

ORPHAN AND VULNERABLE CHILDREN

Health Policy Interventions in India

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“A solid family environment is essential in paving the way for the realization of future dreams and aspirations of children.”

—Nelson Mandela

This paper reviews and discusses studies and interventions which have addressed the problems and concerns of orphans and vulnerable children (OVC) in India. Most of the research and commentary on OVC is based on investigations conducted in African countries. Accordingly, this review focuses on OVC in India in order to facilitate further critical discussion and the development of appropriate programmes and policies for the Indian context. The paper shows that HIV/AIDS programmes and interventions are vital to the survival and welfare of OVC but they have reached only a small fraction of the most vulnerable children in India. OVC in India have also failed to receive the attention they deserve in poverty reduction strategies and other national development instruments. The paper suggests a number of measures that government and civil society could take to rectify the problem. These include mobilizing resources for supporting community care rather than institutional care; strengthening the care and coping capacities of families and communities; involving children and youth as active participants; building broad collaboration among key stakeholders in all sectors; and integrating with other prevention, care and support services. The paper also emphasizes the need to learn from the experience and initiatives of other countries in developing appropriate policy and programmes for OVC.

INTRODUCTION

The HIV/AIDS epidemic has increased adult and child mortality rates substantially in many countries including India (NACO 2006). Adult deaths from AIDS often occur among

men and women in their thirties and early forties. As a result, many people who die from AIDS leave behind young children as orphans. While in India numerous children are orphaned for a variety of reasons, those who are orphaned by AIDS bear a special burden since they are more likely to lose both their parents. In India, such a development has brought to greater public prominence the problem of 'orphaned and vulnerable children' (OVC).

Although the impact of the AIDS crisis has not begun to emerge fully in India, and AIDS-related orphaning has not yet been accurately documented, it is estimated that India has the world's largest number of AIDS orphans. This number is expected to double in the next five years (World Bank). Of the 55,764 identified AIDS cases in India, 2,112 are children (Sridhar 2003). It is estimated that 14 percent of the 4.58 million HIV/AIDS cases are children below the age of fourteen years (Sridhar 2003). The National AIDS Control Organization (NACO) estimates show that 70,000 children below the age of fifteen years are infected with HIV in India and 21,000 develop infection every year through mother to child transmission.

Most AIDS orphans are clustered in extended families or communities. With a lack of resources available in most of these extended families, children often shoulder the adult responsibilities of generating income and caring for the sick in addition to the emotional difficulties they face. Many orphans and other vulnerable children are themselves living with people infected with HIV/AIDS, caring for siblings and chronically ill family members, and living in financially stretched households. Some orphans also engage in high risk behaviours to support themselves and their families. The AIDS epidemic has made these children particularly vulnerable. They are more likely to be malnourished, uneducated, and lack access to basic health care. In addition, they face psychological and emotional difficulties.

Children orphaned by AIDS face the added burden of stigma and discrimination surrounding the disease as a result of their parent's infection and death. According to the National Human Rights Commission (2005), HIV infected people in India face discrimination from multiple sources including schools, workplaces, medical services, and others, compounding social divisions of class and caste. A study conducted by the International Labour Organization (ILO) found that children of HIV infected parents experience serious discrimination with 35 percent of them denied basic amenities and 17 percent forced to take up petty jobs to augment their income (Majumdar 2003). While economic deprivation has resulted in children withdrawing from school to care for sick parents or earn additional income, social discrimination has resulted in the denial of basic services to affected children, especially health and education services. For example, while the state of Kerala has a

very high rate of literacy by comparison with other Indian states, children who are HIV positive have been denied entrance to schools there. The government of Kerala has supported the right of children with HIV to attend schools but some communities have withdrawn their children when they have become aware that some children attending school are HIV positive (Page 2007).

In India, AIDS orphans are more often likely to experience poverty, illiteracy, child labour, child prostitution, and police brutality. Conservative estimates suggest that around 300, 000 children in India are engaged in commercial sex. Many of them are also living as street children. These are children for whom the street has become their home, a situation where there is no protection, supervision, or guidance from responsible adults. Human Rights Watch estimates that approximately 18 million children live or work on the streets of India. The majority of these children are involved in crime, prostitution, gang related violence and drug trafficking (HRW 1996).

