THE LEA TOTO PROJECT

An evaluation report of a community based project for the care of HIV+ orphans and their families

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USAID/Kenya
P. O box 30261
Nairobi

LEA TOTO EVALUATION REPORT

Table of Contents

1. Executive Summary

The increase in the number of orphaned children due to HIV/AIDs is reaching alarming proportions in Kenya. The number of children living with HIV/AIDS in Kenya by 2000 was estimated at 850,000, and will increase to 1.5 m by the year 2005[1]. There are several efforts under way in Kenya to address the HIV/AIDS problem. USAID supports Catholic Relief Services (CRS) to provide technical support to the Lea Toto project, a two-year community-based activity which enables children to remain with their caregivers in their own communities. The project is located in Kangemi a slum on the outskirts of Nairobi. The overall goal of the project is to improve the capacity of the Kangemi community to provide holistic care within a family setting for HIV positive orphans living in the community. The primary purpose of the evaluation was to review progress made towards reaching this goal.

1.1. Project Objectives:

The Lea Toto project has four objectives:

- By the end of the project, 200 HIV+ children will have received physical care and essential medical supplies to alleviate their suffering;
- By the end of the project, psychological and moral support will have been provided to 200 HIV+ orphans and their families;
- By the end of the project, the Kangemi community will have identified or established six sustainable strategies to enable the community to cope with the needs of AIDS orphans;
- By the end of the project, the organizational capacity of the Lea Toto project to manage community-based support to orphans will be improved.

1.2. Findings:

Physical care and essential medical supplies: During the two-year period the project provided physical care to a total of 152 children out of a targeted 200. However the Lea Toto project has been able to reach a lot more children including those not infected but who are family members of infected children. Data used to report achievements do not currently reflect these accomplishments since the program goal is to reach HIV+ children.

There is a lot of stigma attached to HIV/AIDS within the Kangemi community and this has made it difficult for the project staff to identify and enroll HIV+ children. The children receive medical treatment for opportunistic infections, but current procedures do not allow clinical staff to identify symptoms of drug reaction that might occur as a result of long term use of drugs.

[1] AIDS in Kenya, NASCOP, 1999

Psychological and moral support: Lea Toto has been able to initiate support groups in Kangemi thus enhancing participation in counseling services given to caregivers. The program has yet to develop a strategy to ensure that children play an active role in their own lives in terms of living with HIV/AIDS. Many children understand that they are unwell but they do not know exactly what is wrong with them. Counseling is provided directly to the caregiver enrolled in the program and not to children. Child–centered counseling is needed to enable caregivers and Lea Toto staff to better address the psychological needs of the HIV+ children and their siblings.

Sustaining community strategies: Lea Toto has encouraged community health workers working with other NGOs in the Kangemi area to participate in Lea Toto training sessions and has provided some income generation opportunities to a few caregivers. It would seem from the evaluation findings that because community ownership and involvement was not a focus of the design, the Kangemi community tends to see Lea Toto as a service provided to them from the outside. Staff expertise also seems to focus on individual and family level care and counseling and not on mobilizing communities to facilitate community ownership and participation.

There are no other HIV/AIDs focused activities in the area hence the demand and expectations of Lea Toto are beyond what they can currently provide. To achieve results from community mobilization efforts Lea Toto needs to ensure that efforts resonate with the priority needs of the community. As it is currently the community approach was designed without the involvement of the community.

Lea Toto organizational capacity: All staff at Lea Toto demonstrated extensive experience with HIV+ children gained from their previous work at the Nyumbani orphanage and showed a lot of dedication to their work. Lea Toto staff felt that CRS technical support contributed to the implementation of the program. However, the capacity building potential of CRS was not fully exploited by Lea Toto over the two-year period. There is a need to enhance this component of the program to provide Lea Toto staff with technical and management skills necessary to sustain the program.

The current financial management and reporting system is reliable and efficient. However consideration should be given to providing Lea Toto the option to submit electronic expenditure reports to CRS as this will save time and financial resources without compromising financial accountability. While there exist good financial and clinical skills within the management of Lea Toto, there is need for technical leadership especially with regard to programming and community mobilization.

The team recommends that Lea Toto management reconsider staff terms of service and emoluments to retain high quality staff. It would also be useful to have a steering committee at the Board level that would include people outside the board but who can bring some administrative and programmatic experience to the program.

