the survey, and for sharing their best practices and case studies with us.

We thank the administration of the Government Chest Hospital, Hyderabad for allowing us to conduct focused group discussions with PLHAs and FAAs and the hospital's VCTC counselor for his guidance. We are also grateful to the Freedom Foundation, Hyderabad for sharing their experiences on caring for HIV positive children and allowing us to conduct a focused group discussion with the children of DIYA.

We would also like to extend our thanks to Anjanette Chan Tack (Harvard University) for her extensive assistance in the data-analysis and in the composition of this report and in helping us to connect our specific field experiences with larger issues of policy and societal-level impact.

We extend our appreciation to the following individuals and organizations for their assistance:

1. Mrs. K. Damayanthi, Project Director, APSACS and the staff
2. Dr. D. Dhanikachalam, Team leader, TRU
3. Dr. B. Gangaiah, Director of the Regional Evaluation Office, Planning Commission
4. Mr. K. Chandramouli, Managing Director, AP State Trading Corporation.
5. Dr. Samaram
6. Dr. PMN Prasad
7. The staff of International HIV/AIDS Alliance and HIV/AIDS Alliance, India.
8. Ms. Nora Didkowsky, St. Francis Xavier University – N.S. Canada

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ANNEXURES

1. Andhra Pradesh State Statistics At a Glance

Demography

➢ Area	:	Sq. Km	275069
➢ Districts	:	No.s	23
➢ Mandals	:	No.s	1125
➢ Panchayats	:	No.s	21956
➢ Towns	:	No.s	210
➢ Total Population	:	No.s	75.7 million
➢ Urban Population	:	No.s	27.08 million
➢ Rural Population	:	No.s	48.62 million
➢ Density of population per Sq.Km	:	No.s	275
➢ Males	:	No.s	50.6
➢ Females	:	%	49.5
➢ Females for 1000 males	:	%	978
➢ Total Literacy rate	:	%	61.10
➢ Male Literacy rate	:	%	70.80
➢ Female Literacy rate	:	%	51.20

2. A.P.S.A.C.S Facts At A Glance

➢ *No. of Licensed Blood Banks*	:	*146*
➢ *No. of VCTCs*	:	*26*
➢ No. of STD Clinics	:	28
➢ *No. of Care and Support Centres*	*:*	*5*
➢ No. of Targeted interventions	:	114
➢ No. of Sentinel Surveillance Centres	:	13 (ANC – 9, STD– 4)
➢ Total No. trained	:	27,684
➢ Doctors trained	:	3532
➢ Paramedical Staff trained	:	7358
➢ RMPs & PMPs trained	:	8721
➢ NGOs & CBOs trained	:	8073
➢ Population to be covered through CCA model for AIDS free Society	:	12.8 million

3. Recommendations from the One-Day Regional Workshop, March 16, 2003.

1. All local self-governments in AP in panchayats (village-level), municipalities (town-level) and municipal corporations (city-level) should pass and implement resolutions to fight HIV/AIDS-related stigma.

2. In the corporations and municipalities some funds are currently allocated towards Women Development and Child Welfare. Some portion of these funds should be allocated to HIV positive women and to CAAs.

3. The state government currently supports DWCRA groups that work toward woman- and child-development. The state should similarly support the formation of self-help groups composed of PLHAs and members of FAAs – especially women, which should be provided with similar funds and government-subsidies.

4. Departmental schemes for Women and Social Welfare should give priority to PLHAs, FAAs and CAAs.

5. The issue of AIDS orphans constitutes an emergency situation, and the state needs to handle the issue with full force. Some methods the state could employ include making best use of existing programs and facilities like:

    a. Women and Child Welfare programs like "Children Homes"
    b. Social welfare hostels
    c. National Family Benefit Scheme

6. Policies for foster care for AIDS orphans and for abandoned HIV positive children must be formulated at the state and national level.

7. The National Patent Act should be amended so that PLHAs can get medicines at economical rates.

8. Policies should be formulated on pre-marital testing for HIV/AIDS.

9. Coverage must be expanded to groups who are currently not being targeted by present programs (such as the large population of fishermen of coastal AP and migrant populations).

10. NGOs, the government and other players in HIV/AIDS prevention, care, and support, should meet regularly to ensure better coordination at the district level.

11. The government AIDS-control agencies should assume primary responsibility of increasing awareness and sensitization in the police force, instead of leaving the task to the NGOs.

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