DEFINING 'ORPHAN AND VULNERABLE CHILDREN'

Before examining further the major policy and service issues related to 'orphan and vulnerable children' (OVC), it is important to understand how these children are classified. Various institutions, governments and donor agencies have defined OVC differently. 'Vulnerable children' are defined in a number of ways. Generally, they reside in households where one or more members are affected with HIV/AIDS, or a parent or principal caretaker is HIV positive. In other words, vulnerable children are those whose survival, well-being or development is threatened due to the possibility of exposure to HIV/AIDS.

An 'orphan' is defined as a child under the age of eighteen who has lost one or both parents. A 'maternal orphan' is a child whose mother has died, and a 'paternal orphan' is one whose father is dead. A 'double orphan' is a child who has lost both parents. An 'AIDS orphan' is a child who has lost his or her father or mother due to AIDS.

The concept of AIDS orphans has been gradually expanded to include other children made vulnerable by the HIV/AIDS epidemic. The scale and situation of AIDS orphans, however, does not address the full extent of the problem. The HIV/AIDS epidemic and the intensified poverty generated by it are also rendering growing numbers of children 'vulnerable'. According to UNAIDS, the term, 'vulnerable children', refers to children whose survival, well-being, or development is threatened by HIV/AIDS (UNAIDS 2004). However, vulnerability remains difficult to define. The non-governmental

organisation (NGO), World Vision, has identified vulnerable children in the context of HIV/AIDS as children who live in a household in which one person or more is infected by HIV/AIDS, dying or deceased; in households that take in orphans; and in households with persons too old or too young to take care of them.

India also has the phenomena of *de facto* orphans - children whose parents have not died but who usually have to drop out of school to take over their parents' roles because of their parents' illness. 'Maternal orphans' have to take responsibility for household tasks and child rearing. 'Paternal orphans' may have to find jobs, including migrant work. If the widow goes to work, the children become maternal and paternal orphans. Yet children are also often placed in orphanages for reasons other than the death of parents. These include parental abuse of alcohol and drugs, the mother's sex work, mental illness, or divorce. Clearly, then, vulnerability involves more complex factors than those associated with children's basic needs. The most significant are not simply death or desertion by parents, but include severe chronic illness of parents, illness of a child, physical or mental disability of a child, poverty, restricted access to basic social resources such as education, health and social services, and inadequate clothing. They also include emotional problems, abuse of the child, and drug abuse by caregivers or the child. However, there is some debate over the question of grouping OVC under the category of 'vulnerable children'. In a World Food Programme (WFP) report, Landis (2002) comments:

Orphans and vulnerable children have different characteristics. Therefore, it is incorrect to consider them as a homogeneous group of needy children. Each orphan or vulnerable child can face different risks and specific vulnerabilities depending on gender, and whether he or she lives in urban, peri-urban or rural settings, in the extended or a foster family, in an institution or on the street, and whether he or she is infected or not by HIV. *Thus*, most publications consider it useful to distinguish orphans from vulnerable children only for matters related to psychosocial support, protection of orphan's rights, specific interventions for orphans, and epidemiological surveys.

INDIA: AIDS AND ORPHANS—CURRENT STATUS AND PROJECTIONS

The threat posed by HIV to the health of the population in India is accelerating rapidly, with some states such as Andhra Pradesh already experiencing a growing rate of infection of the general population by high-risk groups. Although there is no nationwide study to estimate the incidence of AIDS among children, according to a Press Trust of India report (quoting an official source), 7976 children below 14 years (detected during 2006 up to October),

are HIV positive in India compared to 7,168 in 2005. Of the group of children under 14 years of age with HIV in 2006, 61 percent (4,902) were boys and 39 percent (3,074) were girls. The maximum numbers of cases reported were from Andhra Pradesh followed by Maharashtra. 1,186 (around 15 percent) children were afflicted with HIV in Tamil Nadu. Delhi had 225 cases, while Kerala had 111 children afflicted with the deadly virus.