Potential contribution to OVC: Lea Toto offers a unique model with the potential to inform efforts that focus on children infected and affected by HIV/AIDS on an international level. Lea Toto is a community-based activity that was initiated by an institution-based program thus giving a new perspective on how institutional facilities can operate more effectively. There are, however, many challenges that need to be addressed. Among these are the need to put in place a holistic approach to the care of PLWHA; the effect of stigma on program implementation; linking income-generation opportunities with care of children; resolving the issue of community-based versus community- owned initiatives; and linking care and support with prevention activities.

1.3. Recommendations:

Based on the findings of the assessment, the evaluation team recommends continued support of the Lea Toto project to increase coverage. The team recommends that the Lea Toto program reconsider its community approach and find the necessary technical support to increase community outreach and involvement. Lea Toto should initiate strategic planning with potential partners in and outside the community to increase access to care and support VCT, HIV/AIDs prevention efforts and reproductive health information.

In terms of capacity building it is recommended that Lea Toto improve its technical capacity and make more effective use of CRS' expertise. CRS should work with Lea Toto to allow a streamlining of financial reporting. A steering committee comprising of various partners could help streamline administrative roles and relationships between Nyumbani and Lea Toto. Finally the current monitoring and evaluation plan needs to be improved to collect optimal data for management and implementation of the Lea Toto program.

2. Background

2.1 The Situation of Children Affected by HIV/AIDS in Kenya

It is estimated that 13.3 percent of the adult population in Kenya is living with HIV/AIDS, with the prevalence rate generally higher in the urban areas. The consequences of the AIDS epidemic go well beyond the massive number of preventable deaths. AIDS is having devastating impacts on children, families, and communities. Among those most affected by the disease are children orphaned or otherwise affected by its impacts. The number of children orphaned or otherwise made vulnerable by HIV/AIDS is enormous and continues to grow. It is estimated that the number of children whose mother or both parents have died as a result of AIDS in Kenya by the year 2000 was 850,000 and that this figure will go up to 1.5 million by 2005 (AIDS in Kenya, NASCOP, 1999). These estimates include only children less than 15 years old who have lost either their mother or both parents as a result of AIDS and they greatly underestimate the number of children affected by the disease. The statistics do not include the vast number of children who are living with parents who are ill, often becoming the primary care providers for their parents and for their siblings. Others are living in households where the financial and emotional capacity is over-stretched as a result of caring for increased numbers, often orphaned children. Though the statistics on orphans include children only until they reach age 15, those who are older continue to live with the effects of HIV/AIDS - as a result of trauma and grief; as heads of households; or other circumstances, such as poverty, that are exacerbated by the impact of AIDS. Often, these children and adolescents are living in situations by which they too become more vulnerable to becoming infected. The USAID report, *Children on the Brink 2000*, estimates that over 1.2 million children have already lost their father, mother or both parents as a result of AIDS and of other causes in Kenya. This latter estimate provides data more relevant to programming because program planners and implementers do not generally distinguish between those children whose father has died versus those whose mother has died, or children whose parents have died as a result of HIV/AIDS versus other causes.

Who are the Children and Adolescents Affected by HIV/AIDS?

Children/adolescents identified as vulnerable in communities affected by HIV/AIDS might include:

- Those whose parent (mother or father) or both parents have died;
- Those who live in a household with a parent or other family member who is ill;
- Those who live in families in which resources – financial and emotional – are over-stretched as a result of increased numbers of children for whom they are responsible;
- Those who live in communities severely affected – economically and socially – by the impact of HIV/AIDS

2.2 Overview of the Lea Toto project

The Lea Toto project is a program of the Children of God Relief Institute's (COGRI), as is Nyumbani Orphanage. Nyumbani was founded in 1992 by Father D'Agostino to provide care for children with HIV/AIDS. The orphanage currently provides an extensive array of services for 65 children, including education, nutrition and comprehensive medical care. Recognizing that the orphanage was unable to provide direct support to the growing number of HIV+ children in the Nairobi area, Nyumbani initiated the Lea-Toto/Nyumbani Program in 1998, as a community-based activity by which children can remain with their caregivers in their communities. This project is a mobile outreach activity designed to provide medical care and support to HIV+ children and their families in the slums of Nairobi.

