International HIV/AIDS Alliance in India

Supporting community action on AIDS in India

Vasavya Mahila Mandali

A SITUATIONAL ANALYSIS OF CHILD-HEADED HOUSEHOLDS AND COMMUNITY FOSTER CARE IN TAMIL NADU AND ANDHRA PRADESH STATES, INDIA

A study conducted by India HIV/AIDS Alliance and Tata Institute of Social Science

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International HIV/AIDS Alliance was estabilized in 1993 as a global partnership of people, organisations and communities working towards a shared vision that supports effective and integrated community responses to HIV/AIDS. This approach is based on the belief that those at the frontline of the struggle against HIV/AIDS must have resources to take on the challenges that the epidemic presents.

The India HIV/AIDS Alliance (Alliance India) was established in 1999 as part of the International HIV/AIDS Alliance with a strategic goal to increase community action for and access to, HIV/AIDS prevention, and care and impact mitigation efforts in India. This is achieved through improving coverage of effective community focused AIDS efforts; strengthening leadership and capacity of civil society to respond to AIDS; and improving institutional, organisational and policy environments for community responses to HIV/AIDS.

Alliance India currently provides programmatic, technical, strategic, organizational development and financial support, guided by a commonly agreed strategic framework to four lead partners and one State partner in Delhi, Tamil Nadu, Andhra Pradesh and Manipur States, in addition to its State program in Andhra Pradesh. In turn these partners provide similar support to more than 70 implementing NGOs/CBOs.

The Tata Institute of Social Sciences (TISS) was established in 1936, as the Sir Dorabji Tata Graduate School of Social Work. TISS has been expanding continuously in terms of educational programs and infrastructure. While responding to the changing needs of the social and educational system in the country, the Institute has gone far beyond the initial concern of social work education. TISS has earned recognition as an institution of repute from different Ministries of the Government of India, various State Governments, international agencies such as the United Nations, and the non-government sector, both national and international. It has proven itself to be a centre of excellence, contributing relevant education and research, towards the national agenda of sustainable, participatory and equitable development.

Vasavya Mahila Mandali (VMM) founded in 1969, is a non-profit, nongovernmental, voluntary organisation working for all round development of women, young people and children. VMM is India HIV/AIDS Alliance's Lead partner in Andhra Pradesh and implements the Home and community based care and support programme through ten implementing NGOs in coastal Andhra Pradesh. VMM provides technical and financial support to these NGOs to improve quality of life of children affected by HIV/AIDS, people living with HIV/AIDS and their families.

Palmyrah Workers Development Society (PWDS) founded in 1977, offers development support services to sustain community initiatives. PWDS promotes and works with community based organisations and support service organisations aiming at self management and sustainability. PWDS is India HIV/AIDS Alliance's lead partner in Tamil Nadu and implements the Home and community based care and support programme through twenty implementing NGOS in central and southern Tamil Nadu.

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Acronyms

APSACS	Andhra Pradesh State AIDS Control Society
CAA	Children affected by HIV/AIDS
CBO	Community Based Organization
CHH	Child-Headed Household
HCBCS	Home and Community-Based Care and Support
INGO	Implementing Non Governmental Organisation
MTCT	Mother to Child Transmission of HIV
NHDR	National Human Development Report
NMCT	Native Medicare Charitable Trust
PLHA	People Living with HIV/AIDS
PMTCT	Prevention from Mother to Child Transmission of HIV
PWDS	Palmyrah Workers Development Society
SHG	Self-Help Group
VMM	Vasavya Mahila Mandali
WORD	Women's Organization in Rural Development

Executive summary

In the past two decades, the HIV/AIDS epidemic has seen many transitions. During the initial years of the epidemic, the focus kept shifting from one high risk group to the other. Initially emphasis was given to targeted interventions, but later, as the number of women victims of HIV increased, there was a shift to society at large. Even here the emphasis has been largely on adults because the majority of the people infected by HIV belong to the productive period of their lives.

It has taken many years to understand the devastating effect HIV/AIDS has on children's lives, and recently, there is growing concern over the number of orphans it creates. Children in affected families are deprived of their childhood and the privileges of living in a safe environment. They forego their education to take up jobs and shoulder the burden of their families. Apart from the obvious fallout of malnutrition, other problems relate to increased demands and the problems arising from being orphaned.

The number of orphans and vulnerable children is likely to increase, posing serious threats to existing socio-economic structures. What is required is a proactive response by all stakeholders so as to scale-up support and care services for children orphaned by AIDS.

Child-headed households are a growing dilemma in this era of HIV/AIDS. When orphaned, children are left to fend for themselves, taking on the responsibilities of managing the household and younger siblings with minimal to no financial support. Such children often grow up deprived of emotional and material needs and the structures that give meaning to social and cultural life. They are also are at increased risk of neglect, violence, sexual assault and other abuses. The concept of foster families for children orphaned by AIDS has emerged as a positive approach for supporting such children. It provides a continuity of care in family and community settings, thereby providing a more natural, personal, loving and affectionate environment for children to develop in.

The study was undertaken in the interventions sites of the India HIV/ AIDS Alliance in Andhra Pradesh and Tamil Nadu in collaboration with the lead partner NGOs VMM and PWDS. The study aimed at (i) analyzing the need for community foster care and identifying and assessing the options and constraints. It also sought to aid policy change to support the scaling-up of community foster care in the two States. With respect to child-headed households, the objectives were to conduct a situational analysis, document the needs and challenges faced by children and explore the related legal and policy issues.

The study shows that children who head such households face tremendous challenges and are vulnerable to exploitation. Though inadequately prepared, they have to move into adult roles. Their physical and mental health needs are not taken care of by the existing programs and the case studies in this report illustrate the wide range of problems they face. It also brings out the

advantages and disadvantages of community foster care. The fact that the community is coming forward to take care of the needs of orphaned children is definitely a positive sign. The case studies show that while children are comfortable in foster care, community perceptions remain negative about the people living with HIV/AIDS. The study also brings into focus the challenges of the emerging social environment that impacts all forms of social and economic relationships.

The findings accentuate the need for immediate response at all various levels in order to protect children from abuse and exploitation. Intervention programs should aim at the protection and promotion of children's rights. The following are highlights of the recommendations:

Programmatic

- Strengthen the support systems for people living with HIV/AIDS and children affected by HIV/AIDS.
- Physical and mental health needs of the PLHA and their children need to be identified and dealt with.
- Schools should be sensitized and a flexible education program for CAA should be facilitated. This would make the school a supportive place for the CAA and enable them to continue their studies.
- Poverty alleviation programs should be executed through the community based organizations.
- Community based organizations should ensure that the children are working in child friendly environments and not being exploited at their workplace.
- Orientation regarding foster care and foster family should be given to the children as well as the foster family members.
- Constant support should be available to enhance the quality of care rendered to foster children.
- Monitoring mechanisms should be developed to ensure the quality of care rendered.
- Best model of foster care practice should be identified and up scaled.

Policy

- Provision of small-scale loans from the Government will improve the living condition of these children.
- Setting up community childcare committees to identify and help provide day care, crèches and community food centers, so that the children get emotional and material support from the community without exploitation and abuse.
- Free vocational training camps to be organized. These will equip children with technical skills.
- Inclusion of the foster children's name in the ration cards of foster families and also the foster parent's name in the school's transfer certificate should be made mandatory.

Research

- The mental health needs are tremendous and further studies on mental health of children affected by AIDS will help in designing interventions to help children cope up with the stress of taking up an adult role at a tender age.
- Foster care is a feasible alternative for children affected by AIDS. In order to evolve best practices, an exhaustive study on Foster care and the comfort level of children under foster care needs to be done.
- Foster care can only be a temporary measure. Adoption of the children is the only permanent solution.

Introduction

Acquired Immunodeficiency Syndrome (AIDS) has killed over 25 million people since it was first recognized in 1981, making it one of the most destructive epidemics in recorded history. Despite recent, improved access to antiretroviral treatment and care in many regions of the world, the AIDS epidemic claimed 3.1 million [2.8 - 3.6 million] lives in 2005 and more than half a million (570 000) were children (UNAIDS, 2005).

The epidemic in Asia is rapidly growing. An estimated 7.4 million people are living with HIV in the region and 1.1 million people became newly infected last year alone-more than any year before. Home to 60 % of the world's population, the fast-growing Asian epidemic has huge global implications (UNAIDS, 2004).

In all affected countries with either high or low HIV prevalence, AIDS hinders development, exacting a devastating toll on individuals and families. In the hardest-hit countries, it is erasing decades of health, economic and social progress-reducing life expectancy by years, deepening poverty and contributing to and exacerbating food shortages. (UNAIDS, 2004).

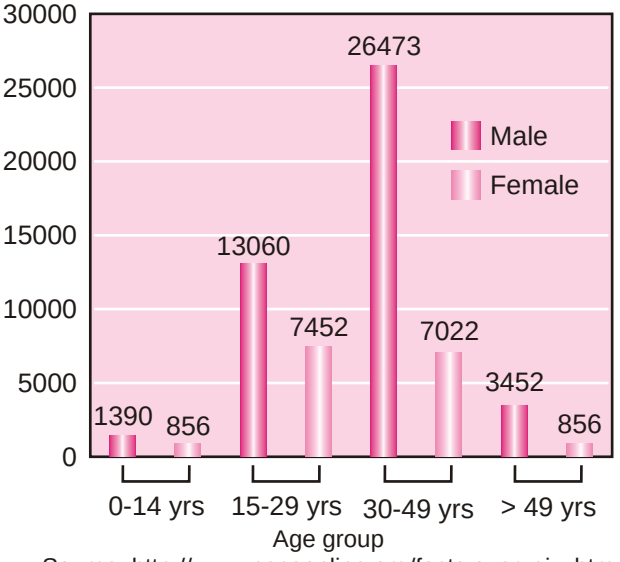
HIV estimates in India are derived on the basis of HIV prevalence observed from surveillance sites covering persons with STD, mothers in ante-natal care, injecting drug users, men who have sex with men and female sex workers. The statistics put the number of people living with HIV/AIDS at about 4.58 million in 2002, and of these an estimated 200,000 were said to be children under age 15 (NACO, 2002). UNAIDS has estimated the number of people living with HIV/AIDS in India in late 2003 is somewhere between four and six million. In 2004, India reached 5.1 million (NACO, 2004), the largest number of people living with HIV outside South Africa (UNAIDS, 2004).

An estimated 2.8 million people died of AIDS in India from 1980 to 2000, and the United Nations (U.N.) projects 12.3 million AIDS deaths from 2000 to 2015, (Mariaetal, 2003). Most of those dying of AIDS are between fifteen and forty-nine years old, the age when many are raising children as seen in the following graph (NACO, 2003).

1.1 Children and HIV/AIDS

The statistics that measure the plight of children and orphans affected by the AIDS epidemic at a global level are chilling.

Age & Sex distribution of AIDS cases in India: December 2003



Source: http://www.nacoonline.org/facts overveiw.htm

- AIDS has orphaned at least 10.4 million children currently under 15 (that is, they have lost their mother or both parents to the epidemic). The total number of children orphaned by the epidemic since it began -13.2 million-is forecast to be more than double by 2010.
- AIDS-related deaths caused some 2.3 million children to become orphans (at the rate of one every 14 seconds) in 2000. UNICEF estimates that upto a third of those children were less than five years old.
- Typically, half of all those with HIV become infected before they celebrate their 25th birthday.
  Many of them die from AIDS before they turn 35, leaving behind a generation of children to be raised by grandparents or siblings.
- The epidemic has forced vast numbers of children into precarious circumstances, exposing them to exploitation and abuse and putting them at high risk of also becoming infected with HIV.
- Most families affected by HIV/AIDS suffer serious economic loss for several years eventually resulting in the death of one or both the parents, leaving the children with very limited financial and social support.
- Research shows that orphans living with extended families or in foster care are prone to discrimination, which includes limited access to health, education and social services.
- Children in households with an HIV-positive member suffer the trauma of caring for ill family members. Seeing their parents or caregivers become ill and die can lead to psychosocial stress, which is aggravated by the stigma so often associated with HIV/AIDS.

Many children are struggling to survive on their own in child-headed households. Others have been forced to fend for themselves on the streets. Consequently, there is an increasing number of unprotected, poorly socialized and under-educated young people. (United Nations Special Session on HIV/AIDS, 2001)

There is a lack of statistics or forecasting about HIV/ AIDS and youth, and the number of children affected and orphaned children by HIV/AIDS. Though not adequately measured, some calculate that as many as 1.2 million children under 15 have lost one or both parents to AIDS (Human Rights Watch, 2003). According to NACO, the numbers of children infected are 4854 (Male: 2860; Female: 1994) as per their monthly updates as on July, 2005.

HIV/AIDS does incalculable damage to the emotional and physical health and well-being of children, both the HIV infected and those millions of children throughout the developing world whose lives are radically altered when their parents become ill and die (USAID, 2001). Not only do children lose the security and safety of their immediate families, they frequently end up taking on adult responsibilities at very early ages. They provide care for ill or dying parents, take over farm and household work, care for younger siblings, and earn money for basic necessities. They are often forced to give up school, have less access to health care and become vulnerable to malnutrition as family resources dwindle. Substantial gains in improving child survival and health are quickly unraveling in countries hardest hit by HIV/AIDS. (USAID, 2001).

In the *Lessons about the Needs of Children Affected by AIDS* published by UNICEF (1999) as well as Donahue (1998), it was reported that at all family levels, loss of family members due to HIV/AIDS changes the household and family structure, results in family dissolution, lost income, impoverishment, lost labor, grief and stress. Together they result in creating an environment where it is difficult to care adequately for children's needs. Studies in the African Region show the terrible impact of HIV/AIDS on children, particularly on girls. For instance:

- In Zambia, a study by the International Labor Organization in several districts shows the majority of children in prostitution are orphans, as are the majority of street children.
- In Ethiopia, the majority of child domestic workers in the capital city Addis Ababa are orphans.
- In Uganda, focus group discussions revealed that girls orphaned by AIDS were especially vulnerable to sexual abuse in domestic housework because of the stigma attached to their orphaned status.
- Studies from numerous regions have shown that orphaned children have substantially lower levels of education than children who are not orphaned

(UNICEF, http://www.unicef.org/aids/index_orphans.html)

Though a correct estimation is not available, the number of children affected by HIV/AIDS and child-headed households are increasing in the country. Children in such conditions are deprived of their childhood and the opportunity to go to school. Economic hardships lead them to look for means of subsistence that increase their vulnerability to HIV infection, substance abuse, child labor, sex work and delinquency.

