

Moving forward

A report on pioneering responses to children affected by HIV/AIDS in Andhra Pradesh, India



A report by Vasavya Mahila Mandali, produced in collaboration with the International HIV/AIDS Alliance

Vasavya Mahila Mandali (VMM)

VMM is a non-profit, non-governmental, secular, voluntary organisation working for the all-round development of women, young people and children. VMM is India HIV/AIDS Alliance's Lead Partner in Andhra Pradesh, and implements a home and community-based HIV/AIDS care and support programme through seven implementing NGOs in coastal Andhra Pradesh. VMM provides technical and financial support to these NGOs to improve the quality of life of children affected by HIV/AIDS, people living with HIV/AIDS and their families.

International HIV/AIDS Alliance

The International HIV/AIDS Alliance, and its country office India HIV/AIDS Alliance, support community action on AIDS in India. Their programmes focus on prevention, low-cost community-based care and support, and impact mitigation, with a special emphasis on children and families affected by HIV/AIDS, and marginalised groups. This includes direct community action and services, capacity building, and the identification and promotion of good practice and policy. India HIV/AIDS Alliance works with four Lead Partner organisations in Tamil Nadu, Andhra Pradesh and New Delhi, who in turn implement programmes through an extensive network of more than 40 implementing NGOs/CBOs.

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Cover image: Children affected by HIV/AIDS enjoy a cultural show/Gundarapu Srinivasa Rao

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Acronyms

AIRTDS	Action for Integrated Rural and Tribal Development Social Service Society
APSACS	Andhra Pradesh State AIDS Control Society
CRS	Catholic Relief Services
DWCRA	Development of Women and Children in Rural Areas
FHI	Family Health International
FXB	François Xavier Bagnoud Society
GO	governmental organisation
HCBCS	home and community-based HIV/AIDS care and support
INGO	implementing NGO
INP+	Indian Network of Positive People
NACO	National AIDS Control Organisation
NGO	non-governmental organisation
NSS	National Service Scheme
PAC	prevention and care
PCR	participatory community review
PMTCT	prevention of mother-to-child transmission
PSI	Population Services International
PWDS	Palmyrah Workers Development Society
STI	sexually transmitted infection
TNP+	Tamil Nadu Network of Positive People
TRU	Technical Resource Unit
VCT	voluntary counselling and testing
VMM	Vasavya Mahila Mandali

Introduction

The first AIDS case in India was detected in 1986. Since then, the spread of HIV/AIDS in Asia has been recent and swift, with HIV infection reported in all states and union territories. Most of India has a low rate of infection, while the epidemic is most extreme in the southern and north-eastern states. Officially, it is estimated that 4.5 million people (0.8 per cent of adults) are living with HIV in India.¹ Many believe this underestimates current HIV prevalence. India is facing an accelerating threat from HIV, with some states such as Andhra Pradesh already experiencing a crossover into the general population from high-risk groups. By 2005, India may have more people living with HIV than any other country in the world.

The impact of HIV/AIDS has not begun to emerge fully in India, and AIDS-related orphaning is not yet occurring on a large scale. Yet, it is believed that India possibly has the largest number of AIDS orphans in the world.² If the evolution of the epidemic in sub-Saharan Africa is replicated in India, then this number will more than double in five years and the proportion of orphaned children will remain exceptionally high for the next 20 to 30 years.³ There are currently more children in India living with an HIV-positive parent than children already orphaned. As more children become orphaned due to HIV/AIDS, the difficulties of meeting the needs of these children will increase. It is very likely that the numbers of orphans who have lost both parents will rise, increasing the number of dependants in households fostering children without parents. It is also likely that institutions will be put under greater pressure, and that the number of street children will also increase.

In response to this worsening situation, the International HIV/AIDS Alliance and its country office, the India HIV/AIDS Alliance (the Alliance), has worked in three states in India since 2000 to establish and support three Lead Partners, including Vasavya Mahila Mandali (VMM), and 37 implementing NGOs (INGOs) to carry out its pioneering programme of home and community-based

care and support for children affected by HIV/AIDS and their families. VMM has drawn on this experience in this report to identify gaps in existing services and propose effective initiatives, policies and examples of good practice for dealing with the issues that children face when they are affected by HIV/AIDS. Although there may be some differences arising from variation in social, cultural and economic circumstances between states and communities across a country as diverse as India, VMM believes that useful lessons can be learned from this report on Andhra Pradesh for India as a whole.

The report includes in its definition of children affected by HIV/AIDS those:

- who have one or both parents living with HIV/AIDS
- who have lost one or both parents to AIDS
- who are living with HIV/AIDS
- whose own family/parents are fostering/caring for children orphaned by and/or living with HIV/AIDS.

The report also refers to particular groups of children affected by HIV/AIDS, such as child-headed households or child widows, when discussing children's needs in detail.

VMM has focused on HIV/AIDS issues in Andhra Pradesh for more than six years. Here, the epidemic is spreading rapidly, and statistics indicate potentially high numbers of children affected by HIV/AIDS, including those who will be orphaned. Information taken from government voluntary counselling and testing (VCT) centres in Andhra Pradesh between April 2002 and March 2003 suggests a high incidence of HIV seropositivity among young people: 17 per cent of children below the age of 14 and 5 per cent aged between 15 and 19 years.⁴

Through the home and community-based care and support programme, the organisation has been working along with seven partner INGOs to provide services to 1977 children affected by HIV/AIDS and their families in five of the 23 districts throughout the state. The INGOs

¹ Based on estimates from the National AIDS Control Organisation (NACO) website (naco.nic.in/indianscene/esthiv).

² This would suggest that India currently has over a million orphans as a result of AIDS.

³ See World Bank website (worldbank.org/sp/safetynets/OVCWorkshop_5-03/Handout_India.pdf).

⁴ 17 per cent out of a total of 3238, and 5 per cent out of a total of 9446 (Andhra Pradesh State AIDS Control Society).

Introduction

have carried out participatory community reviews with the children and families who access their services. These have provided valuable information and input into the redesign of projects, and form the body of information shared in this report.

The majority of children accessing the programme's care and support services are below the age of 10, while a significant proportion are aged between 11 and 15 years. Of these, 37 per cent have already lost both their parents, while 36 per cent have lost one parent, with parental loss being equally divided between the mother and father. Among those who have lost one parent, 13 per cent of the surviving mothers and 28 per cent of the surviving fathers are living with HIV/AIDS. Of the children whose parents are both living with HIV/AIDS, 59 per cent of these have both parents who are HIV positive, with the percentage of infected fathers (38 per cent) being greater than that of infected mothers (23 per cent).