In 1999, USAID provided funds to Catholic Relief Services (CRS) to support COGRI/Nyumbani to implement a community-based program in the Kangemi area of Nairobi for two years, from October 1, 1999, to September 30, 2001 called Lea Toto/Kangemi (henceforth referred to in this report as "the Lea Toto project). Kangemi is a slum area located in the western parts of the city, with an estimated population of 72,000. The location was chosen for the site of Lea Toto because, unlike many of the slum areas surrounding Nairobi, there were no development agencies that were already providing care for people living with HIV/AIDS in Kangemi.

Evaluation of the Lea Toto project – Key Assessment Areas (Appendix 1 - SOW)

- Achievement of goals and objectives
- Financing, management and reporting mechanisms
- Contribution to community-based care of HIV+ children and other children affected by HIV/AIDS in Kenya
- Challenges/opportunities and Lessons Learned

2.3 The Lea Toto project Evaluation

This report documents an evaluation of the Lea Toto project, which took place between April 30 and May 11, 2001, and involved eight team members. The team consisted of representatives of Lea Toto, Nyumbani, CRS, UNICEF/Kenya, USAID/Kenya and USAID/Washington (See Appendix 2 – List of team members). Individual interviews with one or two interviewees were conducted with 29 people, including the Nyumbani/Lea Toto founder, representatives from the COGRI/Nyumbani Board of Directors, project supervisors and staff from Nyumbani and from Lea Toto, representatives from Kenya government and from local organizations, and opinion leaders. Separate focus group interviews were conducted with Lea Toto beneficiaries, community health workers, and Lea Toto staff (See Appendix 4 – List of interviewees); and a meeting of stakeholders was convened, including twenty-five participants (See Appendix 5 – Stakeholders meeting). All interviews were conducted by at least two members of the evaluation team. The objectives of the evaluation are listed in the box to the left and the following sections of this document reflect those evaluation objectives. (See Appendix 1 – SOW; Appendix 3- Methodology).

As a sister-organization to the Nyumbani orphanage, Lea Toto offers a model for programming whereby community efforts have been launched by an institution and supported to initiate community activities. These activities have the potential to reach a much greater number of children than could otherwise be supported through the orphanage. In preparing for the evaluation, the team could identify no other documented example of the type of model offered by the Nyumbani-Lea Toto effort that focuses on HIV+ children and their families. Thus, the project can play an important role in informing similar efforts in Kenya, as well as globally.

Because there is a dearth of experience with this type of intervention to address the needs of children infected by HIV/AIDS, Lea Toto has been tasked with implementing this unique set of activities without the benefit of lessons learned from others. The evaluation has provided an opportunity for Lea Toto and its partners to examine what they have learned during the year and a half since the program began and to strategically plan for the next phase of operation.

The following section includes the results of the assessment, categorized according to the specific areas of focus set forth for the evaluation team by their scope of work.

3. Results of the Lea Toto Evaluation

3.1. Achievement of Goals and Objectives

> ***Lea Toto project Objectives***
>
> - Physical care to 200 HIV+ orphans and their families
> - Psychological and moral support to 200 HIV+ orphans and their families.
> - Six sustainable community strategies to enable community care of AIDS orphans.
> - Improved organizational capacity of Lea Toto project

The over-arching goal of the Lea Toto project is to "*improve the capacity of the Kangemi community to provide holistic care within the family setting for HIV+ orphans living in this community*". Four objectives were identified in the project proposal to achieve that goal, as summarized in the Text Box to the right. A primary purpose of the evaluation was to review progress in reaching these original objectives. Through interviews and review of written reports, the evaluation team identified components of the Lea Toto interventions that contributed toward achieving its objectives and components that did not. Related to the latter - those that detracted from Lea Toto's forward movement toward achieving its goal - the team attempted to identify potential recommendations that might improve program functioning (see Appendix 6 – Questionnaire tools). Thus, the findings of this evaluation can be used as input to a strategic planning process to guide the Program in its next phase of operation.

Objective 1: *By the end of the project, 200 families with HIV+ orphans will have received physical care and essential medical supplies to alleviate their suffering.*

Accomplishments:

- 152 HIV+ children have been enrolled in Lea Toto, 20 of whom have died;
- 140 caregivers of these children have been trained in home-based care of HIV+ children;
- Enrolled children are given prophylactic antibiotics, multi-vitamins, paracetamol to use as needed for pain and fever; and they are treated for opportunistic infections;
- Families of enrolled children are provided medical care as needed;
- 52 beneficiary families have been provided with intermittent food supplies;
- Caregivers and Lea Toto staff describe improvement in physical well being of beneficiary children.