In situations where a large number of HIV affected individuals are from poor and vulnerable sections of the society, children are left in the households with limited or no resources. In such conditions, children often have to look after their siblings and households. Children living in child-headed households, either on the street or with families who regard them as unwanted burdens, are particularly vulnerable to neglect, abuse and exploitation. Those subjected to sexual abuse or exploitation are at an increased risk of becoming infected with the virus that killed many of their parents. Most HIV infected parents, even when aware of their terminal illness, do not attempt to make any legacy arrangements for their children before their death.

1.2 National initiatives

As a follow-up of Article 39 in the Indian Constitution and being a party to the UN declaration on the Rights of the Child 1959, India adopted the National Policy on Children in 1974. The policy reaffirmed the constitutional provisions and Stated that "it shall be the policy of the State to provide adequate services to children, both before and after birth and through the period of growth to ensure their full physical, mental and social development. The State shall progressively increase the scope of such services so that within a reasonable time all children in the country enjoy optimum conditions for their balanced growth." The Government of India ratified the Convention on the Rights of the Child on 2nd December, 1992.

India is also a signatory to the World Declaration on the Survival, Protection and

Development of Children. In pursuance of the commitment made at the World Summit, the Department of Women and Child Development under the Ministry of Human Resource Development has formulated a National Plan of Action for Children. Most of the recommendations of the World Summit Action Plan are reflected in India's National Plan of Action. The priority areas in the Plan are health, nutrition, education, water, sanitation and the environment. Giving special attention to children in difficult circumstances, the Plan gives special consideration to and aims at providing a framework for actualization of the objectives of the Convention in the Indian context. A National Plan of Action for the Girl Child for 1991-2000 was also announced. This plan seeks to prevent female feticide and infanticide, eliminate gender discrimination, provide safe drinking water and fodder near homes, rehabilitate and protect girls from exploitation, assault and abuse. (http://www.indianembassy.org/policy/Children_Women/national_action_children.html)

In April 2005, the Department of Women and Child Development, along with the National AIDS Control Organization (NACO), announced the formation of a high-level national coalition to push for greater prioritization of HIV/AIDS. The coalition will consist of a broad range of agencies: government ministries and departments, non-governmental and community-based organizations, faith-based and other international agencies, donors and the private sector. The coalition will sponsor the creation of a comprehensive national policy for interventions for those living with HIV/AIDS, especially children. This new alliance is the result of recommendations made by participants at the first National Consultation on Orphans and Vulnerable Children, held in New Delhi in March. The meeting was sponsored by UNICEF India and the Catholic Medical Mission Board, a New York-based religious charity. Reintegration of children who have lost one or both parents to HIV/AIDS was earmarked as a major priority.

“We will create many collaborative linkages and networks to ensure that issues of concern to vulnerable populations are accorded the necessary attention, resources and commitment without unnecessary duplication and delays,” said the Secretary of India's Department of Women and Child Development, Loveleen Kacker. (www.unicef.org/infobycountry/india_25908.html).

While one can see the commitments on paper, the national response to the needs of children affected by HIV/AIDS has been very slow.

In the NACP II NACO moved focus from looking only at prevention of HIV/AIDS across groups at risk, to funding care and support programs. Recognizing that more and more children are at risk of getting HIV infection (13-60%) due to the increasing numbers of infected pregnant women, NACO started the Prevention from Mother to Child Transmission (PMTCT) program at 11 institutions in the high prevalence States where the mothers were treated with AZT prophylaxis (April 2000 to July 2001). Nevirapine is given to the mother during delivery and Syrup Nevirapine to the newborn. The NACO guideline on PMTCT mentions strengthening of the well baby clinics run by the department of pediatrics in order to ensure regular follow-up of babies and to facilitate preventive, promotive and care and support facilities. The PMTCT guidelines emphasize the care of mother as well as the young infants; there is less focus

on children. The broad strategy and the guiding principle would be to provide rational intervention for the prevention of mother to child transmission, care of mothers and children affected with HIV, and reducing their vulnerability. The guidelines include providing information and referrals for services and support to the family and home based care to mitigate the impact on mothers and children, including orphans, infected with HIV/AIDS. Community based self-help groups to support individuals and families will be supported for continued participation of the children/orphans in school and their access to shelter, nutrition and social and health services. Linkages will be established for the care and support of orphans.

The State and national government departments of women and child welfare, social justice and empowerment, and health and family welfare have a few programs focusing on children affected by HIV/AIDS that offer short stay homes and provide food, health care, and educational and psychosocial support. The State policy on children who are orphaned is limited to the Central Adoption Resource Agency's guidelines on adoption (Vasavya Mahila Mandali and International HIV/AIDS Alliance, 2004).

However, community based NGOs working in the field of HIV/AIDS do recognize the need to intervene and support children infected and affected by the death of either one or both their parents.

1.3 Response in the States

All the States have reported AIDS cases, and surveys show that the virus is spreading from high prevalence urban areas into rural communities. (World Bank, 2003). The government considers six States to be of “high-prevalence,” that is, with more than one per cent of the general population believed to be living with HIV/AIDS. These are: Andhra Pradesh, Karnataka and Tamil Nadu in the south, Maharashtra in the west, and Manipur and Nagaland in the northeast of the country.

Table showing the distribution of States according to HIV prevalence

High prevalence States 45 districts in the high prevalence States of Maharashtra, Tamil Nadu, Manipur, Andhra Pradesh, Karnataka and Nagaland have been identified as high prevalence districts, based on the consistently high prevalence levels of HIV detected by the three most recent rounds of HIV Sentinel Surveillance. These six States are cited as high prevalence because the HIV prevalence rates exceed 5 per cent among high-risk groups and exceed 1 per cent among antenatal women.	Moderate prevalence States The States of Gujarat, Goa and Pondicherry which share geographical borders with the high prevalence States report HIV prevalence exceeding five per cent among high-risk groups but less than one per cent among antenatal women. Four districts in these States have been identified as high prevalence districts, based on the consistently high prevalence levels of HIV detected by the three most recent rounds of HIV Sentinel Surveillance.	**Low prevalence States** Apart from the six high prevalence and three moderate prevalence States, the remaining States and union territories fall into the low prevalence category because the HIV prevalence rate is less than five per cent in high risk groups, and less than one per cent among antenatal women.
Based on consistent high prevalence of HIV as shown by HIV Sentinel data of last three rounds, 49 districts in the country have been identified as high prevalence districts for intensive program action.		

(Source: http://www.nacoonline.org/facts_overview.htm)

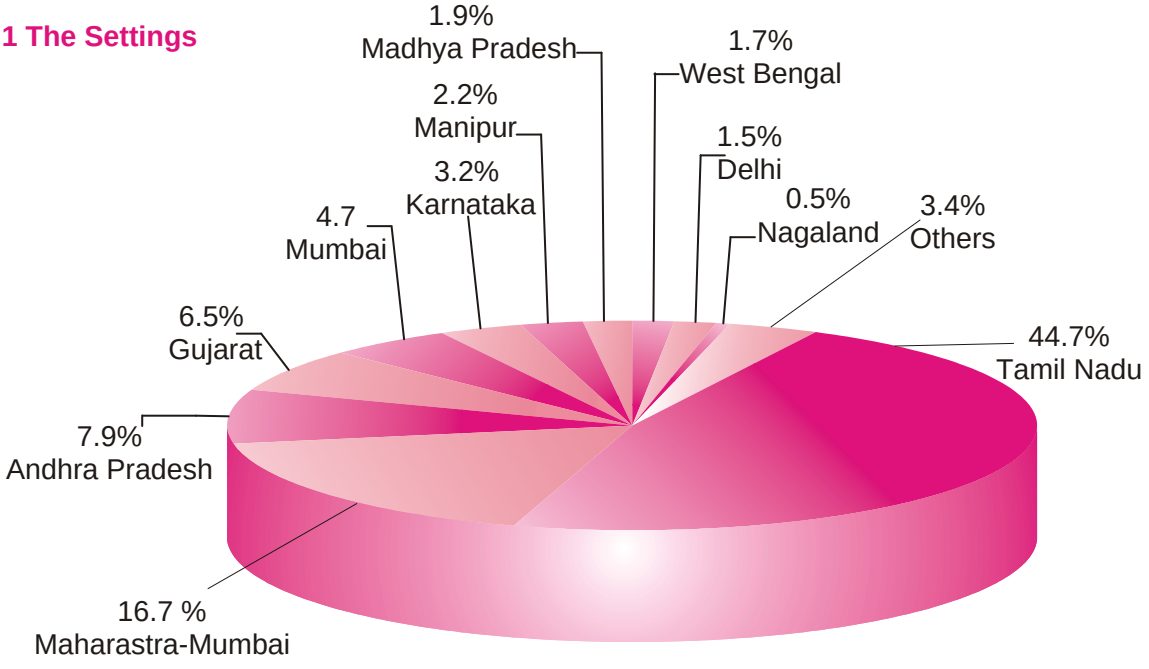
2. The Study

Very little research documents the problems and needs of these children. Nor has much attempt been made to document need based interventions that make a difference in their lives. There is no national policy or program that specifically addresses the needs of these children either those heading households or those who are orphaned.

India HIV/AIDS Alliance has been working on child related issues through community based organizations in three states: Delhi, Andhra Pradesh (AP) and Tamil Nadu (TN). In the last five years, the NGOs have been supported to work with households affected by HIV/AIDS and to innovate meaningful interventions with children heading households. Foster care has emerged as of the options for care and support to the children left behind by their ailing parents in the states of TN and AP. However, no systematic documentation of these efforts and the policy and legal implications of this experiment have been done. Similarly, there is no comprehensive study of children heading households where one or both parents have died due to HIV/AIDS.

Thus this study was conceptualized to develop greater insights into the problems, needs and challenges of children and plan appropriate interventions and models of care for the children affected by HIV/AIDS. The focus is on Andhra Pradesh and Tamil Nadu.

2.1 The Settings



Distributions of reported AIDS cases by State cumulative figures till 2003

As indicated in the above chart, Tamil Nadu has reported 44.7% and Andhra Pradesh 7.9% of the cumulative AIDS cases till 2003. However, the figures for children are not available.

The states implement the programs laid down by the National AIDS Control Organization (NACO). In Tamil Nadu and Andhra Pradesh, the settings of this study, there are no specific policies or programs that focus on children infected and affected by HIV/AIDS, except as part of the PMTCT or isolated initiatives by NGOs and bilateral agencies.

2.1.1 About Tamil Nadu

Located at the southern tip of India, Tamil Nadu is the country's sixth most populous state. It is one of the better-off states in the country in terms of per capita income, economic growth, and human and social development. The state has been successful in its overall efforts to address poverty, and the proportion of those living below the poverty line fell from over 30% in 1993-94 to 19.6% in 1999-2000. However, despite this impressive performance, poverty remains pervasive and Tamil Nadu retains the highest levels of inequality in the country. (http://lnweb18.worldbank.org/ESSD/sdvext.nsf/68ByDocName/CurrentInitiativesTamilNadu)

Among the four southern states, the level of poverty both in absolute numbers and percentage of population below poverty line was highest in Tamil Nadu in 1999-2000 (Union Planning Commission/National Human Development Report 2001). In terms of the Human Development Index (HDI), Tamil Nadu fares very well compared to the other States in India. According to India's first National HDR prepared by Union Planning Commission (March 2002), the State's Ranking in HDI has improved by four positions from 7 to 3 during 1981-2001.

While Tamil Nadu is ahead of most States in the absolute condition of women, the position of women vis-a-vis men with respect to literacy, education, work force participation, wages, asset ownership and political participation needs attention. The Census 2001 shows that the female literacy gap has been considerably narrowed, though Tamil Nadu continues to maintain the 3rd position behind Kerala and Maharashtra in the overall literacy rate. A large section of the population (scheduled castes/tribes, minorities, women) has not benefited from the economic and social development that the state has experienced. The old age dependency ratio is 12.13 (NHDR, 2001) which is an issue of great concern. http://www.tn.gov.in/spc/human_development_report.htm .

The State has very high rates of working children in the age group 5-14 yrs, that is, 4% in 1991 according to the NHDR 2001. However, the State has pioneered several innovative social security and welfare schemes for the disadvantaged and for children.

Agriculture has been the mainstay of the economy employing about 50 per cent of the people and contributing nearly 20 per cent to the GDP. Tamil Nadu is also among the most industrialized States in India and one of the major recipients of donor funds

The Census 1991 and 2001 results show that Tamil Nadu's workforce has been increasing at a faster rate than the growth of population. The increase in rural unemployment in Tamil Nadu (which is twice that at the All-India level) and increase in proportion of educated unemployed between 1993-94 and 1999-2000, are matters for concern. The number of

unemployed was 7.81 lakh in 1999-2000. This accounts for 2.7% of the labor force which does not include under employment. Sex-wise unemployment details show that rate of unemployment rate for males is higher than that for females. (http://www.tn.gov.in/spc/tenthplan/CH_1.PDF)

Response to HIV/AIDS: Tamil Nadu was the first states in the country to form a State AIDS Control Society that is headed by a senior Indian Administrative Service (IAS) officer of Secretary rank to help towards better utilization of funds. Tamil Nadu State AIDS Control Society (TNSACS) supports about 200 NGOs and networks for PLHA (including the Positive Women's Network) working in prevention, care and support programs. It is mandatory for NGOs supported by TNSACS to employ a person living with HIV. Regular training and sensitization of medical professionals has been conducted so as to develop skills for the treatment of opportunistic infections and meet the needs of people who have developed HIV/AIDS related infection.

Besides funding CHES (Chennai Health Education Society), an NGO providing residential care to children orphaned by HIV/AIDS, the state has no systematic plan or program for work with children. Like NACO, the Society (TNSACS) does not have information on the exact nature and magnitude of the problem with children and there is no specific work initiated with children. Child focused initiatives by bilateral agencies and local NGOs have been recent.

2.1.2 About Andhra Pradesh

Andhra Pradesh is the fifth largest state in India and it forms the major link between the north and the south of India. It is the biggest and most populous state in the south of India and known as the rice bowl of India.

Crisscrossed by two major rivers, the Godavari and Krishna, agriculture has been the chief source of income for the state's economy. (http://andhra-pradesh.biography.ms)

Predominantly rural (76% of the population is rural), and one of the country's poorer states, AP's annual per capita income was about US$503 in 2003-04 - near the national average of US$511 in the same period. As in the rest of the country, poverty in the state declined significantly during the 1990s, dropping from over 30 per cent in 1990 to 21.6 per cent in 2000. During this period, the state also witnessed a 39 per cent increase in literacy, a rise in the school enrolment ratio of 6 to 10-year-olds from 73 to 85 per cent, and a 24 per cent increase in the proportion of the population with access to safe drinking water. (http://www.worldbank.org.in/WBSITE/EXTERNAL/COUNTRIES/SOUTHASIAEXT/)

The mean age at childbearing has declined steadily from 27 years in 1981 to 23.2 in 1997, indicating a shift in the age pattern of childbearing with a significant proportion of births occurring among younger women. The early start of childbearing is primarily because women tend to marry at an early age. Forty-five per cent of women in the age group 15-19 are married. The median age at first cohabitation with the husband is 15.4 years, the lowest among all the states of India. (http://www.expresshealthcaremgmt.com/20020215/hyderabad4.shtml)

The State has the highest child labor population in the country and according to the 1991 census the number stood at 16.61 million working children. The figures of the 2001 census have not yet been published. (http://pib.nic.in/archieve/lreleng/lyr2003/rfeb2003/27022003/r2702200312.html)

2.1.3 Response to HIV/AIDS

Specific government initiatives in Andhra Pradesh aim to reduce transmission among high-risk groups and between pregnant mothers and their babies. They also aim to increase awareness among school children.

