

CHILDREN INFECTED BY OR VULNERABLE TO HIV/AIDS:

**OVERVIEW OF CURRENT RESPONSE IN INDIA AND
RECOMMENDATIONS**

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This document provides an overview of an extensive set of activities that might be included in a response to children affected by or vulnerable to HIV/AIDS in India (OVC); information about who is currently implementing these activities and; suggested additional activities that could contribute to the OVC effort.

INTRODUCTION:

A comprehensive OVC strategy must be inclusive in order to actually reach vulnerable children and provide support to children affected by HIV/AIDS. Reports and interviews consistently reveal – in India and elsewhere – that laws and policies that are “on the books” are often not translated into action and the proposed beneficiaries are not benefiting.

The list of activities that has been included in this document is extensive. It includes categories related to policies and legislation, and it also includes action to influence their implementation. The list includes efforts to understand the situation of children affected by HIV/AIDS both as an advocacy tool to enlist support, as well as to design effective interventions. Basic to reaching the intended beneficiaries is the design and implementation of programming. Interventions must be increased to reach more children. Included in the list of activities is also the identification and evaluation of effective programs. Information is needed about what works and what does not work, with systems to facilitate the exchange and dissemination of this information.

CATEGORIES OF ACTION:

The following is a list of categories of activities that could be included in a comprehensive effort to address children affected by HIV/AIDS in India. This list of categories is repeated two times:

- The first includes a **description of the categories**;
- The second identifies **Organizations** that are implementing specific activities on the list; and some **recommendations of activities** that might contribute to an improved response to the growing number of children affected by HIV/AIDS in India.

NOTE: Levels Of Action: nationalsome states....more.... states...districts

The focus of the work in each of the categories below could be at central level, and/or at state level, or even at the district level. Some of the activities will need to be implemented at the central level (i.e. national legislation and policy analysis) and/or at the state level (i.e. state policy and implementation). A national level effort is necessary but not sufficient. The context for children affected by HIV/AIDS will vary between states and the response will be more effective if developed and implemented at the more local level. If states are the target of activities, then it will be necessary to decide whether to begin with the most severely affected states and, if so, the number of states to be included. The situation of children will vary throughout the state. In the states most affected by HIV/AIDS, the impact of the disease is often concentrated in specific districts. Some of the activities listed below might also be implemented at district level.

LIST #1 – General Description of categories of OVC activities

LEGISLATION and Regulation HIV specific AND also HIV related (i.e. child labor; regulation of orphanages)

Analysis

Recommendations

Implementation

POLICY: HIV specific (i.e. NACO policy) AND also HIV related (i.e. education of vulnerable children)

Analysis

Recommendations

Implementation

(The UN General Assembly Special Session (UNGASS) Declaration of Commitment on HIV/AIDS set specific targets for all signatory nations: “By 2003, develop and by 2005 implement national policies and strategies to build and strengthen government, family and community capacities to provide a supportive environment for orphans and girls and boys infected and affected by HIV/AIDS...” India has not met the target for 2003.)

PROGRAMMATIC GUIDANCE and PROTOCOLS – Government and NGO (i.e. pediatric AIDS protocols, guidance for counseling children, etc)

Analysis

Recommendations

Implementation

(In Kenya, for example, the OVC task force developed national programmatic guidance for implementing efforts to support children affected by HIV/AIDS.)

JUDICIAL, POLICE FORCE, NGO/CBO CAPACITY BUILDING

Training and sensitization for implementation of legislation and policy.

(In Ethiopia, for example, police were sensitized to the situation of street children and trained to work with them in a more appropriate manner. In Kenya, community organizations were trained to advocate on their own behalf to access improved government services. As a result of monitoring and reporting on the quality of care at a local primary health care clinic, the clinic staff was upgraded and better services were provided.)

PARTICIPATORY STRATEGIC and PROGRAM PLANNING - to achieve consensus, relevance, coordination, a commitment to implement, and ongoing monitoring of strategic action

(In Malawi, for example, a National Task Force on Orphans was established in 1991 with representation from national and district government, NGOs, CBOs, faith-based organizations and UN agencies. The members of the task force, with advisors, developed national policy guideline for the care and assistance of orphans. In Zambia, a multisectoral OVC structure was formed as one of the technical expert working groups within the Country Co-ordinating Mechanisms to advise on various aspects of the national response to HIV/AIDS.)