Observations:

Lea Toto has identified and provided on-going medical care to 152 HIV+ children and their families. This includes prophylactic medication, as well as diagnosis and treatment of opportunistic infections. Caregivers, as well as staff at Lea Toto and Nyumbani, identify marked improvement in the health of Program beneficiaries. Though Lea Toto targets HIV+ orphans, in fact the

Program also provides medical and other care to family members of HIV+ children and to children who are not orphans. The infected children are not all orphans; many are living with their mothers who are also HIV-infected. In addition, medical care is provided to HIV-negative caregivers, as well as other children living in the household. The latter children, though not HIV+, are vulnerable children who are affected by HIV/AIDS. Data used to report achievements of Lea Toto do not currently reflect these accomplishments because the stated objectives include only HIV+ orphans.

Identification and enrollment of HIV+ children has been difficult for Lea Toto. Stigma regarding HIV/AIDS within the Kangemi community is high. Interviewees report that a contributing factor to the reluctance of caregivers to be associated with Lea Toto is the stigma identified with the program as a result of its exclusive focus on children who are HIV+. Caregivers who do enroll children often express extreme concern that others in the community, including family members, might find out that they are utilizing Lea Toto services.

On-going prophylactic treatment with antibiotics is provided to protect HIV+ children from dangerous opportunistic infections. At the same time, this creates a medical condition among the recipients that necessitates the availability and provision of even stronger (and not commonly available) antibiotics when the children become ill. Therefore, cessation of medication provision currently provided by Lea Toto would be potentially harmful to children now benefiting from the program. In addition, Bactrin is utilized as an ongoing prophylactic for enrolled children. Current procedures do not enable clinical staff to identify symptoms of drug reaction that might occur as a result of long-term use of this sulpha based medication.

Objective 2: *By the end of the project, psychological and moral support will have been provided to 200 HIV+ orphans and their families.*

Accomplishments:

- 142 caregivers receive regular counseling from Lea Toto staff;
- Enrolled beneficiaries and their families are visited at home by Lea Toto staff;
- Four monthly support group meetings for caregivers are implemented by Lea Toto;
- As a result of the Lea Toto support groups, some caregivers have begun to provide informal support to each other outside of the Lea Toto initiated activities;
- Lea Toto has tested 800 children for HIV, providing pre- and post-test counseling to their caregivers;
- Lea Toto has tested 473 adults for HIV, providing pre- and post-test counseling.

Observations:
Counseling is provided to all caregivers of Lea Toto beneficiary families. Regular support groups have been initiated and are attended by caregivers. In fact, informal networks of caregivers have been fostered as a result of the Lea Toto initiated support groups and some members have begun to informally provide support to each other.

Few of the children know their sero-status and even when they reach the age when they are likely to become sexually active, the program has not yet developed a strategy to ensure that children play an active role in their own lives in terms of living with HIV/AIDS. This may be based on an implicit assumption that the child will die before becoming sexually active. In addition, because of the stigma and the reluctance on the part of caregivers to acknowledge that the child is HIV-infected, many children understand that they are unwell but do not know exactly what is wrong with them, living with both their own and their caregivers' anxiety without ever knowing the truth.

Currently, counseling is provided solely by staff members, and concern has been expressed that there are not enough staff members available to meet the needs of their beneficiaries. Counseling is provided to the caregivers enrolled in the Program, not directly to children. Therefore, child-centered counseling is needed to enable the caregivers and/or Lea Toto staff to better address the psychosocial needs of the HIV+ children and their siblings. Though staff members have attended counseling training, the current ability of the staff to address the child-related needs of their beneficiaries should be assessed and technical assistance provided where this support is indicated. For example, interviewees identified a gap in the ability of Lea Toto to work with caregivers in planning for alternative care for the children should the parent become ill or die (76 of the HIV+ children enrolled in the Program are being cared for by a single mother who is likely to also be HIV-infected). This is an especially important area to consider because a large proportion of the caregivers does not inform other family members of the serostatus of the children. Therefore, other family members do not know about the special medical needs of those children.