APSACS (Andhra Pradesh State AIDS Control Society) plans to establish 33 community centers for children affected by HIV/AIDS in 23 districts with two centers in each of the 10 districts with high HIV/AIDS prevalence and one centre in each of the 13 low prevalence districts. Although this is an indication of the State Government's growing awareness of the needs of children affected by HIV/AIDS, the project is still very much in its conceptual stages (VMM and International HIV/AIDS Alliance, 2004).

2.2 Methodology of the Study

2.2.1 Objectives

The specific objectives of the study are:

Community foster care

- Analyze the need for community foster care and identify and assess options and constraints
- Inform on the development of policy to support the scaling-up of community foster care in Andhra Pradesh and Tamil Nadu

Child headed households:

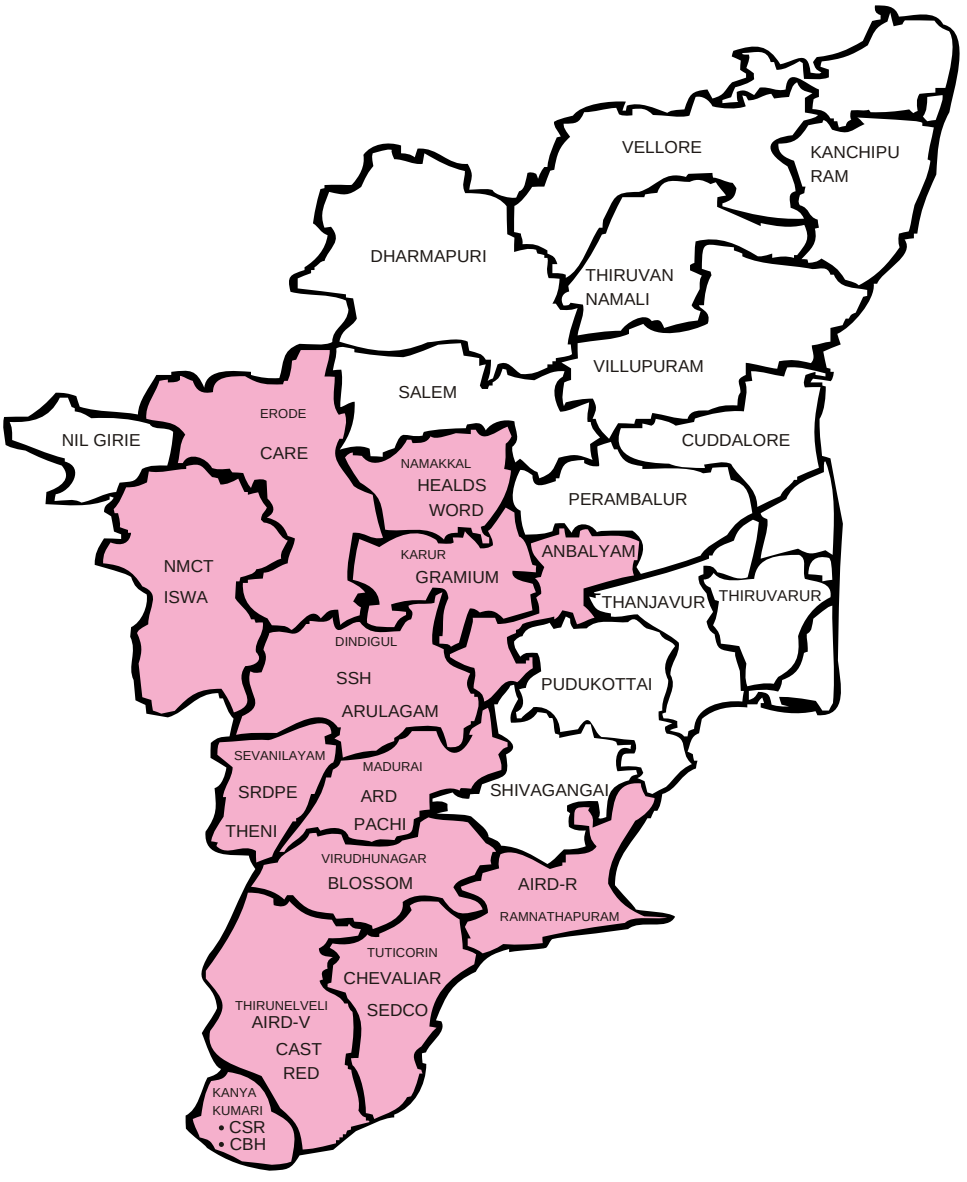
- Conduct a situational analysis on child-headed households in Andhra Pradesh and Tamil Nadu
- Document the challenges faced by the children of child-headed households
- Identify the needs of these children
- Explore the legal and policy issues that concern child-headed households

2.2.2 Collaborating partners

The present study sample is drawn from the children belonging to the families who are the beneficiaries of the Implementing Non Governmental Organizations (INGOs) working in Tamil Nadu and Andhra Pradesh. These INGOs receive technical and financial assistance from Vasavya Mahila Mandali (VMM) at Vijayawada in Andhra Pradesh and Palmyrah Workers Development Society (PWDS) at Madurai and Marthandam in Tamil Nadu. VMM and PWDS are the lead partners of India AIDS Alliance in Andhra Pradesh and Tamil Nadu respectively since 2001.

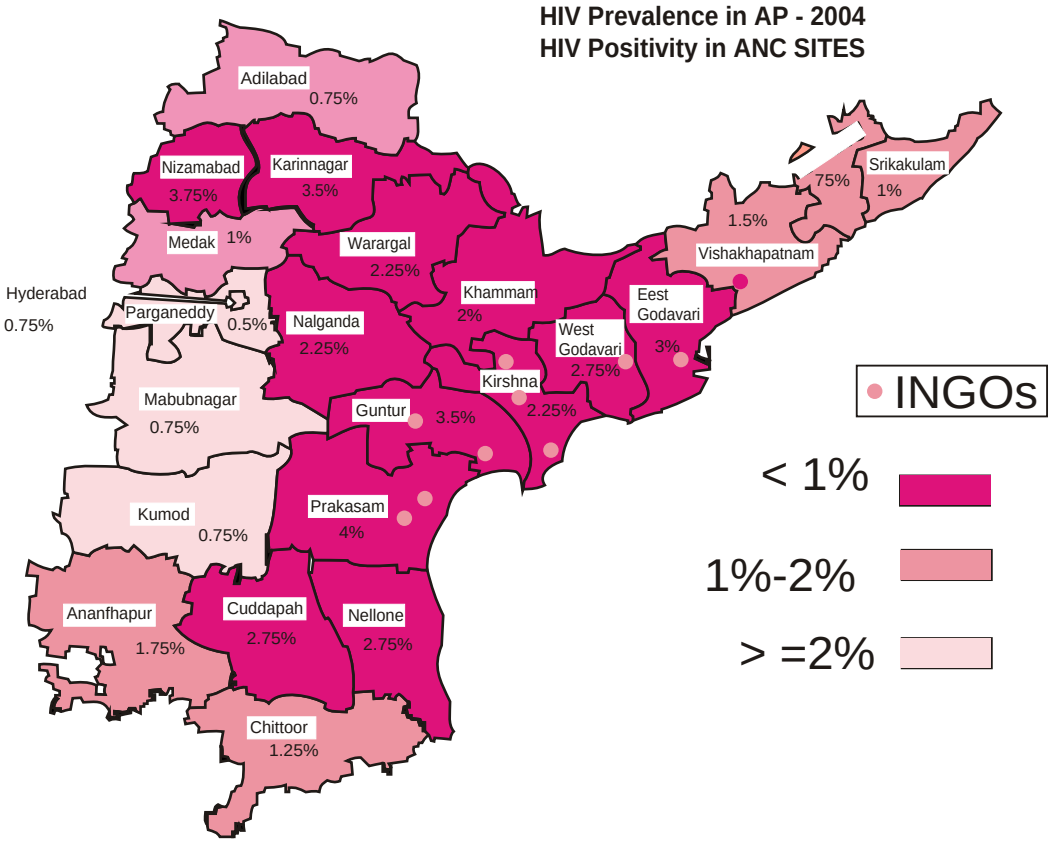
Vasavya Mahila Mandali, founded in 1969, is working in Andhra Pradesh for the development of women and children in need. Palmyrah Workers Development Society, founded in 1977, offers development support services to sustain community initiatives. VMM covers seven coastal districts in Andhra Pradesh and PWDS covers 13 districts in Tamil Nadu. (Detailed Profiles of VMM and PWDS are given in the appendix.). The following maps show the location of the INGOs and the CBOs covered by these organizations.

Map showing the coverage area of PWDS and the location of INGOs[1]



[1](Source: PWDS and India HIV/AIDS Alliance)

Map showing the coverage area of VMM and the location of INGOs[2]



[2](Source: Vasavya Mahila Mandali) **Source ; Sentinel Surveillance - 2004**

The purpose of linking with the NGOs working in these areas was that this was a rapid assessment to be completed within a period of six months. The lead NGOs participated in the research process in various ways: helping to locate staff, providing office space and equipment to the staff; providing access to secondary sources; and overseeing the implementation of the research process in their local areas.

2.2.3 Research design

The study is a rapid assessment with focus on qualitative data to sensitively understand, the situation of children heading households and the challenges faced by children orphaned by HIV/AIDS. The study also looked at the child's perspective, which is very important as this has remained neglected in social science research in India. Though the methodology could have been more child friendly… (Language of questions could have been simpler etc), the advantage was that the research data was conducted by persons who had very good rapport in the community.

As the study had to be completed in a very short period of seven months, it was essential to take into confidence the lead and

the implementing organizations as well as map the area of the study. Thus a pilot visit was undertaken to the two states as follows:

- 25th and 26th of May,2005 : VMM, Vijayawada, Andhra Pradesh
- 31st may and 1st June,2005: PWDS, Marthandam, Tamil Nadu

The objectives of the pilot visit were to:

- Clarify the role of the lead partners and the partner NGOs in the research process
- Discuss the research methodology and financial aspects like disbursement of funds etc with the lead partners
- Conduct focus group discussion (FGD) with the partner NGOs to gather preliminary data on the magnitude of the problem and initiate them to participate in the research process.
- Interview and recruit research assistants for the project

The specific objectives of the focus group discussions with the field staff of INGOs were to:

- Understand the context and magnitude of the problem
- Have an overview of the interventions being rendered by the organizations
- Understand their views of the problem with regard to HIV/AIDS in their intervention areas
- Assess the magnitude of the problem pertaining to child headed families and foster care issues
- Identify the nature and level of support being provided by the lead partners and implementing NGOs
- Outline the key issues for research

The discussions provided the base for developing the tools for the study. The field staff shared their experiences in the field as well as the problems suffered by children heading their households. The staff also shared their views on the emergence of community foster care in the community and their merits and demerits.

2.2.3.1 Recruitment of research officers and research assistants

During the pilot visit, the principal investigators felt that it would be appropriate to appoint local persons as research staff in order to facilitate communication in the language of the children and the communities. The Research Officer was recruited in July, 2005 and the Research Assistants in August, 2005. An orientation was given to the research team in DATA-PWDS, Madurai, Tamil Nadu enlightening them on the objectives of the project and its methodology

2.2.3.2 Tools of data collection

The following tools were used to elicit data from children heading their households, children under foster care and various stakeholders.

Tool I: Focused Group Discussion (FGD) guide for NGO staff on Child Headed Households

Tool II: FGD guide for NGO staff on Community Foster Care

Tool III: In depth Interview Schedule for Children heading their households.

Tool IV: FGD guide for Children Heading their Households

Tool V: Interview guide for Elders in the Families Headed by Children

Tool VI: In depth Interview Schedule for Children under Foster care

Tool VII: FGD Guide for Children under Foster Care

Tool VIII: Interview Guide for Foster Mothers

Tool IX: FGD Guide for Self help Group members

Tool X: Mailed Questionnaire for Project Director, SACS.

The tools were pre-tested in both the sites by the research team. Interview guides and checklists were translated into local languages. After the testing, few modifications were incorporated and the data collection took place in both the states.

2.2.3.3 Sample frame and sample selection

After the pilot visit, the criteria to select children for both studies were finalized. The Lead Partner NGO provided the information of the number of children belonging to each category based on the inclusion criteria developed by the team. Purposive sampling method was adopted to select the key informants among the children.

The Inclusion criteria for child headed households were as follows:

- Child above 11years and below 18 years of age
- Child earning the major source of income in the family
- Child responsible for the well being of siblings and/or dependant parents and/or grand parents

The Inclusion criteria for children in community foster care were as follows:

- Child above 11 years and below 18 years
- Child is all alone and taken care of by unrelated families who are members of self help groups
- Child stays with local guardians who are not related to them.
- Children taken care of by distant relatives, family friends or neighbors.

Across the two states, 29 children heading households were administered an interview

The following table shows the number of children contacted:

Details	Andhra Pradesh	Tamil Nadu
Total number of children heading households	167	108
Number interviewed	18	11
Total number of children in foster families	22	6
Number interviewed	4	2
Number of elders in child headed households interviewed	1	1
Number of foster mothers interviewed	4	2
Focus group discussions with staff of NGOs	1	2
Focus group discussions with self help groups	1	2

Table: Total number of children reporting to the organization and respondents in the study

schedule while in-depth interviews were conducted with six children in foster families. There was equal representation of the staff from all the implementing organizations for the focus group discussions. Self help group members who were actively involved in the welfare of children were invited for focus group discussion. Elders in child headed families who consented wholeheartedly were chosen for in-depth interview. Foster mothers were also chosen the same way.

2.2.4 Process of data collection

Mostly children who could articulate well and earned a major income chunk for their families figured in the sample. Research assistants planned their visits with help from NGOs. Interviews were mostly conducted on the doorsteps of respondents. Those who had difficulty in speaking at home were interviewed either in the temple or the NGO office. The child was never alone during the interview.

Focus group discussions with the children and NGO staff were conducted at the office of the lead partner organization in the respective states. The objectives and process of the study were explained to the children and their consent for participation was obtained orally. The participants who were not interested were permitted to leave during any part of the discussion.