The issues these children face are consistent with emerging country-wide trends. These indicate that:

- feticide is becoming more common among HIV-positive mothers
- the infant mortality rate has increased due to opportunistic infections
- there has been a significant, HIV/AIDS-related increase in the incidence of delayed milestones, retarded growth and under-weight infants
- children living with HIV are experiencing increased morbidity due to opportunistic infections, most notably pyogenic meningitis, bacterial pneumonias, and skin diseases
- insecurity and depression among children affected by HIV/AIDS are on the increase
- nutritional status of children affected by HIV/AIDS has declined.

To date, the state and national government have done little specifically to address the problems of children affected by HIV/AIDS. Few government policies and programmes provide a safety net for these children. Moreover, there has been very little research conducted to estimate the number of children affected by HIV/AIDS, to monitor the impact of HIV/AIDS on children and families and to evaluate existing interventions. This kind of evidence is essential for further planning of policies and interventions.

The response of the non-governmental organisation (NGO) sector in Andhra Pradesh has been slightly more encouraging. Although most programmes are still disproportionately focused on prevention and awareness, a small number have begun to provide much-needed care and support for children affected by HIV/AIDS, with the Alliance/MMM-supported home and community-based care and support programme leading the response at both the community and policy levels. But overall, the response from all actors has been localised, and there is a pressing need for greater networking, resource-sharing and planning for initiatives that provide effectively for all children affected by HIV/AIDS – including those who have been orphaned and who are living with HIV/AIDS.

1 The experience of a child affected by HIV/AIDS: Mohan's story

Looking back, I think our early childhood was happy. We played a lot then. We cannot do that any more. Now there is no happiness in our lives. I do not share my feelings, even with my relatives, because they too will feel bad.

Mohan, aged 14, is the eldest in a family of four sons. His father was a tractor driver and his mother a cotton labourer in a village near Hyderabad. Both died within a year of each other.

When Mohan's father became ill and could no longer work, Mohan had to leave school at the age of 10 to take care of him. Although the family took him to many hospitals, repeated misdiagnoses and lack of treatment meant that he survived for only a year. Mohan's mother was never told directly that her husband was living with HIV/AIDS. Instead, the health care workers told Mohan's uncle, whose fatalistic attitude deprived Mohan's father of further medical care: 'We were trying hard to get some money to take my father to Hyderabad for treatment when my uncle came and advised us not to go. "He will die anyhow," he told us quietly.'

After his father's death, Mohan worked as a bonded labourer, tending buffaloes in order to repay the family's debts. Then Mohan's mother fell ill, and her sister and her parents took the family in. More misdiagnoses and inadequate treatments increased the family's debts still further. When finally she was diagnosed HIV positive, the doctors advised them to stop seeking treatment for her. Again, Mohan was told nothing: 'I don't know much about how one gets AIDS. The doctor did not tell me. He told my uncle, who did not tell me anything.'

Although Mohan's aunt had helped them care for his mother, she has since been forced to choose between her sister's children and her own. Like many women, she has to put up with a husband who 'drinks too much and doesn't look after his own family properly, let alone us.' Mohan believes, 'She does not care about us any more.'

Now the responsibility has shifted to Mohan's grandparents and to the children themselves. His 11-year-old brother has also been taken out of school to try to repay the family debts: 'He has to look after buffaloes.

He does not like it. He wants to stop working and cries. Like me, he wants to study.'

The elders have their own struggles. 'Our grandfather is a watchman. He is very old, but he still works very hard. My grandparents are also surviving through work and we should not depend on them.' The children live with their grandparents in a rented house, and now the owner has asked them to leave. So Mohan is looking for alternative support: 'After the newspapers carried the story, people from the government came and said they would do something. Yesterday, the Member of the Legislative Assembly came and told us that they would admit us in some hostel. Even if we get separated, going to different hostels, it is okay. At least we can get some education. We can go and see each other once in a while.'

Still a child, Mohan faces a life of complexity and great uncertainty. He is shouldering the responsibilities of a father and mother while grieving their loss. He is supporting his two younger siblings' schooling while postponing his own education. And he has to endure the constant abuse of village neighbours. After Mohan's mother died, word spread through the village. 'Then it was all out in the papers and we were ostracised.'

If messages of prevention and care had reached Mohan's family or their village community, and if his parents had been diagnosed early and treated properly, then they might still be living stably with HIV/AIDS. If Mohan's mother had been told the nature of her husband's infection, she might not have become infected herself. If there was capacity to care for children like Mohan, he would not have to worry about where he and his siblings might be living next month. He might even have graduated from 9th grade.

There are millions of children like Mohan. Each of them deserves a better future.

2 The impact of HIV/AIDS on children in Andhra Pradesh

Social impact of HIV/AIDS

This section on the social impact of HIV/AIDS on children draws on three years' experience of implementing the home and community-based care and support programme for children affected by HIV/AIDS and their families.

Education

Despite the emphasis by NGOs on providing educational support, 15 per cent of children affected by HIV/AIDS have dropped out of school and 11 per cent now mainly work rather than study. There are a number of reasons for this drop-out rate. Children of parents living with HIV/AIDS may be denied access to schooling because of the stigma and discrimination within communities and the common misconception that they also will be HIV positive. But often children affected by HIV/AIDS drop out of school in order to support the family economically, while at the same time caring for their sick parent(s) and managing the household. In the long term, inadequate schooling will impact negatively on these children's job opportunities and eventual standard of living.

The family

A child's economic and social situation will worsen with the loss of either parent, but they will face added difficulties depending on which parent dies. Fatherless families, for example, often suffer intense discrimination. A wife may be blamed for the death of her husband, and in some cases she and her children will be turned out of the house by her husband's parents.

Through participatory community reviews, it has become evident that if a child loses both parents, the extended family often will try to care for them if the child is HIV negative. However, such families are often ill-equipped to deal with the responsibility. They may have little income. They may themselves have depended on the relative who has now died. Often, the extended family will help while the parents are alive but cannot afford to care for the children in the long-term. They might also be caring for other family members who are living with HIV/AIDS. Then the relatives may tell the affected children outright that they can no longer provide for them.