SITUATION ANALYSIS AND NEEDS ASSESSMENT – Data and Description

Numbers

Impact of HIV/AIDS on children

Current Response – family, community, NGOs, FBOs, government, etc

Gaps in response

Monitor situation of OVC over time

Quantifying the problem and describing it in a way that allows for recommendations and action to flow from the information has been recognized as central to the development of a meaningful strategy for action. A Rapid Appraisal methodology has been developed and recently implemented by USAID, UNICEF, WFP and POLICY Project in multiple countries in Africa. The results of situation analyses have been used to build commitment and to formulate plans for actions in a number of countries, including Zambia, Botswana, Nigeria, etc.)

PROGRAMMING

Identify and document models of intervention appropriate to Asia

Evaluate effectiveness and cost of interventions – expand knowledge base

Develop tools/training for improved programming

Increase (scale-up and scale-out) effective interventions – public and private

1. Interventions focused on OVC – i.e. identifying and supporting the families of PLHA through VCT, PMTCT, and ARV interventions; and
2. Integrated interventions – i.e. integrating support to children affected by HIV/AIDS into related efforts, such as community development efforts, street children interventions, education projects.

(Programming must address the multiple needs of children, including issues related to food insecurity, nutrition, economic stability, psychosocial support, succession planning, AIDS prevention among vulnerable children, protection of children without adult protection, increased access to education, shelter, vocational support, access to health care for infected and affected children, stigma and discrimination.)

INFORMATION DISSEMINATION AND INFORMATION EXCHANGE

Network identification, development, strengthening, and maintenance

Link with existing networks that focus on various related areas

Electronic networks

Print documentation dissemination; newsletters

Workshops to exchange information and skills building

(intra/inter-state; intra/inter-country; intra/inter-region)

(At the global level there are electronic listserves with participation from India – i.e. CABA listserve and the REPSSI listserve.

Implementing organizations in some countries in Africa have developed non-formal and formal networks for the purpose of information exchange through newsletters and/or site visits and workshops)

REGIONAL

Foster development and implementation of regional agenda

Regional consultation and information exchange

(At the regional level, there are a growing number of efforts focusing on children affected by HIV/AIDS as the impact of the disease continues to increase in other countries in Asia. These efforts in other countries in the region could both benefit from lessons learned in India and, at the same time, could provide an excellent resource to the development of effective action here in India.)

GLOBAL

Bring southern Asia context and experience “to the table” in the development of the global agendas and action.

(At the global level, discussion and guidelines related to children affected by HIV/AIDS has been informed by experiences encountered in countries with very high prevalence - East and Southern Africa. Programming advice for that context may be less realistic in countries where the proportion of vulnerable children who are affected by HIV/AIDS is as low as it is in southern Asia - and probably also in southeast Asia, and even West and Central Africa as well. Documenting and learning from action that is taken in India can provide an important contribution to the global body of knowledge, resulting in improved programming for children affected by HIV/AIDS in other countries of the world, especially in countries where the HIV/AIDS prevalence is relatively low and where there is a high proportion of vulnerable children due to other causes.)

List #2 – Who is doing what (current action) and Potential Next Steps (indicated by an asterisk – “**”)

(The “Next Steps” that are preceded by two asterisks [“**”] indicate activities especially related to policy and legislation.)

LEGISLATION and Regulation (HIV specific AND also HIV related – i.e. child labor, regulation of orphanages)

HIV/AIDS legislation has been drafted by the Lawyers Collective. They will put it on the web next month and then submit it to the government. The legislation was written with input from twelve consultations across the country.

The Lawyers Collective has completed a review of national legislation with regard to HIV/AIDS. The report has been published: *Legislating an Epidemic - HIV/AIDS in India*.

Next Steps:

**Analyze the new HIV/AIDS legislation from the perspective of children affected by HIV/AIDS together with the participants of the December, 2004, OVC policy meeting hosted by Alliance. Work with the policy advisory group and the Lawyers Collective to identify the process by which the draft legislation can be reviewed before it is given to the Government.