Lea Toto entered the Kangemi area because it was under-served in terms of care for people living with HIV/AIDS and their families. This dearth of related activities with which to link strains the capacity of the Program to address the needs of the families who are being identified through their testing and care activities. A challenge facing Lea Toto in the next phase of operation will be to facilitate and maximize programmatic linkage with related programs both within Kangemi and outside of Kangemi in order to improve access to holistic care for its beneficiaries.

Objective 3: *By the end of the project the Kangemi community will have identified or established six sustainable community strategies to enable the community to cope with the needs of AIDS orphans.*

Accomplishments:

- 25 community health workers have been trained by Lea Toto;
- Income generating activities have been implemented:
  - 30 caregivers were trained
  - 11 caregivers received second hand clothing to raise income
  - one co-operative group is producing handicrafts
- 16 youth have been trained in HIV/AIDS prevention
- Community outreach has reached 3,647 people in Kangemi

Observations:

Community health workers (CHWs) who are affiliated with other NGOs within the community are participating in regular training sessions conducted by Lea Toto. They are trained to provide information and education regarding HIV/AIDS in the community and to refer community members to Lea Toto for counseling when necessary.

Of the 25 community health workers (CHW) trained, 11 remain active. Because of the concern of Program beneficiaries for the confidentiality of HIV serostatus, they do not allow these CHWs to work with them in the community unless the CHW is someone they knew before becoming involved with Lea Toto.

Lea Toto has attempted to provide income-generating opportunities to caregivers. Training was provided to 30 caregivers and second-hand clothing was provided for sale to 11 families. Among those caregivers who received training in income generating or second-hand clothing, only two recipients remain active in sustained income generating activities.

Widespread community outreach was accomplished with the support of foreign volunteers who were temporarily available to Nyumbani and participated in door-to-door outreach activities. These activities are not on going.

Identification and development of community-owned strategies to enable the community to provide continuing care to HIV+ orphans has been a major challenge for the Program. Lea Toto seems to be viewed by Kangemi community members as a service provided to them from outside of the community. This perception influences the type of involvement by community members in providing on-going support to children other than those for whom they are the primary caregiver. Community ownership and involvement was not a focus of the intervention from its inception, having originally been developed without community input or partners and situated in a site adjacent to, but outside of, the Kangemi slums. In addition, staff expertise includes a strong focus on counseling and care at the individual and family level, but

does not include strength or focus on mobilizing communities to facilitate community ownership and involvement. The baseline survey, sometimes used as a tool to mobilize community opinion leaders around issues of concern to the community, did not involve community members and was limited in its ability to inform program implementers about community-felt needs and structures that could support community mobilization around HIV/AIDS related issues. Therefore, Lea Toto staff is responsible for all interventions and is faced with a great deal of dependency and high expectations on behalf of the beneficiaries, with insufficient community support or volunteer activity.

The decision to work in the Kangemi slums was partially influenced by the lack of other HIV/AIDS activities already present in the area. There are, therefore, huge gaps in meeting the many HIV-related needs in that community. These needs are in addition to the unemployment, poverty, and other problems that affect the ability of Program beneficiaries to handle the additional stress imposed by chronic illness and death. Even if Lea Toto were to increase its attempts to mobilize the community around sustainable strategies to care for HIV+ children, their attempts may not ultimately meet with success if their efforts do not resonate with the community as a priority for action.

To date, efforts to achieve Objective 3 have been unsuccessful. There are a number of possible explanations: 1) lack of technical expertise in community mobilization; 2) the target of the Program (HIV+ orphans) may not resonate with community-felt needs; 3) Program development did not incorporate community input or community-felt needs from inception; 4) heterogeneity, transience, and stresses such as poverty on community members make it difficult to achieve community ownership and sustainable community responses. Whatever the reasons, future work in this area would necessitate strategic re-evaluation of this objective and modifications in the approach necessary to achieve it.

Objective 4: *By the end of the project, the organizational capacity of the Lea Toto project to manage community-based support to orphans will be improved*

Accomplishments:

- Three Lea Toto staff members attended counseling training;
- Two staff members attended specialized training;
- On-going technical support has been provided by CRS.

Observations:

A large proportion of the Lea Toto staff members had previously worked at Nyumbani; their dedication, their loyalty to the organization, and their experience with HIV+ children is extensive. The dedication of the Lea Toto staff toward their work in Kangemi is impressive. (The team also noted that their salaries are relatively low for similar postings elsewhere.)