Institutional care

When the extended family is either unwilling or unable to care for orphaned children, the children may receive institutional care. This can present added difficulties, regardless of the serostatus of the child, because most agencies:

- are not equipped with counselling services to help children deal with the trauma of their parents' death
- lack programmes to equip children with the skills to survive in the real world
- have strict and exclusive admission policies (for example, based on age or gender) which often result in children being separated from their siblings.

Discrimination

If relatives discover that one child is living with HIV/AIDS while their brothers and sisters are not, they may adopt the siblings and abandon the HIV-positive child to institutional care. However, the number of organisations willing to accept children living with HIV/AIDS is insufficient. Those that do are extremely oversubscribed and underfunded.



This child-headed household is living in a tent on the roadside

Child-headed households

When relatives abandon them and institutions refuse to take them, children affected by HIV/AIDS have to fend for themselves. This has created a growing number of child-

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headed households. The experience of VMM's INGOs has highlighted that children from these households, especially the older ones, generally drop out of school and find unskilled employment. The participatory community reviews indicate that as these children are often insufficiently educated about care-giving, nutrition, health and their legal rights, they are vulnerable to infection, exploitation and the added emotional strain of having to parent themselves.

Street children

As a last resort, some children affected by HIV/AIDS live on the street. Many take advantage of Andhra Pradesh's well-developed rail network and migrate from rural to urban areas. But life on the streets is harsh, and the children are vulnerable to violence, drugs and sexual exploitation.

Economic impact of HIV/AIDS

During the prolonged illness of a parent, household resources will often dwindle due to medical expenses. However, income may be lost completely if a parent is unable to work because they are too ill or because they have been dismissed from their employment on account of the stigma and discrimination against people living with HIV/AIDS. After their parents die, children often lose their property and inheritance either because of laws that disenfranchise widows and/or because of unscrupulous relatives.

There are both micro- and macro-level implications for children dropping out of school. At the micro level, because the children lack training and skills they typically find work in the petty service sector where salaries are low. They exist at subsistence level and are locked into a life of enduring poverty. At the macro level, this diminishing skilled human resource pool is likely to have a significant eventual impact on the Indian economy.

Psychological/emotional impact of HIV/AIDS

Through the experience of the home and community-based care and support programme, and in particular the findings of the participatory community reviews, it is clear that the debilitating psychological and emotional

impact of HIV/AIDS on affected children derives from a number of factors:

Discrimination

This can be encountered by children in the home, at school or in the wider community either because they are themselves living with HIV/AIDS or because of their relationship with a relative living with HIV/AIDS.

They cannot understand why they are being singled out or treated differently from other children. This sense of exclusion affects their self-esteem.

The trauma of adult illness

Affected children go through an extended ordeal of caring for the person they love and watching them suffer and die. If their parents and relatives are also reluctant to disclose their HIV-positive status and discuss their condition, their children experience intense confusion and trauma as they see them growing inexplicably weaker. As the children struggle to come to terms with this, behavioural and emotional difficulties are common. Support for the child when their parents disclose that they are living with HIV/AIDS is imperative. This should include preparing children for the death of their parents and future planning such as foster care.

Identity

Within the family, children are given a sense of place and belonging, and the family teaches them how to relate to wider society. When affected children – especially younger children – are separated from their families, memories of home life quickly fade and family relationships that are essential to their identities become broken or lost. As they grow older, children affected by HIV/AIDS long for answers to questions about themselves like, 'Who am I?', 'What were my parents like?' and 'Where do I belong?' In India, where individual identity is strongly based on heredity and family lines, the need for these answers is especially important.

The future

Children who cannot rely on a well-established system in place for their care and support face a great deal of uncertainty. They may be moved constantly among family members and institutions. This adds greatly to the anxiety of those who are already under significant strain.

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It is important to encourage parents living with HIV/AIDS to carry out future planning with their children in order to create a safety net for the children after they die. This includes: urging parents to save for their children's economic support and education; empowering children with skills to make them self-reliant; and making arrangements for the children's foster care. In addition, parents can pre-empt the identity crisis and rootlessness that affects so many children by, for example, creating family trees, messages and objects which the child may use to remember their parent by.



Often, children have to take on the responsibility for caring for a parent themselves. They need to be shown how to avoid infection, as well as the importance of self-care, such as good nutrition and hygiene

Medical impact of HIV/AIDS

Children with parents living with HIV/AIDS

Many people mistakenly believe that HIV/AIDS is an immediate death sentence. Moreover, parents often assume that when their children become ill it is inevitably due to HIV/AIDS. They may think fatalistically that there is no point in seeking medical help for opportunistic infections, so denying themselves and their children help for otherwise treatable diseases. This can leave children feeling powerless and angry. Interventions that teach how it is possible to prolong life for many years after infection with HIV will increase the lifespan of many parents and reduce the number of orphans.

Efforts to combat the depression and fatalistic attitudes of their parents are essential to the well-being of affected children. Helping the parents come to terms with their HIV status is an important first step. They should be encouraged to discuss their serostatus with their children in an age-appropriate way. This will help the children understand the changes taking place in the household as symptoms develop.

Often children must take on the responsibility for caring for their parents themselves due to either the absence or unwillingness of other adults in the household to take on this role. The capacity of parents to care for their children is also affected by their lack of resources if they are unable to work or need money to buy medication. Then, children will suffer from nutritional problems because of insufficient food. Affected children need to be shown how to avoid infection, as well as the importance of self-care, such as good nutrition and hygiene, while caring for their parents.

Children who are living with HIV/AIDS

The progression from HIV infection to death is more rapid in children than adults. Health services are frequently inaccessible to them, and even basic medicines unavailable. They are also at higher risk of contracting opportunistic infections because most experience poor nutrition and sanitation, overcrowded housing and compromised immunity.

Clinical guidelines for paediatric HIV/AIDS cases are less clear than those for adults, and the follow-up of children living with HIV/AIDS born to HIV-positive parents is very poor. It is often difficult for a health worker to be certain whether a child is living with HIV/AIDS. The experience of the home and community-based care and support programme, and in particular the findings of the participatory community reviews, show that parents are usually unwilling to have their children tested, and the infections that HIV-positive children die of are similar to those that commonly kill HIV-negative children. If a child cannot be identified as living with HIV/AIDS, they may not receive the specific care that they need.