According to UN estimates, the number of children in India orphaned by AIDS is approaching two million. In fact, there is a projection that the HIV/AIDS pandemic in sub-Saharan Africa is likely to be repeated in India (At-a-Glance, India: AIDS and Orphans). Numbers and projections in these African countries are being widely used as a guide to the progression of the pandemic in India. As a result of the current number of people living with HIV/AIDS at the present sero-prevalence rate, India is expected to become the next epicenter of the AIDS orphan crisis (At-a-Glance, India: AIDS and Orphans). This is raising serious concerns about India's preparedness for a scenario as dire as that of sub-Saharan Africa.

IMPACT

At the economic, social, security and demographic levels the AIDS epidemic is having an impact far more devastating than ever imagined. In addition to the untold grief and human misery caused by AIDS, the epidemic is wiping out development gains, decreasing life expectancy, increasing child mortality, orphaning millions, setting back the situation of women and children, and threatening to undermine national security in highly-affected societies. (UNAIDS 2005)

It is expected that the proportion of orphaned children in India will remain exceptionally high till 2020 or 2030 (EU-India 2007). Given the long incubation period between infection and the onset of symptoms, the epidemic's impact will linger for decades even if the rate of new infections is brought under control. India is in the stage of the HIV/AIDS epidemic that many African countries were in a decade ago. The initial impacts of HIV/AIDS are mortality and morbidity but, as the previous discussion suggests, these are also accompanied by major social impacts as the number of adults who can act as caregivers decreases.

Morbidity has specific social impacts that are often overlooked. Seriously ill people cannot work. Productive labour is diverted to caring for them and to meeting growing medical expenses, which reduce family income. As already mentioned children are then often taken out of school to work. Some of the alarming consequences are reduced life expectancy, increased infant and

maternal mortality, child labour, school dropout rates, sexual exploitation of children and youth, low agricultural and industrial production and increased poverty. An especially worrying outcome is the child-headed family, where HIV infects and kills the entire middle-aged generation. The end result is that the very young end up looking after the very old.

“Venkatesh Konda, 15, lost his father, a rickshaw puller, and his mother, a daily wage labourer, in the last 24 months to AIDS. Venkatesh, who cannot read or write, now works in a local cotton mill 30 miles from Vijayawada, starting to haul sacks at 8pm and finishing 12 hours later. For this backbreaking labour he earns 50 rupees (60 paise) a day. He is the only breadwinner in a family that consists of himself and his elderly grandparents. “It is very tiring and my back hurts but how else will we live? My grandparents are too old so they cannot work. I come back from work in the morning and sleep. I am too tired to do anything else.” (Ramesh, R. and MacDonald, L. 2005)

These adverse developments have resulted in enormous demographic pressures in many developing countries, decreasing prospects for healthy meaningful lives for millions of children. This is especially a matter of concern in a country like India where more than half of the population, about 600 million, is below the age of 24. There is a pressing need to learn from African countries, where the AIDS pandemic has taken the greatest toll, about similarities and differences in programming approaches for orphans and vulnerable children. It is anticipated that with earlier interventions, India will never see the number of children orphaned by AIDS that is currently seen in Africa. The following section addresses some of the major law and policy responses in India to the problem.

LAW AND POLICY REFORMS

The Government of India is committed to preventing HIV infections and mitigating the *medical impact* of the virus on the lives of those already infected. It has already provided a detailed vision for achieving this objective in the National AIDS Control Programme 2007–2012 (NACP III). Adopting rights based approach, the first priority of this policy is to prevent HIV infection in order to ensure an AIDS-free generation. In addition, in order to facilitate prompt diagnosis, the policy focuses on ensuring access to medical treatment to prolong life. Treatment of parents is vital to maintain family cohesion and protect the best interests of children. And where families are affected by HIV/AIDS, the imperative is to ensure they are not excluded from the same services and opportunities as others. For families affected by HIV/AIDS the policy seeks to ensure their inclusion and access to services and opportunities.

However, the policy does not address the socio-economic dimensions of the epidemic specifically as it affects children.