The data collection was done during August 05 to November 05 and the average time taken to administer the interview guide was about 50 minutes. Data clearing and data entry was done simultaneously. FGDs were conducted in between October 05 and November 05 and the average time taken to conduct one FGD was four hours.

2.2.4.1 Problems in the process of data collection

The research team faced a few problems during the study. Getting access to the respondents at their place of stay itself was a problem because the respondents who usually head household go to work early in the morning and return late in the night. After that, some had to attend to household chores. The research assistants often had to visit them at odd times and wait for long hours in order to interview him/her alone without any disturbance. As the respondents were spread across the village covered by the NGO, access to respondents was very difficult because of the distances.

Children participating in focus group discussions had to take leave which meant loss of the day's wages. Hence, some anticipated financial favors in return. Some children were totally disinterested in the study and said that they have shared their problems with a number of persons but received no benefits. Some were scared of breach of confidentiality. Handling the emotional trauma became a major task. The children were allowed to take their own time to ventilate their problems and in certain cases, counseling was rendered by the team.

The other limitation was that the children felt threatened that if they spoke very freely about their experience of foster care, they would be withdrawn from this facility, which was one of their options in lieu of institutionalization. This was despite repeated assurances of confidentiality by the researchers.

Conversing and using innovative play and projective techniques with children rather than a formal interview process produced better results. This was undertaken in a limited way as the staff was new, inexperienced and the very brief orientation was inadequate to adopt these child friendly approaches.

Despite all the limitations, the data does raise issues and the need to focus on these children who are managing their little lives against tremendous odds.

2.2.5 Analysis of data

The data entered was computerized and analyzed via Atlas -- software for analysis of qualitative data. Codes and sub codes reflecting the emerging themes and trends pertaining to problems, needs and challenges faced by the children affected by HIV/AIDS have been identified and analyzed. Analysis of schedules was done manually and this data has been integrated along with the qualitative data. The report is descriptive and raises several research questions as well as pointers to the scope of interventions with children heading households and the future of foster care.

2.2.6 Scope and limitations of the study

This is one of the few Indian studies on the very important and neglected status of children affected by HIV/AIDS and the options or experiments tried by NGOs in protecting their rights and providing care and support to them. This study focuses on the efforts of particular NGOs receiving grants from an international NGO. The sampling was purposive with very few foster care children ready to be interviewed.

While the data cannot be generalized, it does provide insights into the various problems and challenges which children affected by HIV/AIDS have to deal with and resolve, with or without support from their families and community. The children are extremely vulnerable to exploitation.

Due to the repeated exposure to researchers, the children were apprehensive on being ``researched'' also as mentioned before, they felt that ``nothing comes out of it''. This raises ethical issues on the research itself in terms of the immediate benefits to the children and the long-term focus on formulating policy and programs for future interventions. There is definite need for follow up on this. This had repercussions on the quality of the data collection process there was reluctance and it was difficult for the researchers to go back to the children. Hence, the original idea of iterative in-depth interviews had to be replaced by a one-time interview using an interview schedule.

The other limitation was that the children felt threatened that if they spoke very freely about their experience of foster care, they would be withdrawn from this facility, which was one of their options in lieu of institutionalization. This was despite the assurance of confidentiality by the researchers.

Despite all the limitations, the data does raise issues and the need to focus on these children who are managing their little lives against tremendous odds.

3. The findings: CHILD HEADED HOUSEHOLDS

3.1 Profile of the children (key informants)

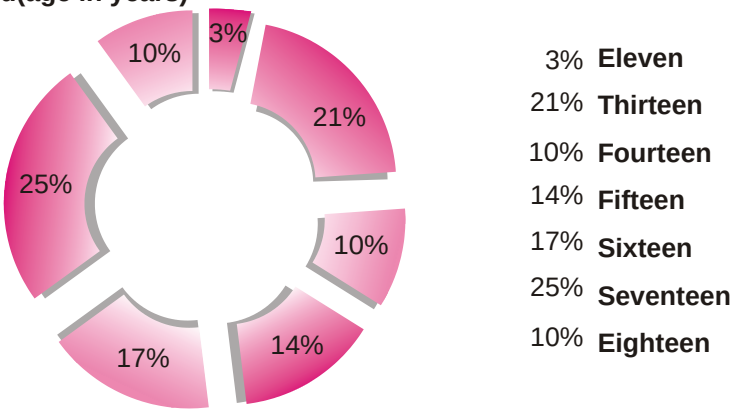
3.1.1 Age and sex distribution

In Tamil Nadu, 11 children (six male and five female) responded to the interview schedule. Most were in the age group of 16 to 18 years while two were in the 12-14 age group. The older children were aware of HIV/ AIDS, highrisk behavior and sexual exploitation.

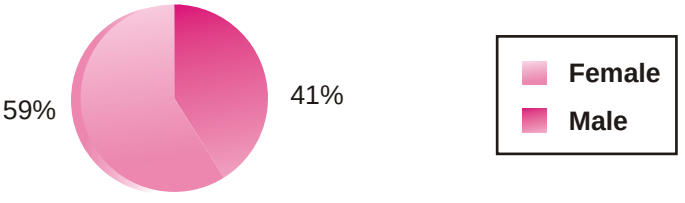
When interviewed, the children were in a despairing mood and it was quite traumatic to even talk about their experiences.

In Andhra Pradesh, 18 children responded to the interview schedule six boys and 12 girls. The respondents were in the 11-18 age group. The following figures show the age and sex wise distribution of the 29 children from both the states.

Age-wise distribution of respondents heading their household(age in years)



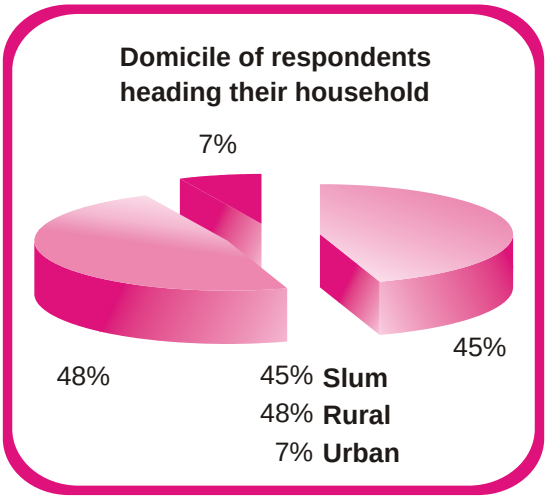
Sex distribution of respondents heading their household



As the figures show, the children are in puberty and adolescence and over more than 50% are girls. At this critical life stage this amounts to a dual crisis for them. Besides the basic means of survival, they need great psychological support to cope and manage their households.

3.1.2 Domicile

Thirteen children belong to slum pockets in the periphery of the towns, 14 belong to rural areas and only two respondents represent the urban setting (towns). This reflects that HIV/AIDS has seeped into the villages and is taking toll of the young adults there.



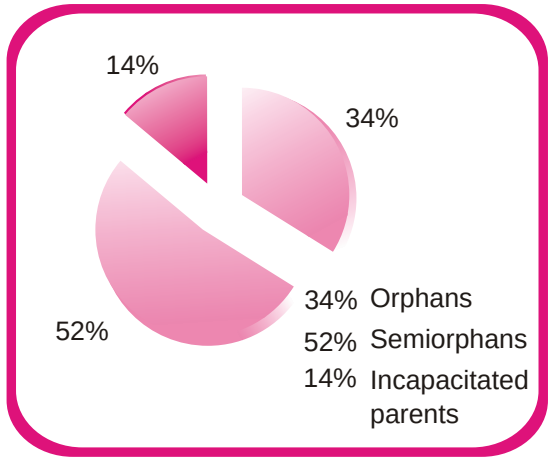
3.1.3 Education

In Tamil Nadu, all the respondents were literate and wished to continue their studies. In Andhra Pradesh, a majority studied up to middle school, that is, eighth standard and a few up to high school.

3.1.4 Family Background

Almost 50 % of the children who participated in the study are semi orphans; 10 have lost both parents and four stay with the ailing parents whom they look after.

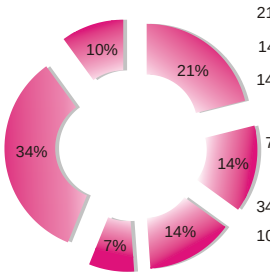
Children who have lost their parents did not give much information on their parents and their means of livelihood. Emotional responses to their parents ranged from tears to hatred, and this was tough to handle during interviews. Few shared that their parents were in agriculture and construction labor. It is important to note that the mothers of two female respondents were commercial sex workers and the grandmother of a female child is also HIV positive.



The parents left no assets for the children except that a few inherited the house. Others have left huge debts to be repaid by the children, which indicates that they were not been earning sufficiently.

The respondents reported that their siblings are very cooperative and willing to share the responsibility. In a couple of cases, siblings are not cooperative. Two respondents shared that their married elder siblings have deserted them and are not rendering any support to the younger ones. It is clearly evident that the elder children are not necessarily taking up the role of heading the household.

Distribution of respondents heading their household on the basis of whom they are staying with



21% With siblings
14% With grand parents
14% With both parents and siblings
7% With father and siblings
34% With mother alone
10% With mother and siblings

The figure above indicates the varying pattern in the structure of the family with AIDS deaths. About 51% are living in single-headed households with one parent, mostly the mother is alive.

What thus emerges is that the children hail from poor families either rural or urban and with very few assets and more liabilities. Debt burdens the little shoulders of the children left behind either with their siblings, or grandparents or a single parent, mostly ailing and non-earning.

The problem is aggravated by a community environment where stigma and discrimination (arising out of lack of information, awareness, myths and misconceptions) continues to exist. However, with the interventions of the NGOs, there seem to be some positive support to the children and their families.

Child Headed Households

3.2 Detailed findings of the study are presented under the following subheadings:

3.2.1 Perception of the NGO staff and the community with regard to HIV/AIDS

3.2.2 Problems and challenges faced by children heading households

3.2.2.1 Lack of prior preparation

3.2.2.2 Discontinuing education

3.2.2.3. Lack of support by family and relatives

3.2.2.4 Stigma and discrimination

3.2.2.5 Community/friends help in locating jobs

3.2.2.6 Working and earning for their families

3.2.2.7 Problems of indebtedness

3.2.2.8 Informal sector and subsistence employment

3.2.2.9 Hunger and ill health

3.2.2.10 Vulnerability to sexual abuse

3.2.2.11 Impact on mental health of children

3. 3 Special needs and challenges for the Girl Child

3. 4. Perception on impact of NGO interventions

3.5 Cases of extreme vulnerability and exploitation of the children heading households

3.2.1 Perception of the NGO staff and the community with regard to HIV/AIDS

NGOs report that the number of people living with HIV/AIDS is increasing in both the states. This is also borne out by the government statistics mentioned earlier.

In Tamil Nadu, the field staff from Imayam Social Welfare Association, WORD (Women's Organization in Rural Development) and NMCT (Native Medicare Charitable trust) situated in and around Coimbatore reported that in the last two years there have been 70-72 deaths of people living with HIV/AIDS (PLHA) and they have nearly 29 children heading the households in their operational area. Field staff from Arulagam, an INGO in Dindigul report that there are 35 children heading households.

The field staff from St.Paul's trust, Samalkot has registered 600 deaths out of 6,500 PLHAs in their project area. They also report that they have 45 children heading households in their project area. Vasavya Mahila Mandali, Vijayawada has registered 300 deaths out of 2400 PLHAs in their operational area. SHADOWS, and Chirala (implementing NGOs) have 45 children heading households in their operational area.

It appears that communities who are affected by mobility and poverty show greater rates of infection. For instance, in Vetapalem, a particular community (which was poor) seemed to be more prone. The incidence seems higher in mobile working class populations and among vegetable and flower vendors. In Chilakaluripeta, women sex workers appear to carry higher rates of infection.

Most are unaware that it is not a communicable disease and is transmitted only through participating in sex ``outside home'', blood transmission from one who has HIV/AIDS, using same needle for injection etc. They are aware that it is caused due to sexual contact. Most tend to blame sex workers and feel that ``the problem of prostitution should be controlled by the government in a serious manner''. Sources of information include the NGO, media, and hospital based programs.

However, a substantial number of people continue to believe that it is a dreadful disease. Some people say HIV/AIDS is 'thappaana vali vandha noyi' (disease acquired by bad conduct). Some myths continue, for instance, women have lesser HIV load due to the bleeding during menstruation.

3.2 .2 Problems and challenges faced by children heading households

The major problems faced by the children were related to their lack of preparation for the illness and crisis in the family. They were pushed into adult roles and forced to assume greater responsibility in their families. This affected their education and had a negative impact on their physical and mental health. Their problems were aggravated by the stigma and discrimination they had to face in the community, in their workplace, etc. The details are presented below.

3.2.2.1 Lack of prior preparation

Almost all children said they were totally unprepared to assume responsibility as head of the family and they found it difficult to run the household. The major factors precipitating this were the family situation and the financial crisis.

In most cases children had no prior information or any preparation on the deteriorating health of the parents. Most were forced into this responsibility after their parent/ grandparents informed them about the crisis. Only when the father is completely bed ridden or has passed away, does the mother reveal or is forced to reveal the father's HIV status. At times the family doesn't know till the father's death. The child may come to know only when deserted by the parents. Such children are totally unprepared and unable to cope with social stigma and loss of community support. A child said that their life has “become upside down”.

Though the neighbors know the HIV status, nobody discusses about it.

The children embark on this responsibility by helping the parent in managing family tasks, which quickly increase manifold as the parent/s become more ill or incapacitated. They understand that additional income is needed in the family. Most have younger siblings and a few have older siblings who cannot take up the responsibility of the household as they are either ill-equipped, disabled, sickly, people living with HIV/AIDS, or unwilling to take up responsibility. Most of the dependent siblings are grateful that they have someone taking care of them.

Shared by a 16-year-old boy: “My father died of HIV/AIDS; my mother is sick and unable to do any work. I have completed my 10th standard and now I work in a quarry, as a coolie. The situation forced me to take up the job but I am happy that I am able to make my elder brother study in the 12th standard and my younger sister in the third standard. At least I am able to give them an education. I willingly took the task of taking care of my family. (Silence and he looked much stressed) Look at my hands and legs, how they are hurt. At times, I pity myself. I studied under the streetlight when

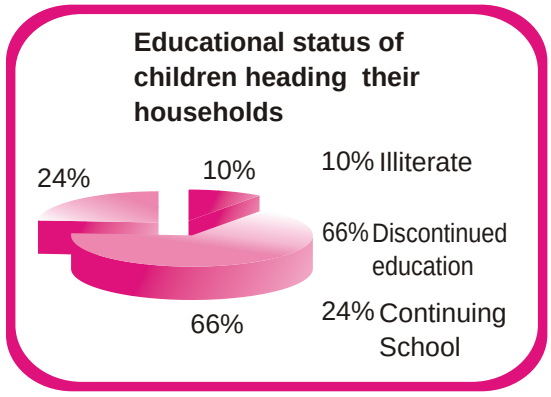
I did my 10th standard and I got good marks, but now I am unable to continue my studies. I feel burdened not because I am working, but because of the nature of the job, I am forced to take up".