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Gender and HIV/AIDS

Gender inequalities add to the difficulties experienced by children who are affected by HIV/AIDS. In traditional communities determined by a caste system, many families have followed the same occupation or trade for generations. Within these families, tasks are assigned along gender lines: men are the breadwinners, while women play a supporting role as homemakers. When a breadwinner living with HIV/AIDS can no longer work, the gender-based employment system is so rigid that women are rarely allowed to replace him in the family trade. This system effectively robs families of their income. Where there is no man to take over the breadwinner role, the dependent widow, girl children and boys who are too young to work become impoverished.



Gender inequalities can add to the difficulties experienced by children affected by HIV/AIDS - but creative ways can be found around them

Parents are their children's primary role models, and their 'instruction', however imperfect, is vital to their children's development. However, children affected by HIV/AIDS – especially those who are not adopted by their extended families – are often deprived of these role models. There may be no one to educate them about their sexuality, and children affected by HIV/AIDS need this just as any other child does. Girls in particular need to be taught about the changes that will happen to their bodies during adolescence: about menstruation, pregnancy and their

changing nutritional needs (for iron, for example). They also need protection. Many who are impoverished and isolated become involved in sex work and can be sexually abused. Their ignorance about sexuality, safer sex practices and their rights then increases the risk that they will become infected themselves.

Gender inequities are manifest in almost all aspects of Indian family life. For example, the best food goes to the husband who eats first, followed by the boys, the girls and finally the mother (so anaemia is very common among girls and women). Girls are less valued and cared for. They are considered to be a burden and are often subjected to multiple forms of abuse. They are often not involved in any decision-making within the family: they cannot choose their own clothes, education, life partner, sexuality or whether to have children. Girls work longer hours doing physically demanding labour: cooking, cleaning, washing, fetching water and firewood. They have almost no recreational outlet. And whereas boys may be sent to private schools, girls are sent to government schools, the parents believing that they do not need a good education since they will leave home after marriage.

The poorer a family is, the more severe these culturally embedded gender inequities. As the resource pool shrinks when a family is affected by HIV/AIDS, girls increasingly risk nutritional and educational deprivation, and are more likely to suffer higher morbidity than boys. These problems extend to women living with HIV/AIDS. In India, men live for an average of five years post HIV infection, while women live for an average of only two-and-a-half to three years.

The options available to boys and girls also differ outside the family framework. Among street children, it is much easier for boys to survive by hawking, begging or rag-picking, while girls are quickly targeted by pimps and traffickers. This has implications for education and care and support programmes. The street boys, who are largely outdoors, are a visible population that is more easily targeted through proactive outreach. By contrast, street girls who are absorbed into institutions for sex work and by trafficking networks, are mainly an invisible population that requires more sensitive and carefully planned outreach.

2 The impact of HIV/AIDS on children in Andhra Pradesh

Among families who perceive girls to be burdens and boys to be assets, there have been instances where the extended family has refused to adopt a girl affected by HIV/AIDS specifically because she was female.

Child widows

In rural and semi-urban areas in particular, girls are taken out of school and married at the onset of menstruation. If their husband has been living with HIV/AIDS and then dies, these girls are discriminated against as widows and because of their association with HIV/AIDS. They must cope alone with debts, insecurity about the future and psychological trauma. They may also have to look after other children even though they are still very young themselves (most are aged between 14 and 18). Moreover, in many places widows are either not entitled to their husband's property or are unaware of their rights, and so they often lose badly needed economic resources.

A girl's difficulties are increased by intense traditional discrimination against widows. In Andhra Pradesh, widows are ostracised, alienated and commonly blamed for the death of their husbands. If their husband's family throws them out of the house, they are often unable to turn to their own families for protection and support.

Traditionally, widows are not allowed to remarry. They may become extremely vulnerable to sexual exploitation from men, yet blamed by the community for supposedly encouraging them. Girls who are widowed are particularly at risk of sexual abuse and exploitation, and they have few options for redress.

Many girls become widowed shortly after they are married, but typically will have become infected through having sex with their husbands. Because of multiple stresses, the physical and mental health of these girls – especially those living with HIV/AIDS – deteriorates rapidly. At present, there are no programmes in place to meet their specific needs.

Adoption and foster care

Usually, once it has been established that an affected child is HIV negative, relatives, community members and orphanages will provide for their basic needs for food, shelter and clothing, and often for some form of education or skills training. However, they generally lack the capacity to provide the emotional counselling, care and support that affected children need. It is not usual in India for couples to adopt a child who is not a blood relation. Nor can adoption by relatives be depended on when harsh economic necessity forces many to turn affected children away. Overall, there are too few community networks and state and non-governmental institutions able to absorb the growing numbers of affected children. One of the few institutions or programmes currently prepared to provide care and support to children affected by HIV/AIDS is Action for Integrated Rural and Tribal Development Social Service Society (AIRTDS). This INGO partner is carrying out a pioneering approach to foster care through its child-centred home and community care and support project in Tenali, Andhra Pradesh (see case study opposite).

Families will often abandon children living with HIV/AIDS to the few over-burdened and under-funded institutions that will accept them (in Andhra Pradesh there are only 20 beds available). Nevertheless, adoption by relatives and community foster care remains the most viable solution for children living with HIV/AIDS. The success of this strategy depends on the ability of the government and the non-governmental community to encourage people to accept children living with HIV/AIDS into their homes, to introduce laws to ensure the rights of children living with HIV/AIDS to adoption and foster care and to mobilise funds for their care. Both the quantity and the types of care and support services available to children living with HIV/AIDS need to be expanded. Services must constantly balance these children's medical, nutritional and psychosocial needs without making them feel alienated or different.

2 The impact of HIV/AIDS on children in Andhra Pradesh

Community fostering for children affected by HIV/AIDS, Tenali

As an agricultural labourer, Krishna Rao was earning just enough to meet his family's basic needs. When his wife found out he was living with HIV, she decided to leave him and their two children, and Krishna was left to care for the children as well as his elderly parents who were unable to work. Krishna was very worried about his children's education and future.

At this time, as part of their care and support programme, AIRTDS were making house visits to Krishna's family. They provided psychosocial support to the whole family and Krishna was provided with medicines for opportunistic infections. He was also referred to a drop-in centre for treatment, and the children were provided with educational support.