** Conduct a systematic analysis of state law with regard to HIV/AIDS and OVC

** A National Law on Children is currently being written; a committee has been formed to develop this Law. Analyze the draft with regard to vulnerable children affected by HIV/AIDS

** Analyze existing law related to vulnerable children; identify laws that, with better implementation, could improve the well-being of children affected by HIV/AIDS; and identify practical recommendations that could improve implementation. Be sure to include the Adoption Acts and Guardianship Acts in the analysis.

POLICY (HIV specific AND also HIV related – i.e. education for vulnerable children, child protection, etc)

Alliance/India with its local partner, MAMTA, has initiated policy mapping and analysis, conducted through the review of existing policies, and some legislation, in the context of children affected by HIV/AIDS. The focus of the analysis is National policy and State policy in Delhi (plans are to include AP at a later date) Recommendations will be included in the final report, which will be completed toward the beginning of 2005.

NACP II, which guides NACO funding, does not address children affected by HIV/AIDS. NACP III is currently being drafted.

Next Steps:

** In conjunction with Alliance and the Alliance partners and policy advisory group, identify and contribute to the “next steps”, following the completion of the policy analysis initiated by the Alliance. For example, the policy analysis may result in recommendations for strengthening or implementing existing policy or for repeating the analysis in other states.

** Identify and support the process by which to influence the inclusion of children affected by HIV/AIDS in NACP III

PROGRAMMATIC GUIDANCE and PROTOCOLS – Government and NGO

India has received Global Fund support. Children are mentioned in the proposal, but there are no operational guidelines as to how many children and adults will be targeted. The government of India, along with donors, made a commitment to a significant expansion of VCT sites, PMTCT interventions, and the provision of ARVs.

Next Steps:

** Analyze implementation plans for Global Funds and identify how children affected by HIV/AIDS are included in those plans, including children who are HIV-positive.

** Identify how (and whether) HIV+ children are receiving treatment and how (and whether) they are included in the plans that are being developed to increase access to treatment. (Refer to analysis conducted by SAVE/UK on barriers to treating children). Include prophylactic and opportunistic infection treatments. (There is a protocol for treating children with ART that is included in the Global Fund proposal.) Identify recommendations to increase the inclusion of HIV-infected children in plans to expand access to HIV/AIDS treatment.

** Identify and analyze guidance for children and young people who are receiving VCT, including issues related to confidentiality and consent. Conduct assessments with regard to the treatment of young people and children in the context of VCT, according to approved guidance. (FHI is currently preparing a protocol to address children, especially on issues of confidentiality and consent)

** Assist NGOs to develop protocols related to children infected and affected by HIV/AIDS, with careful attention to the rights of the children involved, including protocols related to ARV, VCT, PMTCT, STI treatment, HIV/AIDS prevention, institutionalized children.

JUDICIAL, POLICE FORCE, NGO/CBO CAPACITY BUILDING

There are laws and there are government systems and schemes that protect and provide for children's welfare in India. As DV Rao writes when referring to some laws, they "remain on paper. There is no adequate follow up to ensure that the well intended provisions of the law do not remain a theoretical exercise and are not circumvented due to failure to put them into practice in a consistent manner". Children, their families, and even their communities are not able to bring their "voice" forward to demand that the law is enacted or that they receive benefits they are entitled to.

The Lawyers Collective has provided capacity building on the Juvenile Justice Act, providing training on what can be expected from implementation of the Act and other issues to empower people to understand their rights under the law.

Next Steps:

*Identify possible areas of intervention wherein children affected by HIV/AIDS are not receiving the protection or benefits to which they are entitled under Indian law. Assess whether there is a way to influence sustainable and reasonable change – whether through training, monitoring, sensitization, advocacy, etc. For example, train NGOs to recognize the rights of their beneficiaries under the law and to help them access protection and benefits to which they are entitled through existing programmes/schemes. (This would entail linkage with ministries such as the Department of Women and Child Development and the Ministry of Social Justice and Empowerment, as well as NACO. Similar work has already been initiated to support IDUs) Implement and evaluate various approaches, scaling up those that are most successful. Work with related networks for implementation of laws and policies (i.e. organizations that focus on child rights issues)

PARTICIPATORY STRATEGIC AND PROGRAM PLANNING

There has not been a situation analysis of children affected by HIV/AIDS in India to provide information for strategic planning.