3.2.2.2 Discontinuing education

The first casualty of HIV/AIDS is the school drop-out. All children interviewed in Tamil Nadu were literate; one respondent had completed her fourth standard, and nine children reached their intermediate college. Some had to leave school but wish to start when they feel more settled (after a brother finishes studies, or a sister is married). Some are studying and working part time with great difficulty. Some children get marginal help from their grandparents for their education but have started getting bad grades in school, which makes them feel they should discontinue their education.

In Andhra Pradesh, of the 18 children in the analysis, six left studies completely while five discontinued temporarily, but plan to restart with support from the NGOs. In Tamil Nadu, six dropped out of school, but three want to continue. The rest are managing between schools and household chores. They are also on the verge of quitting because of the burden and the bad grades they get at school.

The following pie chart shows the percentage of children who have discontinued their education in order to take care of their families. What is promising is to see that 24% of the children are managing to continue their education despite the responsibility they are shouldering.



Some have mentioned other reasons like they are getting teased by their friends about their poverty.

My father died of HIV six years ago. Since then, I started working to meet my family needs. I was not able to go to school, as I had this huge responsibility. A distant relative placed me in a grocery shop. I have to do the packing, supplying, cleaning etc

I own a tailoring shop and earn a decent amount. I do not have any restrictions at work. Work wise I am ok, but I long to study and speak English.

A 13 year old in his 9th standard goes to school in the morning, comes home and takes care of his two siblings and works at a grocery shop in the evenings. (5.30- 9.30 pm) He is so tired when he returns late at night - he is half dead. "I won't even have energy to eat, so I am not able to concentrate on my studies, I do not know how long I can work like this. I am getting bad grades in school and am wondering whether to continue schooling or not."

In the school children wear new cloths and come to school on cycle. When I see that I feel like having one but I cannot afford it. What we earn is not sufficient for our daily sustenance. What to do -- some lives are not meant for such happiness. Along with that my class mates tease me by saying that I am an orphan.

3.2.2.3 Lack of support from family and relations

Except for a few who are totally neglected by their relatives, most of the children are cared for in a superficial manner. None receive any financial help from their relatives. Grandparents visit them occasionally and bring some eatables. A few find that help from relatives is more forthcoming when there is an issue like marriage. Mostly the relatives visit to see that all is well in a general sense. Some criticize the way the children live, but there is no specific effort in terms of guidance, financial support etc. In most cases, grandparents are more supportive.

A young girl said, “My maternal grandparents are supporting us. I stay in a hostel, provided by the company and visit my grandparent's once in a year. I earn for my siblings and myself. There are my mother's sisters in my grandparent's house as well. They are looking out for an alliance for my last Chithi (mother's sister). I love to stay in my grand mother's place, but my granny says that according to my horoscope it is not good I stay there. So I have to stay outside the home.”

A 16-year-old boy said, “My paternal relatives helped me to get my sister married but now we do not get any financial help from them. However, they still visit us which is a great source of support. We got my sister married quickly because we were afraid that if anyone got to know about our parents, no one would agree to marry her. She will be a sellakaasu” (money which cannot be spent)

When my father died, none of my relatives came to help. Only after I began earning, did they visit us, because they are now sure that we will not ask for financial support.

In certain cases in Andhra Pradesh, family members like an older brother and his family or uncles and aunts are unable to take care of or even extend active support to the children. Even brothers do not visit often nor support in any way. Some provide financial advice and guidance. Generally grandparents extend psychological support freely but when it comes to financial support, most have little to give. Where the grandparents take on this responsibility, the children have to help them by earning a substantial amount.

In a few cases the mothers are not accepted by the in-laws and this social isolation is passed on to the children. Inter family conflicts aggravate the discrimination and this is an additional reason for lack of active support to children heading their households.

A girl sister whose brother is just a year younger to her narrates:” We don't fight but he doesn't speak to me. He is always annoyed with my mother and me. My relatives always scold me. For example, they say, “Your mother is HIV positive so you must get married and go away as early as possible. My brother earns but doesn't give us any thing. My paternal aunt told him that my mother poisoned my father and killed him. Though my brother knows that my father died because of HIV he still believes her. He doesn't listen to my mother.”

My peddamma (father's brother's wife) and peddanna (father's brother) have taken my brother to their house -- he is a boy so they took him. I am a girl so they did not take me.

A 15-year-old girl shares her experience: “Brother does not give anything towards for the house, nor does he give any emotional support. He does not help in any way. It's so difficult to look after the family. After my fathers death things were very difficult and we starved for some days. It is nice when people assist us”.

In certain cases, the children are not allowed to play with others and nobody speaks to them. Even when closely related, parents tell their children not to eat nor drink with affected children."

"My mother's condition became serious and she went into coma. My mama (maternal uncle) and I would put milk and tulsi water in her mouth. A purohit (priest) came and told us she would die in a week. All the villagers would tell their children "Don't go near these children". My mama took us to his house but his children came and told us that he had asked them not to play with us... Later we came to our grandmother's (maternal) house but they are also very poor. The NGO staff said that they would help us. Once again, our uncle asked us to come along with him. But we refused…we felt very bad because our own mama had told his children not to play with us."

3.2.2.4 Stigma and discrimination

Although NGOs claim that awareness has led to fewer stigmas but there continue to be those who treat persons living with HIV/AIDS with fear and would prefer to exclude them. The children however are not treated badly when the parents have passed away.

In Andhra Pradesh, data from the focus group discussions with NGO staff and Self Help Groups reveal that the social stigma continues for everybody: Children, women and men. Men face HIV/AIDS related stigma more than women and children. Men are blamed for "going with other women". When a woman gets it, then they say ``She got it from her husband'' and show more sympathy to her.

Stigma towards children has reduced. People now realize that if children play with affected children or drink water from their glasses, there is no problem. Neighbors do help, but the affected children get little support in school. According to the NGO staff, the formation of children support groups at the community level has been one of the interventions that provide psychosocial support to the children affected by AIDS. Awareness among children has increased tremendously because of the support groups.

Community acceptance is however only partial. Children above 10 do not face any stigma and are more willingly accepted in the community because people believe that they will not be affected by HIV/AIDS. But younger children - in the age group of 4-5, do because it is assumed that they have acquired the disease.

After the death of the father (due to HIV), the family was ostracized by the community. Now they are not. The community is however, unaware that the mother and child are infected. The child does not want to disclose this, because of the fear of social exclusion. Although the grandparents support the family, the aunt (mother's brother's wife) treats them badly and uses abusive language. She shouts at them without any reason.

The community members treated the mother very badly they would wash the place where she sat and serve her in separate utensils. After the mother's death, however, the children were not treated badly in fact they were treated like the rest of the children.

A young boy gets tense when he thinks of his sister's marriage. He has no savings and the sister has no jewelery left behind. With the stigma attached to his parents, he says, "Who will marry her? We have no money. I am unable to sleep when I think of this responsibility. She is getting older by the day. But no one helps in this regard."

A young anganwadi helper finds there's

discrimination even in her work place. “If I talk to men they say 'Do not talk to us. We may get AIDS'.”

3.2.2.5 Community/friends help in locating jobs

The community is more helpful than relatives. They help the children get employment this is the only possible help they can give as they themselves earn a meager amount and are struggling to make both ends meet. Most children said their neighbors were unaware of the HIV status of their parent who had succumbed to the disease. A substantial number found that their neighbors helped them find jobs, NGO support, etc. Some were concerned and also provided food. At the same time there are some who do not bother at all. Some children are just satisfied that their neighbors do not trouble them.

A few children said that some of their friends helped them at the time of crisis.

“My peers who have similar problems helped me in finding a job and they had been a moral support for me.”

“My friend who is also a CAA helped me in finding a job. I was very numb when I faced the harsh reality. He helped me out in coping with the situation.”

3.2.2.6 Working and earning for their families

The children not only take on major household chores, like cooking, washing, cleaning etc. but strive to earn a substantial income which can enable them to manage their household expenses. Except for two children (among the key informants), the rest work for 12-14 hours per day as casual laborers, construction workers, in a factory, as shop helpers, as domestic workers and as salespersons.

Their monthly family income ranges between Rs 200 to 2,500 per month. The children's income forms between 30 - 85% of the household income. About 25% of the children are sole earners of the family. Generally the hours of work are not proportionate to the income they earn (except in the case of an anganwadi helper).

Most children are being guided on financial maters by their parents, grandparent/s and sometimes by uncles, aunts and neighbors. However certain children from Tamil Nadu have reported that they had no information from their parents of the debts which needed to be repaid.

Most have siblings who are just one or two years younger than them and they are also earning and contributing to the household income. Wherever there are older brothers and sisters, they are married and live separately and so they do not share the family responsibilities.

3.2.2.7 Problems of indebtedness

Most children are totally unaware of family loans or assets. Some have inherited a family house and almost all have inherited loans taken by their parents. Significant stressors are money lenders and the burden of unpaid loans. The children are burdened at the thought of repaying loans and by the attitude of money lenders. Fear and insecurity prevails and many hide themselves from the moneylenders.

A 16-year-old girl from Andhra Pradesh says: “Why do we have so many problems? When moneylenders come for repayments of loans, I feel very bad. They come for money… at times we have some, so we repay, but at times we don't, then we feel very bad… they come and say so many things. They do not understand our situation. They just want money then we have to arrange for money by asking our neighbors.”

The loan ranges from Rs 1000 to Rs 1, 00, 000. A majority of the loans have accumulated at the time of parent/s' illness.

The burden of loan keeps increasing multifold when the second parent has to be treated for ongoing ailments. Some loans are taken for survival -- when work is not available. Only a few loans were taken for other purposes like buying or repairing a rickshaw which is an asset for earning. Most were unsure of the amount that they had to repay. There was no account kept of amount paid by parents and now by them.

Repayment has been possible in the case of some children who have been loaned amounts by the NGO to repay part of the amount taken from money lenders. Most children depend on mothers, older relatives and grandparents to guide them in financial matters but often these adults themselves might are unable to provide sound advice, ignorant in financial matters or bound by traditional mores rather than pragmatism. With no appropriate guidance or training about dealing with financial matters, some children get caught in an unending cycle of taking another loan on higher rate of interest to repay the previous one.

"A loan was taken for my grand father's death ceremony, also when my mother was sick and for her funeral. We are repaying… but I don't know the details. My grand mother knows them."

"After my father's death, our family was in a total mess. Our problems increased because we became answerable to persons who loaned us money for our father's treatment. We did not even know the amount he had borrowed".

I am burdened and scared thinking of how I will pay my debts. At times I feel that death is the only solution.

An 11- year- old girl child said: "I am the sole earning member. I have to take care of my seven- year- old sister whom I plan to educate. At times, when my mother falls sick then we face problems that time we take money from money lenders."

"Sometimes I won't go for work due to ill health and in that week if I don't repay the Spandana loan money, then it is difficult to meet the basic needs; so again I have to take loan and like that ….the loans are increasing."

3.2.2.8 Informal sector and subsistence employment

Most children (regardless of gender) work in the informal sector as unskilled labor as indicated in the figure below:

They have insecure incomes and are unsure of days of work. Some work part time and continue to go to school. Some are engaged in strenuous unskilled jobs like working in quarries and construction sites, in bars, shops and in the fields. They are vulnerable both to health problems and exploitation. The working hours are extremely arduous for their age. A few have to stay away from the village for work. Only three children are in skilled occupations like tailoring.

Although the children have practically the same workload as adults they get paid a fraction of what the adults get.

"I work in a quarry, where I need to carry stones. I have hurt my hands and legs. It is a hard job, but I earn Rs 50 and Rs 20 (for a bus) per day, this is enough to run my family. But I do not know how to repay my loans. I cannot work harder than this. My mother tells me that when my brother completes his +2, he will take up the responsibility and I can continue my education. (Hope glittering in his eyes)"

"We are born to suffer and born to work" Recreation is a dream. "Adhukkellam oru kodupinai vendum" ("need a blessing for it"). See I do overtime to earn more money. I will watch TV once a week and that is my only entertainment. My work is very tedious but we cannot grumble, we have to do it".

"The long hours of work makes me sick I do not get enough sleep. I do not get a day off. On one occasion, I lied to my employer saying I that I had to go home because of an emergency. He does not like my attending meetings organized by NGOs. I need to work for seven days a week. I am unable to stay with my family. I want to appear for my exams privately but I don't think I will be able to study with the job I am doing now."

When the child asks for a salary increase, employers threaten them with termination, so they have to remain quiet and take what they get. The employers exploit their vulnerable situation.

A 13-year-old-girl said: "Even after working so hard I get very little money. Though we work as much as adults we are paid less the reason we are told is because we are children we don't require so much. But they don't think twice making us work like adults."

"I work for 10 hours a day but I am paid only for eight. We cannot fight back. We will lose our jobs if we do so. The job is so important to us" says a 16-year-old boy.

A 16-year-old boy shares his experience: "My employer's watch was lost and they said I had taken it, so I was also beaten by the owner. They deducted the cost of the watch from my salary so I left the job. My owner found the watch but I didn't d feel like going back as I felt insulted."

The children are quite fatalistic. Bowing to fate they did not have the strength to fight back. The casual nature of employment leaves them insecure and they fear that if they protest, they may not be employed again. At times children are accused of being thieves or of wrong behavior this is just an excuse for the employers to throw them out of jobs or to underpay them. Thus they are exploited both physically and financially and children lack negotiation skills.

3.2.2.9 Hunger and ill health

When children are unable to get work as casual laborers, they are forced to beg for food from neighbors, or borrow money to buy food…else they stay hungry. Most of the family income is spent on food. Some children get the advantage of NGO intervention, whereby the NGO provides the HIV affected families with foodgrains. This saves the families from facing starvation.

Over half the children are affected by some illness. The children complain of stomach problems, headaches, weakness and body pain. Some have boils on their hands, palms and some have developed allergies. They do not go to a doctor they feel it's quite useless as the illness is related to the nature of work also they have very little time and no day off

"I work in a cashew nut factory, I need to remove the outer shell of the nuts, and due to this sometimes I injure my fingers. I work from 7am to 6pm with a break of half an hour. I need to sit continuously, so I have developed stomach pain. I have a constant pain in my lower abdomen. There is no time to go and see a doctor. And I think you know how strenuous my work is. See my fingers; they have lost color. It looks like a man's hand." So speaks an 18- year-old girl.