Krishna said that after he died he would like his children to continue to live in a family environment. The issue of informal foster care was brought up at one of the self-help group meetings held by AIRTDS. The advantages, concerns and challenges with regard to this idea were shared by all who attended the meeting. Afterwards, Meera, one of the members of the women's self-help groups, discussed the issue of

foster care with her husband. They have three daughters, two of whom are married. After discussing the possibility of fostering with the whole of her family and her neighbours, Meera was encouraged by their responses. She went to AIRTDS with her husband to say they wanted to be foster parents. Their decision has really given momentum to the community fostering of orphans in AIRTDS's care and support programme.

Accompanied by staff of the NGO, Meera and her husband went to see Krishna and his family and discussed at length the idea of fostering his two children. Everyone agreed that this would be the preferred option. Krishna was very sick at this time, and died a couple of days after the visit. Soon afterwards, Meera and her husband informally fostered the two children. They have been accepted by all the family and are attending a nearby school.

Meera had not wanted to separate the siblings – it was important that she fostered both of them. In order to increase her family's income, she started a small shop with the assistance of the micro-credit programme of AIRTDS. She is confident that she can provide for the basic material needs of the children, as well as give them the necessary love, affection and emotional support.

3 Current care and support responses in Andhra Pradesh

Government initiatives

Government, bilateral agencies and local NGO initiatives for children affected by HIV/AIDS mainly focus on prevention. 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.

In the area of care and support, the Andhra Pradesh State AIDS Control Society (APSACS) targets people living with HIV/AIDS under Component IV of Phase – II of the National AIDS Control Programme. At present, APSACS provides 12 community care centres and two drop-in centres for people at a terminal stage and who are affected by severe opportunistic infections.

All of the state centres are aimed at adults; there is no specific focus on children. APSACS is seeking to establish 33 community care centres for children affected by HIV/AIDS throughout Andhra Pradesh's 23 districts, with two centres 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 Andhra Pradesh Government's growing awareness of the needs of children affected by HIV/AIDS, the project is still very much in its conceptual stages.

In the area of policies and services, the state and national government also has no specific provision for children affected by HIV/AIDS. The three state and national government departments of women and child welfare, social justice and empowerment, and health and family welfare have a few programmes 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.

Government medical services

There is an enormous disparity between the needs of those with HIV/AIDS and public health service provision. This affects children directly, as services are equally unavailable to children and adults, and indirectly, because

the support available to their parents or other caregivers is inadequate.

Since March 2003, 15 physicians from 10 districts and the teaching hospitals in Andhra Pradesh have begun training in the management of HIV/AIDS. However, there is no specific training for nursing staff beyond increasing their general awareness about HIV/AIDS.

Currently, the law demands that people living with HIV/AIDS should be managed on the same wards as everyone else, while maintaining their confidentiality. However, although universal precautions have been advised to reduce HIV/AIDS transmission during surgeries, deliveries and other medical procedures, there are almost no facilities to enable these precautions to be observed.

VCT centres are now widely available in government hospitals. However, most people are unaware that they exist or uncertain of their affordability, so they are under-used. Counselling at the centres is available only during restricted hours and supplies of testing kits are irregular. Questions are also being raised over the nature of the pre-test counselling that is taking place and the extent to which informed consent is achieved prior to the decision to undergo a test.

Initiatives by local and international NGOs

Home and community-based HIV/AIDS care and support programme

Since 2001, VMM and its implementing NGO partners in coastal Andhra Pradesh, with the support of the Alliance, have been implementing a pioneering home and community-based care and support programme for children affected by HIV/AIDS, people living with HIV/AIDS and their families (see Section 4).

DIYA

The Freedom Foundation has been running an institutional care and support centre since 2001. It is located in Hyderabad, and provides medical care for adults living with HIV/AIDS and affected children with opportunistic infections or who have reached a terminal stage. In response to the need for long-term care of abandoned children living with HIV/AIDS, the Foundation

3 Current care and support responses in Andhra Pradesh



Care and support NGOs encourage children affected by HIV/AIDS to give each other peer support. Children themselves often say that their greatest need is for acceptance

created a residential home, DIYA ('light'). DIYA has capacity for 20 children aged from birth to 15 years. Although it is located in Hyderabad, it has been receiving children from all over Andhra Pradesh as it is currently the only home for children living with HIV/AIDS in the state (see Section 4).

The Catholic Relief Services (CRS) funds six programmes in Andhra Pradesh that also provide education, medicines and recreation to children affected by HIV/AIDS.

Prajwala, an NGO, works with the children of sex workers, and provides them with emergency health care through financial support and referrals to the Freedom Foundation's care and support centre.

Family Health International (FHI) supports five prevention-led programmes with specific focus on psychosocial, educational, medical and recreational support to children affected by HIV/AIDS.

François Xavier Bagnoud (FXB) Society has a centre in Vishakapatnam that provides counselling to high-risk groups and people living with HIV/AIDS, prevention of mother-to-child transmission (PMTCT) centres and medical support for street children. They offer nutritious food, institutional and home-based counselling, and medical support for opportunistic infections to children affected by HIV/AIDS.

Population Services International (PSI) supports a port-based HIV/AIDS programme focusing on VCT, sexually transmitted infection (STI) treatment and awareness generation. It aims to reduce the vulnerability of the people directly or indirectly dependent on the port.

World Vision Care and Support Program, based in nine locations in Andhra Pradesh, has built on the learning and experience of the Alliance/VMM home and community-based care and support programme in order to provide counselling, nutritious food and medical services to people living with HIV/AIDS and affected families.

The majority of these care and support NGOs devote their resources to providing health care (specifically, treatment of children affected by HIV/AIDS for common illnesses and treatment of children living with HIV/AIDS for common opportunistic infections), support for education (school books, bags etc.) and recreational activities. Very few provide or arrange shelter for children affected by HIV/AIDS. As more of these children become orphaned, NGOs will almost certainly need to expand their activities into this area. Additionally, none of the NGOs provide clothing other than school uniforms.

The care and support NGOs divide their efforts almost equally between children affected by HIV/AIDS, people living with HIV/AIDS and families affected by HIV/AIDS. This is encouraging, as programmes addressing the emerging problems of children affected by HIV/AIDS should target not only the children themselves but also their parents and extended families.