Alliance/India and FHI/India have each hosted a meeting of their partners and other stakeholders to share information about their activities (Alliance – 2003; FHI – 2004) Government representatives were invited to make presentations at these meetings.

Alliance hosted an advisory group of stakeholders on September 10, 2004 to discuss the policy analysis that they are conducting with their local partner, MAMTA. A second meeting of this policy advisory group was held on Dec 17, 2004, at which time objectives of this group were identified.

Next Steps:

* An OVC task force could be created at national level to identify priorities and ensure that action is taken to move an agenda forward to address children affected by HIV/AIDS. (It is as yet unclear whether the advisory group hosted by the Alliance will evolve into an OVC task force)

** As follow-up to upcoming national consultations, support States to develop a comprehensive response to children affected by HIV/AIDS, using a participatory approach

** Link with other related networks for advocacy and information exchange (i.e. networks that focus on child rights)

SITUATION ANALYSIS AND NEEDS ASSESSMENT – Data and Description

ILO conducted a study examining the impact of HIV/AIDS on the socioeconomic status of people living with HIV/AIDS and their families, including the impact on education and child labor. FXB produced a document estimating the number of OVC and describing the situation of OVC.

Next Steps:

** Conduct situation analyses of children affected by HIV/AIDS and the resources that are available to provide support. The target area – whether it focuses on national, state or district level - would need to be determined based on feasibility, usefulness, and political will. The situation of children affected by HIV/AIDS will vary by state, district, and even by the more immediate context. The analysis can contribute to the formation of more relevant policy, guidelines, and resources distribution. In areas where plans to implement programs are being developed, a situation analysis in the districts of implementation would contribute to the design of more effective interventions. (The AIM (AIDS Impact Model) included in the Spectrum Module of Futures Group is an effective tool for this purpose)

PROGRAMMING IMPLEMENTATION

FHI/India, with USAID support, has implemented numerous types of activities that include a focus on children affected by HIV/AIDS, working with a variety of different types of local organizations, providing capacity building and resources. Alliance/India has supported the integration of support to children affected by HIV/AIDS into community development activities and other local organizations involved in HIV/AIDS, providing capacity building and resources. In 2005, UNICEF will begin to address the provision of care and support to women and children in conjunction with PMTCT interventions. ILO has supported a pilot project in which they linked an income generating project to a project that provided support to people living with HIV/AIDS and their families, including children. PCI, with CDC support, has implemented community-based care and support activities in Pune and Salem. There are multiple other organizations supporting local interventions related to children affected by HIV/AIDS, including: World Vision, PCI, PLAN, Save the Children, ActionAID, NAZ, Salaam Balik, faith-based organizations, and many local organizations.

Next Steps:

* Increase the number and quality of interventions to provide support to children affected by HIV/AIDS. Current programming is covering a limited geographical area. Identify other states/districts where there is a gap in the availability of these types of activities and expand the reach of interventions to provide support to the increasing number of children affected by HIV/AIDS.

PROGRAMMING TOOLS

FHI/India has developed materials and a methodology for HIV/AIDS prevention and life skills training to be implemented by local organizations working with vulnerable children. International HIV/AIDS Alliance has produced a toolkit to help local organizations address various technical issues related to programming. ILO is developing a manual on HIV/AIDS for children.

Next Steps:

* Identify barriers to implementation; develop methods by which to help implementing organizations overcome these barriers; and provide training and support to address barriers in order to achieve more efficient and effective interventions that can be sustained.

PROGRAMMATIC RESEARCH and EVALUATION

AIRTDS, with support from Community REACH, is conducting research on the community based model of intervention involving the support of foster families. Alliance/India is planning to initiate formative research that will provide information to improve interventions to support children affected by HIV/AIDS. Small loan programs are being implemented in self-help groups in Tamil Nadu. ILO is considering plans to evaluate this type of intervention

Next Steps:

*Conduct evaluations and research of intervention models to identify what works and what does not work and how to increase the reach of effective programs.