NACP III focuses on ensuring that HIV positive children receive medical treatment and after-care, but the policy is silent on other social and environmental factors such as access to schooling, adequate nutrition and a safe environment. However, this policy framework seeks to broaden the focus, to address the needs of the overwhelming majority of children affected by HIV/AIDS, in recognition of the fact that the virus has a profound and permanent effect on their lives. The policy framework should recognise the need for a universal approach in addressing the needs of children affected by HIV/AIDS subjected to social exclusion, neglect and abuse. This implies that these children and adolescents should be provided with equitable access to social services and opportunities, without in any way compromising on the need to ensure prevention of infection among adolescents most at risk.

Despite various initiatives and concerns raised by the government, India does not have legislation and policy to safeguard AIDS affected orphans and vulnerable children. There are presently no specific policies that prohibit discrimination in access to medical services, education, employment, and housing, and protect the inheritance rights of widows and orphans. There is only the most limited access to relevant information and appropriate health care including clinical and preventive health care services, nutritional support, palliative and home based care. OVC are confronted with severe threats to their physical and psychological well-being including isolation, loss of income, educational access, shelter, nutrition, and other essentials. The AIDS pandemic has increased the urgency to address the psychological problems of children on a par with other interventions. It has resulted in a growing number of children who are unable to attend or continue in school because of psychological stress.

In response to the growing epidemic, the government of India has decided to provide free Anti-retroviral treatment to HIV positive parents and children. A new law is being drafted under which doctors will no longer be able to refuse treatment to people with HIV, and discrimination against children with HIV will also be banned. Harsher penalties for selling fake medicines or making claims about the effects of untested medicines are also likely to be included in the legislation (Alcorn 2003).

RESPONSE OF NON GOVERNMENT ORGANIZATIONS IN INDIA

There is no doubt that NGOs have played a vital role in prevention, advocacy and care but there is a pressing need for their further involvement,

particularly in relation to the provision of rehabilitation services to OVC. According to estimates there are approximately 470 NGOs working with vulnerable children in India and 30 works directly with AIDS orphans (SAATHII 2003). Family Health International in India is working with 22 partners in high-prevalence areas to address the needs of nearly 12,000 OVC. There are organizations in India such as the Naz Foundation and Solidarity and Action Against the HIV Infection in India (SAATHII 2003) who are doing commendable work for OVC. Through disease awareness and education efforts, NAZ helps prevent the spread of HIV and supports those living or affected by the virus. NAZ runs the Care Home, a Naz shelter for orphaned children and women living with HIV. On average, 170 patients and 80 family members access the facility for treatment and counselling each month. Currently, more than 25 orphaned children with HIV/AIDS reside at the home. To address the rising number of children who are orphaned or left vulnerable by HIV in the rural communities of Andhra Pradesh, SAATHII established the HIV/AIDS Orphan Community Care Programme. SAATHII provides medical care, nutrition, and psychosocial support to 2,500 children. In addition, SAATHII created a network of 10 NGOs through which affected children are reintegrated into families, schools, and communities. Francois-Xavier Bagnoud (FXB) is another international organization doing commendable work for OVC. It was FXB's initiative to declare an 'AIDS Orphans Day' to raise awareness of the situation of children affected by AIDS in India. FXB has also worked in Rajasthan on rural awareness projects that aim to alleviate the stigma attached to orphans whose parents have died from HIV/AIDS.

RECOMMENDATIONS

Orphans and other vulnerable children need support on many different levels, as do the families who care for them. Given the broad economic and social costs associated with the extent of the problems faced by OVC, there is a crucial role for governments in providing such support. Among the most significant areas of public provision in which governments could be involved most fruitfully are psychosocial support, socio-economic assistance, and human rights protection. Additionally, voluntary counselling and testing, prevention of mother-to-child transmission, home based care services and, in some areas, antiretroviral therapy could also alleviate some of the strain placed on families. To date, however, there has been no public response that has attempted to systematically map the dimensions of the problem in its full social and medical complexity, to identify what

resources are available to address them and to formulate a plan to guide how they might be co-ordinated and deployed. The development of policies and strategies specifically addressing the growing population of OVC is well overdue.