Reports a 16-year-old boy, "I have boils on my palm -- the hard work I do is so painful that at the end of the day, my whole body aches like anything. This is related to the work I do. So going to a doctor will not help."

"I work in the grocery shop; I am fed up and want change my job. I miss my family too. I have to stay here and feel very bad with the workload and timings. I have developed rashes all over my body and this is bothering me a lot. I sweat also a lot; water oozes out like anything the place where I stand becomes wet. The owner shouts at me and makes me clean the shop. No time for myself and no time for recreation. At times I feel wonder why we I should live." reports an 18 - year - old boy.

It is also probable that children understate the health problems they face. The problems are likely to be ignored since they cannot afford treatment. Falling ill means a loss of daily wages and therefore no money to buy the day's necessities. The only option is to starve or to take a loan.

The children report that HIV positive persons are charged three times more at private hospitals. Certain INGOs provide medical assistance and referral services. Organizations like SHADOWS in Andhra Pradesh and Arulagam in Dindigul have a hospital and hospice attached to their NGO which renders free treatment to ailing parents.

3.2.2.10 Vulnerability to sexual abuse

Some children report that they are teased by immediate supervisors, and also added that they manage those problems on their own. An 18-year-old girl reports that the shop owner talks and comments on women who are passing by in an obscene manner in front of her. He brings in a number of friends to the shop, which makes her uncomfortable. There are no reports of physical abuse. However, children who are working at odd hours are more vulnerable to exploitation.

An 18-year-old girl headed the household when her father died and her mother became incapacitated. She started dancing when she was 14 earning Rs. 300 or Rs 400 per program. "We get lots of money but this has to be shared so we are left with very little. We also have to pay the police because they catch us and take to police station and the owners have to pay and get us back. There are no fixed timings -- when ever I go for program I get money. Usually these programs are in the night."

A 16- year-old girl working in dance performances expressed her dilemma: "I am a dancer so boys also dance with me. They touch my body and make lewd gestures. I have to bear with this if I object, I will not be able to continue. This is very common so I always say that I do not have any problem. Else, my family will suffer because of a lack of money."

A 12- year- girl who is an orphan stays with her grandmother, who is 60 and an HIV positive sex-worker. The girl works till late night in a bar and is addicted to pan-parag, gutkha and liquor. It is said that she is also

abused sexually but she doesn't reveal anything.

A 15- year- old boy who stays with his grandfather said, “When we take the rickshaw and go out people try to abuse me physically and also verbally. Because I am very young people take advantage of that -- I am helpless and can't do any thing.”

A 14- year- old girl who is an orphan and who has studied up to the 3rd standard has an elder brother who does not work. She started working a year and a half ago. ``Previously I worked in spinning mill but for the last six months I am working as a construction laborer…... Initially I did not feel anything, I was just working, but now I realize how difficult it is. I pray to God, that nobody face the problems that I do.” With no family assets to fall back upon, she is now doing construction work for 11 hours and earns Rs.400 per month. “I have no debts but the income I get is insufficient. At times I have nothing to eat. My neighbor gives me vegetables, daal, etc. ...She has sympathy for me. At the same time she is also an outsider. How much can she help me? I feel very alone and often cry by myself. What else to do?” The neighbors say that she might follow the footsteps of her mother a sex worker.

3. 2.2.11 Impact on mental health of the children

The data shows that the parents with HIV/ AIDS develop helplessness and a negative attitude. Due to this, they vent their anger and frustration on the children and are devoid of affection towards their children. There is lot of tensions and conflict in the family. All this affects the children psychologically.

The children can no longer behave like children as they take on household responsibilities without any mental and emotional preparation and guidance from family members. In case they refuse or act ``childish'', the parents (generally fathers) use their ``old method of dealing with conflicts'' i.e. angry, abusive language and violence on them or the other parent usually the mothers. Children live in fear: “if we go against father he may beat mother”. Moreover the children are unable to share these family problems with other children or friends.

Some children develop hatred towards society as they have seen only bitter things in their life. ``They are feeling vengeful and are becoming more adamant and deviant''. In some instances they lack respect for elders.

After the death of their parents, children crave for love and affection. They feel so insecure that they easily fall in love with a person who shows a little care and concern; they are ready to do anything for them. People exploit this insecurity and the community turns a blind eye to these criminal acts.

The range of problems like illness, death, negative attitude of relatives and neighbors, the hysterical behavior of parents and the negative environment in the family creates a tremendous negative impact on the psychological well-being of the children. Most children expressed anger, hurt, sadness, bitterness and frustration. They are in the “why me” phase or blaming God/ fate for what has happened to them. Some are so depressed that they do not wish to live. A few revealed they wanted to commit suicide. Some of the varied expressions of anger are presented as follows:

“I feel sad most of the time. Why my life has become like this? I am not able to overcome my stress. I am becoming duller by the day.”

"I too get angry, but it is our fate that we can never show it on others. Already we are in mercy of so many people. We don't have the right to ventilate our feelings. I bury it … deep in my heart. What else can I do?"

"I also get angry; I have born to see only bitter things in life. Enna Vazhkayo?(What life is this?). I am really frustrated."

"At times I feel sorrowful. (varutham). I feel better when I go out with my friends. We have to take life as it comes. Even if we stand upside down we cannot change our fate."

"When I feel depressed, I ventilate my feelings to my grandmother. But it has not helped me to cope with depression." (Even her voice broke down while she spoke, she is so depressed)

"I feel restless all the time. I am insecure. What I will do in future?"

"Yes I too feel the same way at times. I feel like drinking something and die, but who will take care of my family?"

The long duration of work, managing several family tasks and responsibilities is both physically exhausting and mentally draining.

The children are also upset and discouraged when they become aware of the impending loss of their ill parent or old grandparents. Most resort to crying and staying alone to deal with their emotions as they know no other way of dealing them.

A 14- year-old boy says, ``I have no free time. If at all I do get some free time, I want to spend it in a park or in a place where I see people happy. I want to spend time with family members and speak to them. I feel like watching TV together. But mother is not well and we have to go for work. We don't feel like disturbing her''.

With the support from NGOs, some children have started reading books, playing with friends or toys.

There are no studies addressing the impact of HIV infection on the mental health of children affected or infected with HIV. A recent prospective cohort study designed to examine long-term outcome among HIV infected children and HIV uninfected infants born to HIV infected parents reported an incidence of 6.17 psychiatric cases per 1000 person-years. This was significantly higher than the incidence of 1.70 cases per 1000 person-years in the general pediatric population. The majority of patients were admitted because of depression or behavioral disorders while 47 per cent underwent multiple psychiatric hospitalizations (Denise et al quoted in Chandra et al, 2005).

3.3 Special needs and challenges for the girl child

As the head of the family the girl child faces many more challenges than boys. They are taught to accept discrimination, neglect, violence and abuse. In times of the HIV/AIDS crisis, these discriminations continue and lead to greater problems. The surviving parent scolds the female child if she talks with a male child who works in the similar place. They have to work as adults but in all other matters they are treated as children and have to follow rules laid by guardians and parents. Even casual interactions with boys lead to major conflict in the family. Some female children have to stay alone during the night and they are likely to become easy targets of sexual abuse by neighbors, relatives and outsiders. Their insecurity is likely to be exploited by unscrupulous people. There is no action taken against them as the children are not ready to take the risks of informing the higher

authority. They are more concerned and satisfied if their immediate needs are met.

A 17- year- old girl feels so responsible towards her family that she ignores her needs and health. She rarely eats and consumes more tea. She never carries her lunch to the shop, because food will not be adequate. “When I see the food bowl with less rice, I do not feel like taking it for myself, I want my family members to have it”. She tells her mother that her boss provides her food. On most days she eats only one meal and that too at night. She complains of head ache and stomach pain.

“I am 17 but they got me married because they feared that none will come forward to marry me after my mother's death. Even after marriage, I help my family. I have been working for the past seven years”.

A family of four sisters, a sick mother and a grand daughter living together, does not have a male member in the family, nor any support from any male relative. They face threats, harassment from their neighbors. During one of the neighborhood conflicts the neighbors broke the door of their house. When they asked them to replace the door, they threatened, “We will chase you away from here; behave yourself”. They have to listen to all kinds of people as they are scared of their status in the society.

An 11-year-old was sexually abused after she lost both the parents to HIV. In course of time she changed to such an extent that she would herself call people home for prostitution. This happened because she was left all alone with no adult protection and care and she did not have any proper guidance.

3. 4 Perception of Impact of NGO interventions

The NGO staff believes that after the Home Community Based Care and Support (HCBCS) program started by India HIV/AIDS Alliance, the community has increased awareness of HIV/AIDS in Andhra Pradesh. In the East Godavari district, all Government departments know of HIV. This could be because of the work of the APSACS and NACO. The staff also said the District Collector is very dynamic. Through *Balasiksha* groups, awareness programs on HIV/AIDS were conducted. After this there was a change in the community and people are freely talking to children affected by AIDS.

3.4.1 Attitude towards the Self Help Groups and their contribution

The community's attitude towards the self help group (SHG) of women has changed. The SHG members are not called names and people do not talk ill of them openly after years of efforts by the organizations. Earlier when they visited the community to conduct meetings and awareness programs, the community members used to say that ``they were bad and immoral and that is why they are propagating for ``immoral people''. “But the situation is changed now, the community members greet us, invite us in their home, it has taken a long time for the change to happen in the community.” (SHG in focus group discussion).

In the operational areas of the INGOS, the self help groups help them to get food and to continue their education. In other areas the self help groups have started an account in the name of the children they have adopted and save Rs 100 every month in their name. In some cases, the bank managers donate Rs 100 every month for the good cause of these children. But this support is just a one

time support and not creating any major change in the lives of the children.

3.5 Cases of extreme vulnerability and exploitation of the children heading households

The following case studies represent some unique examples of children where family members are scattered because of work and repayment of loans. In the other case, the youngest daughter out of five siblings has taken over as head of the family. The details are given below.

Case study I

A 17-year-old girl who studied upto primary school lives in Coimbatore with four siblings. Two of her siblings, the eldest brother and sister are now married and live separately. She says the family has not received any support from this brother and other married sister. The family has a debt of Rs 50,000 and is paying the interest.

She takes care of the large family and the infected sister (who lost her husband to HIV) as well as sister's infected daughter. The third sister is unmarried and also earns but earns a meager amount. The whole family is dependant on her income. She has been is heading the family since she was seven. She said “I have to earn, my married sister and my brother are not interested in helping us. My brother-in-law abuses us. Even when my sister offers some small help to our family, he makes it a big issue. Therefore, I started earning. Being the youngest in the family, I started earning more than everybody, so all the responsibilities fell on my head. Seeing the situation, I could not sit quietly at home. I am bold also so I managed to get a job. I have the responsibility of taking care of everyone and I am much worried about our Paappa (sister's baby). She falls ill frequently.”

Problems

She feels overburdened at times with work and responsibility. The hardest part is the medical expense of the infected sister and her child. The major problem is in managing the financial problems of the family. One of the sisters of the respondent shares the financial burden. At times there are conflicts between them.

When the money lenders come and shout at her workplace, she feels like committing suicide. She always feels that they should all die as a family as there is no scope for living further. She wants to live with dignity. If that is not possible, she will try to end her life.

Work

The respondent is working in a photo framing shop for years. The owner and his wife take care of her well. They provide her with loans in times of emergency. She is very sincere in her work and does the work perfectly. Though the work is strenuous, she manages to do it. At times, the owner leaves the shop to her and goes for a trip and she manages the whole show. The work is so hectic and at times when she has to cut the metal sheets she suffers severe body ache. She never takes a day off, and works even on Sundays. She starts at 7 am in the morning from home and returns by 9p.m

She never works at home, “I will not even wash a spoon, because I am so tired at the end of the day. I rarely stay at home. That is how I do not interact with neighbors. I do not have a single second either for relaxation or recreation. Sometimes I feel so frustrated with this hectic routine of mine".

Attitude and behavior of relations

When her uncle was ready to marry her,

The family made all preparations for the wedding. However, when he asked for dowry and demanded 80 grams of gold, she became very dejected. The family could not afford this although the employer promised her eight grams of gold but she had only two. She disapproved of the way they demanded for dowry despite knowing of the family's condition. She also felt they were greedy and would prevent her from helping her family. She refused to get married and decided that marriage was only a dream and she should not think of it any more. She has developed a hatred for men; she thinks that all are interested in monetary gains. Now her ultimate goal in life is to take care of her family and to give appropriate care to her father.

She also has some problems with her brother's family. The sister in law is very rude to them. The brother is not helpful and also creates lots of trouble to them. He comes drunk sometimes and yells at everyone and demands for money. “Oru udhavi kidayathu aanaa ubathrivam mattum undu” (Not a single help but only troubles).

Needs and challenges

She is proud that she is able to take care of the family, but at the same time feels overburdened with the responsibility. She also has some wishes like, new dresses, wearing flowers everyday, but even these small wishes are not fulfilled. She wishes to have a small home 'Chinnatha irundhalum sondhama oru veedu venum” (Even if it is small we need our own house), because most of the income is spent on rents. Since all of them are women in the family, they are worried about their safety. In fact at times she has to assume the role of a man in the family. She thanks the Lord that she is born with enough courage to tackle problems. She identifies herself with one of the popular TV media characters (Radika) who is found to play a bold role. She also wants to cope up with all her problems as the character does in a serial.

Observation

The respondent is more concerned about her family. She looks mature and courageous enough to handle problems. At the same time, she appeared quite tense and anxious. She looked pale with dried lips. She had not eaten anything even at the time of the interview. When she spoke about her broken engagement, she looked very disturbed. She did not wish to speak about her father even when probed.

Case study-II

The respondent is a 17-year-old girl from a rural area. She completed her SSLC (High School). She has one sibling and an ailing mother. She lost her father three years ago due to AIDS. The mother is alive and not HIV infected. However, she is not well, because she had three surgeries for stomach ulcers. As she is not able to work much, she has taken up a job as a house cleaner in Kerala, where she stays. After her father's death, the whole family is scattered, far from each other but they occasionally meet.

Her younger brother is 14, physically challenged due to polio and cannot walk. However, he has been forced to take up work in a photo lamination shop in Tiruvallur, away from home.

She stays with a distant relative (grandmother) in her native village. She cannot move out of her home due to the heavy debts incurred for the father's treatment. She says that she has not maintained any account but she keeps paying out whatever she earns every month.

As head of the family

She took up the responsibility as head of the family three years ago, when her father died all of a sudden. He was infected with HIV during a surgery. As she was the only healthy person in the family, the family became her responsibility. She has never felt it as a burden. “We never anticipated this twist in our life. This crisis forced me to quit my education. I wanted to complete higher secondary school at least. But I was not able to afford it.”