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VMM's home and community-based care and support programme

Community advocates: women's self-help groups

In the villages of Andhra Pradesh, women's self-help groups or government-initiated Development of Women and Children in Rural Areas (DWCRA) groups are actively involved in saving and micro-credit schemes to assist families affected by HIV/AIDS to set up small income-generating projects. Based on the innovation of the Alliance Lead Partner for Tamil Nadu, the Palmyrah Workers Development Society (PWDS), the women's self-help groups have started *Sarvodaya Patra* (Bowl for Holistic Development). Each member contributes a handful of rice every day. The rice is stored in a group-owned pot, and every month it is divided among families with children and young widows affected by HIV/AIDS. This practice has been taken up as a model by VMM's home and community-based care and support (HCBCS) programme, supported by the Alliance. The model is now being replicated in other communities.

Supporting child-headed households

The stigma encountered by people living with HIV/AIDS means that many relocate away from their extended families to communities where their HIV status and identities are unknown. Consequently, children often find themselves without support when their parents die. Sometimes, these children are so young that they do not even know who their relatives are.

The Needs Serving Society (Needs) was told of three young children in such circumstances, who were thrown out of their rented house following their parents' death. Needs spoke to community leaders about the children. Then, through collaboration with the community, a small hut was built for the children. Needs now provides them with clothing, and psychosocial and medical support, while the community gives them food and other kinds of support.

Creating student/youth volunteers

In partnership with AIRTDS in Tenali, VMM encouraged two colleges to make working with people living with HIV/AIDS and affected children the focus of their National Service Scheme (NSS) programme – an annual two-week government-mandated scheme for universities and colleges.

In Vijayawada, college students adopted two urban slums and ran a camp for children affected by HIV/AIDS. The children were encouraged to draw, paint, sing and role-play, and were given rewards for their efforts. This experience at the camp inspired some of the student volunteers to go on to provide weekly supplementary education to the children who had attended the camp.

Students also surveyed the HIV-related health status of high-risk groups in Tenali and five surrounding villages. Following this initiative, some students volunteered to make home visits and provide support to families living with HIV/AIDS.

Using the media for advocacy

Children affected by HIV/AIDS speak out VMM visited the homes of 30 children affected by HIV/AIDS with a recording team from All India Radio – one of the most important governmental agencies for information and broadcasting. They were asked about their feelings, experiences and needs as children affected by HIV/AIDS, and their responses were then broadcast throughout coastal Andhra Pradesh.

The children's ballet Every year, All India Radio broadcasts a programme about children's issues on the eve of Children's Day. In 2001, they approached VMM to suggest focusing on children affected by HIV/AIDS. Out of this collaboration, affected children from Vijayawada performed a ballet *Goranta Deepam* (Tiny Lamp) to raise awareness among a live audience of more than 2000 people. An audio version of the ballet was also recorded and broadcast throughout coastal Andhra Pradesh, with narration and commentary by the children themselves.

Television and print media A number of television channels and a newspaper approached VMM for help in increasing public understanding of how children are affected by HIV/AIDS. With the children's consent, the news agencies interviewed street children in VMM's care and support programme who had either been orphaned by AIDS or forced out of school on to the streets in order to support themselves or their HIV/AIDS-affected families.

The children (mostly boys) were asked why they were on the street, how they support themselves and how they

4 Examples of good practice

would prefer to be living. They were also asked to describe their sexual behaviour and what they knew about HIV/AIDS and safer sex practices.

The interviews were broadcasted locally and internationally. They have helped to raise awareness of the children's difficulties, (such as lack of schooling) and needs (such as skills training for better employment and education about sexuality and HIV/AIDS).

Overall, these efforts to raise awareness and mobilise the public through the media have been well received. All India Radio, for example, received thousands of letters in response to these programmes.

Community-wide acceptance and integration of people living with HIV/AIDS and affected children

Stigma and discrimination present major difficulties for people living with HIV/AIDS and their families. Children are especially vulnerable to discrimination. They are greatly affected by ostracism, particularly in public places and social spaces like the playground, the village well or standpipe, the school and at community cultural events.

As part of its community capacity-building efforts, one of VMM's implementing NGO partners, SHADOWS, has been challenging the stigma surrounding HIV/AIDS. SHADOWS raised the awareness of a number of people living with HIV/AIDS and their families in Soloman Village, Prakasam District, Andhra Pradesh, who then became volunteer advocates themselves. These volunteers went on to convince the Soloman Gram Panchayat of the seriousness of HIV/AIDS discrimination, and they responded by discussing the issue in their regular meetings. As a result, the whole village has become more informed about HIV/AIDS and has passed an anti-discrimination resolution.

The commitment and powerful co-operative ethic of these volunteers were invaluable in bringing about change. Their story of community empowerment has become inspirational for VMM and its implementing NGO partners. It shows the immense resources available at the community level to combat stigma against HIV/AIDS – resources that have remained until now largely untapped.

VMM hopes to replicate this example of community-based advocacy and expand its impact to the state level.

Links with government programmes

Widows affected by HIV/AIDS: The Apadbanbhava programme The Government of Andhra Pradesh runs a scheme, Apadbanbhava (Helping Those in Need), which gives a one-off grant to widows to meet their families' immediate financial needs following the death a breadwinner. If the breadwinner had been living with HIV/AIDS, their family is often left with heavy debts from medical care. Moreover, the stigma attached to HIV/AIDS means that the widow often has difficulty accessing the already limited livelihood options that might be otherwise available to her.

VMM partner NGOs, Mahila Mandali in Chirala and St Paul's Trust in Samalkot, refer widows affected by HIV/AIDS to Apadbanbhava. The bridge funds provided by the programme help them maintain a minimum standard of living. In addition, it has given them the space and resources to save for their children and to invest in income-generating self-employment schemes, as the story about Gouri shows.

Gouri's husband had been living with HIV/AIDS. But after his death, 24-year-old Gouri was faced with debts, as well as needing to support herself and her two young daughters. Thanks to the funds from the Apadbanbhava scheme, Gouri was able to pay off her debts. She divided the remaining money equally between herself and her children, and opened fixed-deposit accounts in their names. Gouri now has a financial safety net for her children. In addition, she plans to invest her share in a sewing machine, which she will use to support herself and the children.