* Identify, synthesize, and document lessons learned from programming in India

*The situation of children affected by HIV/AIDS will vary by state, district, and even by the more immediate context. Conduct formative research to inform interventions that address the specific context of children in the proposed area of intervention. Include identification of local barriers and local resources that are available to provide sustainable support.

INFORMATION DISSEMINATION AND INFORMATION EXCHANGE

Next Steps:

* Develop and implement systems for the exchange of information among OVC stakeholders and implementing organizations. This could be in different formats – i.e. electronic, newsletter, etc.

* Support opportunities for information exchange, skills building, etc.

* Link implementing organizations and support program-to-program mentorship and exchange.

* Link to networks of information that focus on related areas such as education for vulnerable children, street children, child rights, etc.

REGIONAL (South and Southeast Asia)

There has been discussion in the Region about convening a regional OVC meeting. OVC programming is being implemented in other Asian countries, including Thailand, Cambodia, and Nepal. OVC policy work has been initiated in Cambodia, including a review of legislation related to HIV/AIDS. Stakeholder meetings were convened in 2004. ILO regional office has expressed an interest in pursuing regional work related to child labor and HIV/AIDS. (In May, 2003, they produced a report on HIV/AIDS and working children in Nepal).

Next Steps:

**Participate and contribute to regional consultations

** Synthesize information about OVC efforts in other Asian countries, as well as in India. Implementing organizations are struggling with similar barriers that are encountered in India. Facilitate the exchange of information and lessons learned between countries.

GLOBAL

Next Steps:

*Bring southern Asia context and experience “to the table” in the development of the global agendas and action. Representation by India in Global Partnership process/meetings and contribute to the global research agenda for the purposes of

- Information exchange:
- to develop common strategies based on successes and lessons learned
- strengthen cooperation and coordination with public and private partners, donors, and other international organizations

Conclusion:

According to the National AIDS Control Organization (NACO), the number of Indians living with HIV has grown from 200,000 in 1990 to 5.1 million in 2003. The proportion of orphans due to AIDS increases almost a decade after the initial infection of their parent(s), reflecting the period of time between when a person becomes infected and when they experience AIDS, illness, and death. Commitments to prevention and care activities have recently increased in India, both by government, and by public and private donors. These include commitments to increase VCT sites, PMTCT interventions, and the provision of ARVs. These activities will result in increased numbers of individuals and their families, including their children, who know their HIV status. In addition to the increasing numbers of children who will experience the loss of a parent due to AIDS, there will also be increasing numbers of families who will experience the grief, the stigma, and the discrimination that will accompany the knowledge that they, or a family member, are HIV infected. At the same time, there will be increased opportunities to identify families, and their children, in order to link them with the support that is available to help them deal with the impact of HIV/AIDS.

A comprehensive response to children affected by HIV/AIDS in India will include a broad array of activities, requiring numerous partners with a variety of skills. Though families and communities have been responding to the needs of children affected by HIV/AIDS as they began to experience the impact of the epidemic, increased support from donor funding in the last four years has provided a boost to the ability to support local organizations in their efforts. USAID, with FHI IMPACT as its implementing partner, has provided funding and capacity building to numerous local organizations to provide support to children affected by HIV/AIDS. Alliance/India has worked with local implementing partners to integrate the needs of children affected by HIV/AIDS into community development activities. At the national level, there have been workshops and meetings for the purpose of information exchange and capacity building that were hosted by FHI and also by Alliance. The Lawyers Collective, as background to the drafting of HIV/AIDS legislation, reviewed legislation related to children affected by HIV/AIDS. MAMTA, a local partner of the Alliance, has begun a review of policy and legislation as it relates to children affected by HIV/AIDS. In September, the Alliance hosted a meeting of stakeholders to discuss this review. A follow-up meeting was held on December 17. At the same time, there has been increasing interest on the part of the government of India and UNICEF to initiate a coordinated and comprehensive response to children affected by HIV/AIDS.

Recommendations:

In the upcoming months, commitments to move the agenda forward will result in the identification of objectives and action steps. It will be important that this process involve the stakeholders who have the skills and experience to inform the process. A participatory process will be imperative in order to achieve consensus and commitment to action. Though there are numerous potential activities that are identified in List 2, above, it is as yet unclear which of these will be identified as priority activities in the joint efforts that are currently being initiated.

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