A year ago, her brother and mother felt that they should not overburden her and started to work. Her mother sends her Rs.300 per month and brother is not able to send money because his earnings are just sufficient to cover his own expenses. She earns Rs.800 per month. She says the toughest part is to manage the money. She has to spend it for their daily expenses as well as to repay the loans.

When her father was alive he would help his relatives. But after his death, none of the relatives helped the family. “We are treated like sinners that I am not able to bear this. I feel like dying at times. Then I control my feelings because then my brother has to struggle a lot. I need a better job so that we can pay off the loans very fast. Paying the loans is the toughest part; I tremble with fear when the persons who have loaned us money visit our place. Even our relatives who had given money push us terribly to repay it. I am not at all able to sleep. I am getting headaches almost every day”.

Work and income

She is working in a fancy store which she does not like. The owner is a male and when his friends come there they use ``dirty'' language; they speak of women's physical attributes in a vulgar way though they have misbehaved with her. She says, “I feel like killing myself when I hear them talking, but I cannot quit the job until I find another job. I go there in the morning and return at night. All through the day I do not get to sit. So in the night I get severe leg pain. Even that is bearable; but the tension of repaying the loan is not bearable.”

Trauma

The respondent seems very desperate and traumatized. She wants to stay with her mother and younger brother. The sudden transformation in their lifestyle is too difficult for her to cope with. She was in tears at the time of the interview. She was a pampered child and is now exposed to the harsh side of life. Even after getting her mother tested negative for HIV, she is still worried if her mother could be infected. The trauma she faces is tremendous and she is fighting a lone battle with her family members far away from her.

Needs

The respondent wants to repay the loans fast, so that she can stay with her mother and brother. She also wants a job, wherein she works with more dignity. She has a desire to complete her higher secondary education at least on a part time basis.

Observation

The respondent is timid, sensitive and anxious. She was crying throughout the interview. She is very attached to her mother and brother. She still grieves for her dead father.

4. Community foster care for children affected by HIV/AIDS

This section highlights the need for extending foster care to children affected by HIV/AIDS, the pros and cons of foster care as an option to the biological family, process of foster care, adjustment to the new environment, needs of the foster children assets and debts, gender issues, suggestions from Field staff to make foster care more effective. Few case studies are presented at the end of this section to raise the needs and challenges faced by the foster mothers and the children.

4.1 Extending foster care to CAA

Foster care is the process of temporary placement of the child with families who are not related to the child. It emerges as a need in the context of no close relative coming forward to take responsibility of bringing up a child in a normal environment. This is not a new concept and has existed since the process of acceptance of legal adoption. Communities have responded in cases of parents falling ill due to TB or other conditions and families have come forward to look after children of their neighbors for a temporary period. The Juvenile Justice (Care and Protection of Children) Act 2000 contains certain provisions for foster care of juveniles. The Act provides criteria for the families taking children in foster care which is permitted upto five years only.

India HIV/AIDS Alliance has through its lead and field NGOs extended this concept to the care of children affected by HIV/AIDS.

4.2 Need for community foster care

HIV/ AIDS awareness has not yet removed all the myths surrounding the disease. It is for this reason that one rarely finds that a relative comes forward to take care of these children. In some cases the NGO has witnessed that children who are sent to live with relatives are abused and neglected. Thus they prefer to get away from those relatives and stay on their own and earn for themselves and lead a life of their own.

> “We were staying in the house and after mother's death we went to our maternal uncle's house we stayed there for two days. My maternal uncle's children came to us and told us that “My father said neither to play with you nor eat with you. He also asked us not to take anything from you. The children are young so they came and told us everything. My uncle has also arranged for separate plates and glasses for us. We did not like it so we quietly left their house and came back to our house.”

Foster care started when the NGOs placed children for their well being with a known family. It is still on an experimental basis and has not taken proper shape. Some field staff said that they had not worked much on foster care in their field area.

However, they feel that it is a better option for children affected by HIV/AIDS, and it should have the full consent of the foster family members. Instead of staying alone they can stay with some adults so that they are protected from exploitation in the community. The NGO staff said that the children are`` like flowers'' and facing trauma continuously makes them sick and tired to continue on

their own. So when they are given this option the children readily agree. They do not think of the repercussions. They surrender to this fate completely.

A field staffer from Tamil Nadu reports: "The girl was desperate and she was having a tough time in her relative's house, so she readily accepted to be placed in foster care. But I ensured meetings to make the child to talk with them before placement. It worked well for both sides because the child wanted a place to stay peacefully and the family also wanted a child to fill their home."

The NGOs felt that placing children in foster care was not an easy task. In the villages there are very few who are ready to provide foster care. People are ready to take care of partial needs rather than the complete responsibility of a child. However the situation is changing as the NGOs and self help groups have begun providing for the child's basic needs. In some cases the child is placed with a family who does not have biological children.

In Andhra Pradesh, the families of *Dommari* community are also looking after the orphan children voluntarily without any expectations; nobody has to tell them to take care of the children they themselves come forward to help the CAA.

4.3 Pros and cons of foster care

The NGO staff, the self help group members and some of the children from Andhra Pradesh advocated foster care as the better option than hostels or orphanages for CAA. These are the reasons:

- The upbringing of children in the home environment was better compared to institutional care. In the house the child gets love and affection along with food, clothing and shelter. This is not the case in a hostel.
- In orphanages and in hostels, children are called orphans but not so in the home situation.
- The child also experiences the joy of having elders to care for him/her if he/she stays in the home than in the hostel.
- They are protected from exploitation in the community
- The burden on children will reduce - provided the family is genuine and ready to take up the responsibility of the child.

A proper monitoring system was suggested to check the status of the child in the foster family. While the foster child would not be considered a biological child, and there might be differentiation, what was more important was to see the child in a family set up.

The children under foster care reported that they are more comfortable. They prefer to be in foster care rather than in hostels.

A 14-year-old girl says: "In my opinion foster family is the better one where we will have. Here we have Peddamma (paternal aunt), Peddanaana (paternal uncle), and Amamma, -- this is not there in a hostel."

"The siblings of the biological family talk very freely with me. My foster mother treats me equally like their children."

However, data from Tamil Nadu presented a completely different picture-a negative attitude towards foster care. The self help group members showed some apprehension about community foster care. Though they agreed that the children would be in a home environment, they were doubtful about the child's comfort in a stranger's family. According to them, the children cannot be themselves. They also felt that there would be a greater differentiation in the care provided for biological children and the foster children.

The Tamil Nadu field staff felt that community foster care is a better option, but expressed reservations. They felt that the child's opinion should be sought first. The placement should be based on the child's interest and it should not be a forced one.

They also suggested that the motive of the foster family should be assessed before placing the child. The motives for taking children under foster care varied: In case of female children it could be because they can make them work without payment. This was based on the experience of children suffering in the homes of their own relatives; thus there was skepticism about care to be provided by strangers.

A self help group member shares, “I know a family where the children were taken care of by their aunt. Her husband yelled and screamed at her everyday. There was conflict in the family. Do you think the children would be happy there when someone is constantly fighting because of their presence? They slowly moved out of their home. When this happens in the own family, how can a CAA be comfortable in a strange family? (Sonthame indha latchanam, Asal enna pannum)”

Disadvantages listed down by NGO staff are: re-location at a strange place; separation from siblings; anxiety and confusion about their identity. Continuing education in the same school also becomes a big question.

The interview with the foster parents and foster children in Tamil Nadu revealed that the expenses of the children are taken care of by the foster parents, and they do not expect anything from the NGO. However, the interview with the foster mothers in Andhra Pradesh revealed that they expect monetary benefits from the NGO. But they also added that they will continue taking care of the children even if they stop the monetary benefits. More probing was required on this issue.

“We have to adjust as we have decided to be as foster parents. We are not bothered about what NGO gives us. The organization also applied for Government schemes to get some support for us. But we haven't got anything yet. Let us see… but we think that we can look after the children”

When asked how much money they required to take care of a child. The response: “According to me we require Rs 1000 per person per month. This would be sufficient till the child is 15.”

“Around Rs 1000 to Rs 1500 because we have to look after their education and other needs. If the NGO can give us something then it will be easy for us to take care of the family.”

4.4 Process of foster care

The NGO staff felt that the children should be adequately prepared and oriented to the foster family even when the parents are alive.

From the children's point of view, to leave their own family when their parents were alive, was a painful experience. There were certain attempts made by the field staff to prepare the child for the new environment. For instance, the NGO placed a 13-year-old girl in the foster family while her mother was alive. The girl remembers how it was painful it was for her to leave her ailing mother,

“I felt sad to leave my mother and come to this house. Two days before she died I went to my house and I stayed till my mother's death ceremony. I felt more pain when my mother died”.

“I felt sad when my mother left us with the foster family and asked us not to meet her again. She did not tell us anything she left us and did not come again.”

The orientation to the children is mostly done by the field staff. In certain cases, they take the initiative seeing the condition of the

children. In other cases, the parents have approached them for help

A 13 years old girl child recollects the advice given by the NGO staff: “In the foster family everything will be nice, you will have parents, sisters and brothers. So it is better for you to go and stay there”

4.4.1. Adjustment to the new environment

Almost all the children responded that they were very anxious when they were transferred to a new family setting. When first entering the foster family's home, the children are very tense, thinking of how they will be treated in the new family as some of them had already undergone bitter experiences in their relatives' homes.

A 12-year-old girl recalls: “They did a small pooja and from there they took me to the house where I stay now. I was so tense and anxious. I do not know who they are and how they would take care of me, when my own blood refused to keep me with them (flow of tears)”

A 15-year-old girl said that she felt very bad when they took her to the foster family: “If my mother did not have HIV/AIDS, I would have stayed in my house like other children.”

The foster mothers also reiterated the same fact: “Initially it was difficult but slowly after two or three months they adjusted.”

“I did not make any special arrangements for the children, they were hungry, which is their main problem. I fed them and gave them all kinds of facilities like food, clothing, education and shelter, this eased adjustment.”

The foster mothers shared that the whole family is supportive. When asked about the adjustment between the biological children and foster children, they responded that they have never faced such a situation.

“I did not come across any such kind of problem and our children show much more affection to these children. My daughter who is married wanted to take them along with her but I did not allow this. She is very fond of them.”

“They go to school with my children and play together”

The foster children also shared that they do not have any conflict with the biological children. They are very fond of them and maintain a good relationship. “The biological children talk very freely with me.”

However, the data showed that the older people in the family did not accept them. In a couple of cases, the children have reported that they do not talk to these children. The children are also instructed not to talk to them.

4.4.2 Needs of foster children

The children placed in foster care had needs similar to other children. This was revealed by both the children and the foster parents when asked to list their needs. They identified needs like educational expenses, clothing, food and medical expenses. The NGOS and foster families were trying to fulfill their basic needs. But this was not sufficient for the foster children.

When asked if her needs are fulfilled, a foster child from Andhra Pradesh replied: “Schoolbooks, bag, uniform, school fees and tuition expenses are taken care of by the organization. The organization also gives provisions for both of us. So the money that she earns is for those three people only”

“In the beginning I wanted school bags and clothes but now SHADOWS (INGO) is giving all these things. Once in a while my Peddanaana (foster parent) gives Rs.20 for both of us but that money is not sufficient.

Whenever my teacher asks me to buy anything like map or chart and also when I see other children buying and eating, I cannot buy anything due to lack of money."

The children were very reluctant to expose themselves with regard to their emotional needs but at times they did say that they missed their parents a lot. When asked to draw a family tree, they drew it both for their biological family and foster family. In that they expressed how much they missed their biological siblings and parents.

The children also shared that they did not want to burden their foster family with their negative emotions. Either they preferred to keep these to themselves or they discussed and ventilated during the children support group meetings.

4.4.3 Assets and debts

According to the children, they did not have any debts to be paid and in a single case, the child reported that the money lender had assured the child not to worry about the loan.

Three children reported that they have a house and were getting a rent of Rs.200 per month which was deposited in their name by the foster parents.

A 15- year-old girl says, "I have my own house from which I get a rent of Rs.200. That money is been saved in the post office on our name by my Peddanaana. (foster parent)."

A 10-year-old boy says, "My father took a huge loan but repaid only half of it. After his death the money lenders told us we don not have to repay the loan."

Another 10-year-old boy says, "We have our own house but nobody stays in it as we are with the foster family. My grand mother said she would sell the house and give the money to my paternal uncle to construct a new house. She said we could stay in our uncle's house but my elder paternal uncle did not agree to this. He said that the house should be left as it is so we will have a house once we grow up."

4.4.4 Gender issues

What was significant was that most of the children placed in foster care were girls. The relatives were more open to take the boys than the girls as they believed that ``the boys will bring them income while the girls would only bring in problems''. None were ready to spend money on their marriage.

After the death of the parents, the male child is permitted to continue his education or he can work for some time. In case of the female child, the foster family gets her married at the earliest, so that they are not left with the risk of having an adolescent girl at home for a long time. They feel free once their duty of getting her married is over.

"An incident from Dindugal shows how gender discrimination gets aggravated in case of HIV/AIDS. An adolescent girl was paid Rs 30,000 advance to work in Tiruppur on contract basis. After the end of the agreement, the foster parent arranged for her to get married. And the marriage expenses would not have exceeded the amount that the girls have earned in the contract."

4.5. Making foster care more effective

The staff made the following suggestions:

- Sensitizing and orienting foster parents and children
- Children's opinion should be sought on whether they are interested in staying with the foster family.
- Helping the foster families to earn some income through income generation activities to take care of the additional burden.

- Better to place foster children in families which can afford to manage the needs of the children.

In contrast, according to the self help group from Tamil Nadu, the best model was that of institutional care where only CAA could be together to facilitate better understanding of each others' problems. Another option suggested was institutional care within the community, that is, about 20 children could live together in a house in the same community. This was because the children do not have any rights in a foster family; they cannot demand their needs as they do with their biological parents.

5. Case studies of Foster care

Case study: Case Study 1

A 23-year-old housewife, wife of a construction worker had two children of her own. She took a seven-year-old girl for foster care.

After the death of the parents, the grandmother took the male children with them to their native place and deserted the female child. The respondent also felt that this happened because they felt the male child would have an income generation potential. The female child was not cared for and had no place to go and the neighbors isolated her and treated her very badly. This made the respondent give the child shelter in her house. She was provided food, shelter and comfort to the deserted child. But she was not sent to school.

She found her in-laws were supportive. The foster child is comfortable in the new atmosphere. The child calls the respondent as akka (sister) and her husband anna (brother). There is no sibling rivalry as the children are found happy among themselves. They play with each other. The neighbors are indifferent.