Pensions Many elders do not draw the government pensions to which they are entitled because they cannot manage the overly bureaucratic application process. But now that many grandparents have been forced by the HIV/AIDS epidemic to become breadwinners in order to

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care for their grandchildren, the pension represents another source of badly needed funds. VMM and their partners are helping these elders access pension funds by assisting with the application process.

State-run hostels for vulnerable children

The Government of Andhra Pradesh runs hostels that provide food, clothing, shelter and education to vulnerable children (those who are poor and those belonging to scheduled castes and tribes). VMM have been helping to direct children affected by HIV/AIDS into these hostels. Most are still in contact with their extended families, but if they were to live with them, they would

be forced to drop out of school to help the family support them. By linking with the government's hostel services, the children are able to continue their education while maintaining contact with their relatives.

The success of these initiatives has encouraged VMM to expand their linking initiatives between the government and those affected by HIV/AIDS. At present, VMM and their partner Mahila Mandali are researching, documenting, and cataloguing existing governmental services in Andhra Pradesh, and are mapping these services to the emerging needs of people living with HIV/AIDS and affected children and families.

Finding creative ways around gender-specific roles

Eleven-year-old Lakshmi lives with her four sisters, mother and grandmother in a small coastal village in Chirala, Andhra Pradesh. Her family is part of the Jalari community, who for generations have earned a living through fishing. Lakshmi's father had been living with HIV/AIDS. When he died two years ago, he left the family a small thatched hut, a vacant plot of land and a fishing net which he had used to support them.

After her father's death, Lakshmi's family was unable to support itself because of traditional rules that prevent women from becoming the breadwinners. Lakshmi's mother is also living with HIV/AIDS, and a large percentage of the family's limited funds are spent on her medical care. To make matters worse, Lakshmi's uncle stole their land, depriving the family of their inheritance rights and monetary resources that are critical to them at this time. The combined pressures have forced Lakshmi and her two older sisters to drop out of school.

A team of workers and volunteers from SHADOWS, one of VMM's implementing NGO partners, brought Lakshmi's family to the attention of the community leader. He became committed to finding a solution to their problems, and immediately approached Lakshmi's father's former employer, who donated money to cover the mother's medical expenses and the family's daily needs. Although the donation was a great help, everyone knew that a long-term, sustainable solution was needed. Through discussions with the Jalari community, they were able to devise an innovative solution. Lakshmi's family would be allowed to rent its fishing net out to community members at a daily rate.

This practical and strategic solution works within existing social structures to get around the culturally embedded restrictions that were depriving Lakshmi and her family of a means to support themselves. Solutions such as these, which are sensitive to the fact that social change occurs in incremental steps, will help those in immediate need and provide the building blocks towards a more egalitarian society in the future.

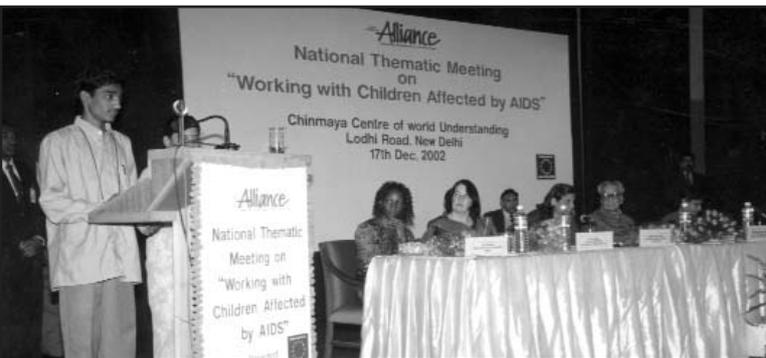
4 Examples of good practice

Protecting children's identities before their parents die

In response to the crises of identity that children face when they are separated from their parents and extended families, VMM and its implementing NGO partners have encouraged parents living with HIV/AIDS in the HCBCS programme to make family trees with their children. This is to help the children build memories and maintain their connection to their families. During the family tree activity, parents also tell their children about family traditions and how to keep in touch with their extended families.

Parents living with HIV/AIDS have highly praised the family tree activity. They say that it helps them as well as their children, encouraging them to remember happier times. Once their children get involved, parents find it easier to start discussing their deaths with them and the changes that lie ahead. These discussions have prompted parents to begin to make plans with friends and relatives for their children's care after their deaths. They say that these preparations have made them feel both physically and emotionally stronger. In many cases, parents said the family tree activity has helped them to talk to their families for the first time about HIV/AIDS. As they are no longer hiding the truth from their children, parents say that the conversations have filled them with a greater sense of peace.

By helping parents who are living with HIV/AIDS cope with their illness and take a proactive approach to protecting and providing for their children after their deaths, the family tree activity helps to lessen the difficulty of the child's experience. The activity also increases children's awareness about HIV/AIDS, and so reduces their risk of infection later on.



A young volunteer from AIRTDS gave a presentation at a national meeting about his experiences and how he and other volunteers have helped to sensitise the local community to minimise the stigma and discrimination against children affected by HIV/AIDS and their family members

Children as agents of change

Arjun's father had been living with HIV/AIDS, and by the time he died, Arjun's mother and two younger brothers had been forced to spend all their savings as well as borrow extra money for his treatment. The children had become stigmatised as untouchables because of their father's illness, and Arjun's mother had tested positive as well. Although she had been working in the fields to earn money for food and to clear their debts, as her health deteriorated she became unable to continue working. At this point, Arjun, a 16-year-old boy studying in the 10th grade, had to leave school in order to take over all of the family responsibilities. Although he had wanted to continue his schooling, he set up a coconut shop with money he borrowed from a moneylender.

Then Arjun learnt about the HCBCS programme being run by AIRTDS, a local NGO supported by VMM. Their counselling has helped the family gain confidence. With medical treatment, Arjun's mother, who had been bedridden, recovered enough to be able help her son in the shop. The family has also been promised educational support for Arjun's two younger brothers and financial support for the coconut shop, if needed.

Arjun has himself become an agent of change, spreading awareness about HIV/AIDS and enthusiastically promoting the HCBCS programme. He feels that no one should have to experience what his family has been through, where the community felt that the very air his family breathed out and the water that came out of their house from the drain would pollute the village. Slowly, Arjun's relatives and neighbours are changing their attitudes about HIV/AIDS, and are renewing their friendships with Arjun's family.

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Participation of children affected by HIV/AIDS

When adults begin to listen to what children know about their lives, they are often surprised to discover how insightful children are. This is why VMM and their partners recognise the importance and the benefits of making children active participants in the formation of policy and in the implementation of programmes aimed at promoting their interests.