Given the significance of the impact of specific local conditions and environments on the problem, community inclusion is imperative. *A Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS*, a multi-organizational effort led by UNICEF, suggests that an effective public approach should be based on five key strategies: strengthening the capacity of families, mobilizing and supporting community based responses, ensuring access to essential services, ensuring that governments protect the most vulnerable children, and raising awareness to create a supportive environment. It is vital, then, that communities are involved in the policy process to produce long-term solutions that will be effective in addressing the problem. Yet there are urgent demands related to the situation of OVC that could be addressed through immediate public interventions. These include: identifying OVC in a community; increasing the capacity of communities, extended families and child-headed households to be able to take care of OVC through credit schemes, income generation, and so on; enabling OVC to continue attending school by waiving or reducing school fees, buying books, etc., or by ensuring they receive skills training; and changing legislation to protect children's rights, particularly in relation to inheritance.

It is evident that strategic interventions to address the situation of OVC demand identifying what kinds of services and policy changes are needed. Yet, the social and political relations of the major stakeholders involved are also critical. Accordingly, while communities need to be key players in the policy process, the effectiveness of their participation demands on-the-ground, regional and local government involvement, and their collaboration with community based organizations. A co-operative approach is required in which government and NGOs work together as equal partners to promote meaningful advocacy for OVC. This could involve establishing NGOs as extensions of state agencies, resulting in an enhanced mutual capacity for action and advocacy.

The 1997 and 2000 editions of *Children on the Brink* (USAID) consolidate existing knowledge from a wide range of sources. According to both versions, interventions must include five basic strategies: (1) strengthen the capacity of families to cope with their problems (2) mobilize and strengthen community based responses (3) increase the capacity of children and young people to meet their own needs through access to quality education, protec-

tion from exploitation and excessive labor, and building the capacity to care for themselves (4) create an enabling environment for children and families through such activities as ensuring basic legal protection through laws and policies to protect women and children, decreasing stigma, and behavior change interventions and (5) ensure that governments protect the most vulnerable and provide essential services.

CONCLUSION

In the face of the deepening crisis generated by HIV/AIDS, government leadership has been weak and resource coordination and facilitation have been fragmented. Organized programmes on HIV/AIDS have reached only a small fraction of the most vulnerable children, while the demand and need for guidance and capacity building to expand the response is mounting. So far, OVC have failed to receive the attention they deserve in poverty reduction strategies and other national development instruments. Non- government donors have also responded tardily and unsystematically to the situation. Clearly, the HIV/AIDS epidemic and its impact specifically on children is not yet seen as an urgent priority.

The deleterious social and economic impact of HIV/AIDS on children and their families derives from a complex combination of factors that exceeds the constraints on medical services and treatments. Such factors involve the fundamental social institutions of Indian life, such as families, workplaces and schools. It is these that demand immediate attention from public policy makers and non-government organizations. India has been struggling to provide basic amenities to the already existing vulnerable children. The stigma associated with HIV/AIDS has been a barrier to integrating children affected and infected by HIV/AIDS into mainstream society and the country is currently not equipped to deal with AIDS orphans.

In the face of this challenge the government and civil society need to mobilize resources to provide health care, education and shelter to these children in an environment that is conducive to their growth and well being. There is also a need to emphasize community care rather than institutional care, strengthening the coping capacities of families and communities, involve children and youth as active participants, build broad collaboration among key stakeholders in all sectors, apply a long-term perspective, and integrate with other prevention, care and support services. Despite the promises made, we are lagging behind in providing effective care and support to orphans and other vulnerable children. There is need to learn from the experience and initiatives of other countries and develop appropriate policy and law, human

rights, medical care, socio-economic support, psychological support, education, and community based programmes. The social costs of the AIDS pandemic are long-term and affect children disproportionately. Interventions must respond to the need for large scale and long-term efforts that address both the direct and indirect impact on orphaned children. Taking into account the diverse cultural and socio-economic settings in India, models of care need to be modified accordingly. To this end, recent guidelines developed by UNICEF can help to identify and target vulnerable communities, build national systems of care that support local coping, enhance organized community systems of care, strengthen information exchange and partnerships, and increase stakeholder participation in the care and protection of orphan and vulnerable children.

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