Case study 2

A 35-year old foster mother from Andhra Pradesh was married for 19 years but had no children of her own. The neighbors, infected with HIV, had two daughters. Due to the ill health they were not able to take care of them. The second daughter was also had been diagnosed with HIV. The child was three months at that time and the doctors suggested waiting till 18 months for the confirmation. The relatives and other neighbors of this family neglected them completely.

The child needed special care. The biological parents were very ill. The respondent and her husband putting the burden on God took her to their home and took care of her very well. At the end of 18 months the doctors said that she was HIV positive. Yet they continued to take care of her with same care and affection. In the meanwhile the biological parents died when the child was five, and the elder daughter who was six years old, also came under their parental guidance.

The loss of both parents by AIDS created stigma. There were a number of pressures on the husband and wife to stop caring for the two foster children. The maternal side gave her support and the respondent's in laws started putting pressure on them to leave the children in an asylum. The neighbors also advised them to adopt healthy children from a good family. But they were already emotionally attached towards the two fragile kids. Both husband and wife were very firm and they started keeping the children with them.

The couple is working on daily wage basis. Her husband earns Rs.80 per day. The respondent earns Rs. 30 per day. Because of the ill health of the second child, the respondent has to taker leave frequently.

Today the foster children are considering the foster parents as their own. The little

one does not even know that she is a foster child. She does not know the biological parents. The elder one also is very much affectionate towards the foster parents. The children were bonded to them in a natural way. They took care of them like their own children. They never had to make any special efforts in comforting the child. However, the recurrent problems given by the in-laws, they had to shift from Andhra Pradesh to Coimbatore. They also wanted the children to be happy in a peaceful atmosphere. The frequent conflicts create a fear in the children's minds. So they decided to shift their native and they settled down in Coimbatore.

She feels that the change in her life has been on the positive side. The children have brought them cheer and happiness and they feel that they have a purpose for life.

She identified the needs as follows:

- If the child is normal the needs are the same as that of other children like food, safety and shelter. But if the child is positive the needs are tremendous in terms of continuous care, special nutrition, medicines. The respondent takes leave frequently as the second child falls sick often.
- They have a limited family structure and they are able to meet the needs with no constraints (except for the medical needs).
- The NGO is helping them in terms of medicine, referral and guidance.
- The programs that the NGO conducts for support groups are really an energy buster for the children.

Case study 3

As I had no proper interaction with Peddanaana and Peddamma's family initially I had some fears to go to their house. I thought that I won't gain anything by feeling sad as these people are looking after me so I should forget everything and study well. None of my relative knew that my father died of HIV -- he did not let me come near him because he feared that we would get AIDS. Two days after the 10th day ceremony, we went to the foster family. My father requested the NGO to spread the word that two children were up for foster care. My sister (daughter of the foster mother) was working in the organization and told her mother. They organized meeting in the community hall and they came forward to take us. We were happy when we went there after going there we went to school and the other children became our friends, even though they knew we were orphans. We don't have any problems in the foster family. Even our neighbors are good. They take care of us and are interested in taking children for adoption

Case study 4

For a year and a half, a 13-year-old girl was undergoing a lot of humiliation and hardship in her relative's home. After the demise of her parents, she was sent to a family with no biological children. The child is very comfortable and all her needs are met by the foster parents. She has memories of her biological parents, but does not share them with her foster parents thinking it would upset them. Otherwise the child is more comfortable in the family. The grand mother has not accepted her presence in the family. She does not even speak to the child. The child said that she is used to it and has not attempted to speak as it will lead to conflict in the family. The foster parents are motivating her to study well. And she is the topper in the class. She is now staying in an entirely new locality. But

because her transfer certificate had her biological parent's name, her identity is disclosed as a CAA. She does not have a single friend in the school. She misses her previous school friends very badly. But she is very determined. She says that she will study well irrespective of the problems the peers give her at school. She is grateful to her foster parents and she will work hard to earn a good name for them also.

6. Recommendations

The study has brought out certain noteworthy findings. It is very obvious from the primary as well as secondary sources that the children affected by HIV/AIDS are left with inadequate resources and are excessively vulnerable to exploitation. The scarcity of policy guidelines also aggravates the problems. The only positive sign is the increasing support from the community, which again seems negligible before the escalating numbers of affected children.

The vulnerability of AIDS orphans starts well before the death of a parent. Children living with caregivers who have HIV/AIDS will often experience many negative changes in their lives and can start to suffer neglect, including emotional neglect, long before the death of the parent or caregiver.

Children can be empowered by regarding them as active members of a community rather than just victims. Many children already function as heads of households and as caregivers. They are a vital part of the solution and should be supported in planning and carrying out efforts to lessen the impact of HIV/AIDS in their families and communities.

Based on the data, several recommendations have been listed for child headed families and foster care under the following subheads:

1. Programmatic
2. Policy
3. Research.

6.1 Child headed households

6.1.1 Programmatic

6.1.1.1 Developing support systems

1. Support Groups: Both the NGOs and the Government need to encourage the formation of support groups for people with HIV/AIDS where they meet others with the illness and discuss common problems, feelings and ways of coping. Support groups for children should be developed separately so that they can talk to each other more freely. Parental support groups can help them to cope with their terminal illness, with their emotions and frustrations and to communicate with the children.

Government and NGOs could offer treatment for all opportunistic infections as well as antiretroviral treatment at clinics and health centers, wherever possible. This will prolong the lives of parents and reduce the burden of illness on the family.

Setting up home-based / mobile health care projects in communities will facilitate the care rendered to the people who are ill at home and workplace. Step-down facilities linked to hospitals for people who are discharged and cannot be cared for at home can also promote the care available to the PLHA which lessens the burden to a significant extent from the shoulders of the younger ones.

2. Mobilizing communities: Effective measures need to be taken by the NGOs to mobilize support from the community to provide both immediate and long term support to the families and children affected by HIV/AIDS. The active role played by the

self help groups in community mobilization needs to be up supported and up scaled.

6.1.1.2 Empowering the children and protecting their rights

1. Life skills training: The children can be provided with life skills training whereby they are able to cope with newer challenges facing them, with the death of loved ones. They need to learn coping skills, self assertiveness, negotiating skills, money management, and decision- making.

2. Health care services: Children's specific health problems should be identified and health care made accessible to them at convenient timings. This is to encourage children to take care of their health problems as there are instances where the children neglect their health problems as work becomes their priority. Although there was a reasonable knowledge of HIV, it is felt that child headed households are at risk of HIV infection due to their need to support themselves and the lack of protection they have in the community. The health of children in CHH will have to be monitored from time to time till they become adults.

3. Education: Most of the children are keen to continue their studies. The school needs to be sensitized to the special needs of these children who are carrying multiple burdens of house work and labor outside the home and, hence, may not concentrate on classroom teaching.

School programs need to be enhanced to ensure that children who are affected by HIV/AIDS get the necessary support to stay at school. For example, if a child drops out of school and teachers find out that parents are ill, the child should be referred to projects for support and the parents should also be referred to the support and treatment programs that exist. Otherwise the children can be referred to non formal education centers with flexible education services so that they can continue their studies as well as work for their livelihood.

The organizations can conduct some special sessions on HIV/AIDS related to different subjects about rights of PLHA and their families

The schools can provide life skills development program and if the schools are not equipped for the same the organizations can take up the responsibility.

4. Vocational Training: The organizations can provide vocational training so that they better qualified and secure in the future.

Sponsors can be identified to reduce the burden on children. The donors can either provide them with education or nutritional supplements or medical care according to their convenience.

6.1.1.3 Psychosocial support

Psychosocial support is a must to all the children affected by AIDS and especially to the children heading their households. The children are exposed to the harsh realities at a very tender age. The stress they face is tremendous and during the interviews the children were filled with suppressed emotions. Their needs are met very superficially but more interventions are required in this regard to make them grow as healthy adults. The deprivations they had might lead them to end up in developing certain unhealthy practices making them vulnerable to HIV and it is a vicious circle.

Inadequate attention is given to prepare the child for bereavement. The children have not overcome the loss of their parents. The role reversal happens all of a sudden which affects the children's mental health to a greater extent. So the organization should ensure that they conduct programs for the positive mental health by ameliorating the

emotional distress among children. The staff should be trained in crisis management and dealing with psychosocial needs which encompass the diversity of children affected by AIDS and their problems.

6.1.2. Policy

6.1.2.1 Fulfilling basic needs of hunger and poverty alleviation

Persons living with HIV/AIDS and their families should be linked with poverty alleviation projects. Efforts should be taken to make sure that they have easy access to the available grants and government support. Nutrition, vegetable-growing and wellness projects should be supported to help people stay healthy for a longer time. Small scale help from the community should also be mobilized like the one palm rice scheme of the self help groups.

6.1.2.2 Financial matters

Most families are indebted to the local money lenders who charge horrendous rates of interest and this is passed down to their children after their death. The money lenders could be brought under some legal restrictions by the government and the NGOs need to facilitate the return of the loans.

6.1.2.3 Hostels for single parents and their children

In families that have no family assets and no one to take care, there might be a need for providing hostels. Most children would prefer to stay with parent/s and siblings. So there is a need for hostels for homeless PLHA mothers and children together, where they can be given basic meal and necessities. Wherever foster care is possible, the attempt should be to keep the siblings together.

6.1.2.4 Stringent measures against stigma and discrimination

Some children live with constant fear that their status might be exposed at any time and they will have to face neglect and abuse. Others live facing abuse and neglect even from their own relatives which is a factor of greater stress among the children. Government should bring in certain stringent measures to reduce the stigma and discrimination which affects the children to a greater extent. The local organizations and support groups also can play a significant role in bringing down the stigma and discrimination by identifying such instances and to ameliorate the same and developing effective strategies based on their best practices.

Every community should be involved in identifying children affected by HIV/AIDS those who are living with parents who are ill, those whose parents have already died, and children who have HIV/AIDS themselves. A multipronged approach is required to promote the quality of care to the diverse problems of the children heading their households.

6.2 Community foster care

6.2.1 Programmatic recommendations

6.2.1.1 Mobilizing community support including Panchayats

There is a need for more awareness programs that focus on issues like non-discrimination, rights of PLHAs, and child rights and community responsibility, so that the community accept and take on foster care themselves.

6.2.1.2 Orientation to foster care

Sensitizing the foster parents is a must before giving the child for foster care. The organization should ensure that they properly orient the foster parents and their children as well as the foster children regarding the process. Preparation of children is advisable before placing them in the foster care. The child can be introduced to the foster family

which can be done as part of end of life planning of PLHAS. But at the same time measures should be taken that the child should stay with the parents during their last stage. Dislocating them from the parents at their last stage puts them in greater stress as well as a scar that can never be healed.

6.2.1.3 Fulfilling needs and protecting rights

1.Education

Poor families find it difficult to continue to send their children to schools. Moreover, orphans may be the first to be denied education when foster families cannot afford to educate all the children of the household. Sponsorship schemes for the education of foster children should be initiated by the organizations.

The teachers need to be sensitized to reasons for the foster children being shifted to a different school, and also to maintain confidentiality with regard to the details of the child's family history.

2. Nutrition

Special health and nutrition programs can be introduced in the families that undertake foster care so that their health and nutrition needs are not undermined.

3. Emotional needs

Somehow the children are getting satisfactory material needs but their emotional needs are left unfulfilled. Their emotions towards their biological parents and lost siblings are buried deep down in their hearts. They are in a dilemma to share it with their foster parents thinking that it will hurt them. Efforts need to be made to lessen their negative emotions because of their miserable past.

4. Quality of care

There is need for constant monitoring (by Government organization/NGO/Community members) of the physical, emotional and mental development of the children so that cases of neglect and abuse are prevented. Monitoring mechanisms need to be developed and implemented by the local organizations.

Although most children and foster parents said that they had adjusted well to the new homes and its members, there might be a need to constantly encourage them to communicate their feelings to each other and to express feelings of love and trust.

5. Support to foster families

Foster care families would benefit from support. Effective support mechanisms include visits from community volunteers, modest levels of material support and training in effective parenting.

Helping the foster families to learn some income generation activities and giving them income generation programs will facilitate them to give better care for the additional children. Periodical meetings need to be organized wherein they can share their difficulties which should be sorted out in time.

6. Gender issues

The organizations should orient the foster parents to treat both genders the same way. Boys can stay back and study or work whereas they are getting the girls married at an early age. Sensitizing on gender issues is a must and the organization should stress on the importance of education for girls.

7. Legal assistance

This may be required to protect the assets of the children which may be in the form of property or rent etc.

6.2.2. Policy Recommendations

1. Setting up community childcare committees

These will help provide day care, crèches,

community food centers, so that the children get emotional and material support from the community without exploitation and abuse.

2. Enrolling names in foster parents' ration cards

There might be a need to see that the children's names are enrolled on the ration cards of the foster families and their status and identity is maintained. Also decisions regarding change of name in the transfer certificate and school records should be taken after a joint meeting with the foster child, parent and field staff.

3. Protect legal and human rights

Much can be done to ensure the legal and human rights of AIDS orphans. Many communities are now writing wills to protect the inheritance rights of children and to prevent land and property grabbing (an adult attempting to rob orphans of their property once the children have no parents to protect their rights).

4. Need for clear rules and regulations

Foster care seems to be emerging as a positive alternative for the children orphaned by AIDS. The existing foster care facilities do not follow any patterns or norms. It has emerged as a temporary solution for the orphaned children at the community level. To make it an effective intervention, the government and non governmental organizations should formulate norms for foster care. The norms and conditions of foster care, the duties as a foster parent and the boundaries of foster care should be clearly outlined.

5. Monetary support

The Department of Women and Child can develop and float a scheme of providing monetary support to families ready to take CAA for foster care.

6.2.3. Research Recommendations

1. Limitations of focusing on a single group

This study only focused on children who were not living with their extended families and other relatives. Hence, it gives an incomplete picture of the range of issues related to temporary caring of CAA in different types of family structures. There is thus emergent need to undertake more in-depth studies on foster care to come out with better models of alternatives to the biological family. These studies should look at issues of gender, planning for the future of the child, effect of age difference between the children and the foster parents, grant receiving and non-grant receiving families, those with biological children and those without, etc.

2. Need for monitoring and evaluation indicators

While community foster care may be the better alternative available to keep the children in a family setting, there is need for proper monitoring mechanisms to ensure the well being of the child. Monitoring and evaluation indicators need to be developed for this purpose till the families are ready for long term care through adoption.

7. Conclusion

This study is not exhaustive but has raised significant issues pertaining to children heading households and community foster care. There is definite need for more in depth studies on foster care, which can only be a temporary measure for CAA. To protect the legal rights of the children, they would need to go in for adoption according to the current laws.

Ideally, every child has a right to a fulfilled life, and should not be carrying the burdens of a sick family. The concept of the child heading the household goes against all rights that are due to him/her.

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