In participatory community reviews, children often report quite different needs from those that adults identify for them

Children contributing to participatory community reviews The Alliance and VMM have supported seven implementing NGO partners to conduct semi-annual participatory community reviews (PCRs), using community feedback to modify existing programmes so that they can be better aligned to community needs. During the first PCR, children affected by HIV/AIDS (mainly aged 11 and older) were asked for their views. Interestingly, the needs that the adults had identified for the children during the PCR differed from those expressed by the children themselves. For example, parents (especially mothers living with HIV/AIDS) stressed their concerns for their children's education and future security. The children, however, emphasised their need for acceptance despite being affected by HIV/AIDS, and their need for integration into community-level social activities through outings and other recreational events. They also identified medicines for parents and food for the whole family as

among their most pressing needs. This disparity between adult and child concerns shows that adults alone cannot represent the needs of children affected by HIV/AIDS. The children's priorities are for care and support efforts to be geared towards maintaining the health of their parents and the happiness of their homes.

The PCR also highlighted the strong desire of children affected by HIV/AIDS to become active participants in policy-making. During the first PCR, the children noted that when NGO volunteers visited their families, they would typically talk only to the parents. The children proposed that instead of being ignored or asked to leave, they should be included in the process, and that a regular forum be provided for them to voice their opinions and concerns.

In light of these responses, VMM and its partners have developed child-centred initiatives such as support groups, peer counselling and training on HIV/AIDS for affected children. These initiatives have empowered the children and enabled them to express their feelings through murals, poetry and role-plays, which they have introduced into their local communities or through one-to-one discussions between themselves and their peers, and even their elders.

Networking between non-governmental organisations, governmental organisations and bilateral agencies

VMM organised a one-day regional workshop in 2003 to network with representatives from donor agencies (such as Plan International, World Vision, Lepira India and International AIDS Vaccine Initiative), government agencies (APSACS, TRU, District Leprosy Officers), networks of people living with HIV/AIDS (INP+, TNP+) and 96 NGOs working on HIV/AIDS prevention and care and support in coastal Andhra Pradesh.

The purpose of the workshop was to:

- learn about government initiatives for HIV/AIDS prevention, control and care and support
- discuss the role of NGOs in HIV/AIDS prevention, control and care and support
- document and present the challenges in the various HIV/AIDS programmes and to propose solutions
- propose strategies for a co-ordinated approach

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- learn more about the situation in the coastal districts of Andhra Pradesh and identify areas for improvement in existing programmes.

Through group discussions, workshop participants discovered that the majority of programmes are currently focused on prevention rather than on care and support for people affected by HIV/AIDS in Andhra Pradesh, and target high-risk groups like street children, sex workers, truckers and slum dwellers rather than the general population. Those care and support efforts that do exist

are highly localised, piecemeal and unconnected to a larger strategy.

The dialogue enabled participants to share examples of good practice and begin to design more comprehensive and co-ordinated initiatives for people affected by HIV/AIDS. It will help to ensure that fewer resources are wasted through badly conceived efforts and will encourage links between referral services. It has also served as a platform for proposing policy changes to the government.

Freedom Foundation

When you work with these children, you develop an emotional attachment to them. We know that these children are going to die, but we try to give them everything that they need, including our love. When a child dies, we feel ... as if we have lost a member of our own family.

DIYA, the only full-time residential care and support centre for children living with HIV/AIDS in Andhra Pradesh, is run by the Hyderabad-based Freedom Foundation. It has capacity for 20 children aged from birth up to 15 years.

Food, clothing, educational materials, toys for the children and appliances for the centre have been provided either by the Freedom Foundation or private donors. Since local schools will not accept them, the children are taught within DIYA by a counsellor. To reduce their feelings of exclusion, DIYA has created school uniforms for them and provides them with schoolbooks and bags.

DIYA was created out of scarce funds and continues to operate on a shoestring without support. They need more staff, ideally on a ratio of six children to one counsellor (rather than the current 15). Although some community volunteers come in to play with the children or take them on outings, none are willing to invite the children into their homes for fear of discrimination by their neighbours. Those children who still have families never visit as they have been rejected by them.

As well as dealing with feelings of exclusion and abandonment, the children have to come to terms with death – both their own and those of the other children in DIYA. Their counsellor provides them with psychosocial and emotional support. She encourages the children to believe that their lives, though brief, are still worth living. Two women workers provide the children with 24-hour care. None of DIYA's children are on antiretroviral treatment because they cannot afford it. However, their health is constantly monitored and they are treated for opportunistic infections.

Conclusion

As mentioned earlier, India appears to be at a similar point in the epidemic's evolution as countries in sub-Saharan Africa found themselves a decade ago. Then, HIV prevalence rates were rising rapidly, but the full impact, particularly on children, had yet to emerge to its full extent. However, there is a major difference in terms of the response to the AIDS epidemic in India compared to Africa during the last decade. Learning from the Africa experience, it is vital that there should be a rapid scale-up of effective home and community care programmes working with children affected by HIV/AIDS, people living with HIV/AIDS and their families. Through the experiences of VMM and its INGO partners in the past three years, a number of good practice approaches have emerged offering care and support to those affected by HIV/AIDS, such as integrating community care programmes into existing community development initiatives. This strategy has enabled the rapid, effective scale-up of community care, ensured sustainable community ownership of the programmes and effectively addressed stigma and discrimination within a short period of time.

Since 2001, VMM and some its partner INGOs have been particularly focused on developing child-centred approaches within the home and community-based care and support programme. However, increased capacity-building around specific issues related to working with children affected by HIV/AIDS is necessary. Issues that might be addressed include:

- psychosocial needs of children and psychosocial support activities
- child development
- discrimination against children affected by HIV/AIDS
- care needs of children
- child rights
- child fostering
- child-headed households
- sexual abuse of children.

There is an urgent need for the national and state governments to strengthen their political will to invest in care and support for children affected by HIV/AIDS, people living with HIV/AIDS and their family members by expanding policy initiatives and committing resources. Beyond the government, there is still an urgency for greater financial resources and an increased number of players working collaboratively to respond holistically to the needs of children affected by HIV/AIDS. VMM and its partners are well placed to play leading advocacy roles in community care at their respective levels.

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