Technical support for increased capacity has been provided by CRS to Lea Toto and has been described by Lea Toto and by CRS as having contributed to increased capacity and improved programming implementation of Lea Toto. A supportive relationship exists between the field staff of the two organizations. However, the capacity building function that CRS has to offer has not been fully utilized by Lea Toto during the past two years. Representatives of both organizations expressed a desire to maintain a more consistent relationship during the next phase of operation.

3.2 Financing, management, reporting mechanisms

Financial management and Reporting

Lea Toto's current financial reporting system is reliable and efficient. The accounting system is computerized and has the capacity to produce electronic monthly financial reports. Each month, financial reports are prepared in a detailed Excel document and sent to CRS, together with a stack of third party documentation. These are processed by CRS/Nairobi and submitted to CRS/Baltimore, and then to USAID. Source documents are filed according to the monthly submissions to CRS. The program manager basically controls and manages the system single handedly.

With respect to financing of Lea Toto activities, CRS advances funds to Lea Toto to support its activities based on quarterly cash needs. The turn-around time for funding requests is usually within a week. The current system is therefore sufficient and effective.

Observations:

Segregation of duties with regard to financial procedures is recommended and would necessitate delegation of more bookkeeping responsibilities by the program manager to the secretary. The assessment team reviewed the accounting qualifications of the incumbent secretary and found that she is competent to do the bookkeeping duties and additions.

In order to increase the efficiency by which financial reporting is conducted, consideration should be given to providing Lea Toto with the option to submit electronic expenditures to CRS, in conjunction with periodic on-site third party document reviews. The electronic process can save both Lea Toto and CRS time and financial resources without compromising financial accountability.

Budget

The current budget was developed prior to implementation of the program activities. Because this was a new set of activities, there was no pre-existing data available to guide its development. Therefore, the current budget is based on inputs rather than experience with program activities that contribute toward achievement of Program objectives. For example, the current budget was developed with the expectation that the Nyumbani medical facilities would be utilized more often by acutely ill Lea Toto beneficiaries than was ultimately the case. The budget, therefore, includes a significant amount for renovation of the Nyumbani facility.

Observations:
Development of the budget during the next phase of operations can benefit from the experience gleaned as a result of Lea Toto's initial eighteen months of activities. The next phase of activities will focus less on start-up costs and more on expanding technical capacity and coverage of program activities. Technical considerations should be considered primary in developing the budget for the next phase of operations. These considerations should reflect a comprehensive strategic planning process conducted by Lea Toto and CRS staff in light of lessons learned during the first phase of operations and during this evaluation process.
Monthly financial reports submitted by Lea Toto to CRS are based on over thirty line items. CRS controls Lea Toto expenditures on those items with little flexibility. The assessment team is of the view that CRS should consider giving Lea Toto increased flexibility by allowing them to report on major expense categories (e.g., personnel, travel, etc.). This would reduce the line items reported from over thirty to less than ten. The reduction would save time on reporting and would, at the same time, improve the quality of budget oversight and control by CRS.

3.3 Program management and reporting

According to the current organogram, the Lea Toto project manager reports to the chief manager at Nyumbani, who then reports directly to the founder and director of Nyumbani orphanage. Monthly programmatic reports are prepared by the program manager in conjunction with the financial reports and submitted to CRS and subsequently to USAID.

The position of project director was unfilled from the inception of the project in October, 1999, to May, 2000, at which time the current director was hired. His background is in financial management at Nyumbani and his skills are excellent and of great benefit to the financial accountability of the Lea Toto project.

There remains a need for technical leadership within the Lea Toto project, especially with regard to community mobilization and increasing Program coverage, the number of beneficiaries reached.

Nyumbani staff and the Chairman of the Board of Directors expressed support for the Lea Toto project. The Board of Directors has had little opportunity to become directly involved with the Lea Toto project, though doing so would enable them to provide increased support and encouragement to the Program staff. The Chairman undertook to bring to the attention of the Board of Directors the need to show more interest and involvement with Lea Toto project and to discuss it regularly at Board meetings.

The administrative roles and relationships between Nyumbani and Lea Toto, and between CRS and Lea Toto are unclear. For example, the process of hiring a consultant, such as for the design and implementation of the baseline survey for the Lea Toto project or for technical consultation to the Program, was managed through Nyumbani. The distinct roles of Nyumbani, Lea Toto, and CRS, including the process for making administrative, financial, and technical decisions is in need of clarification and these policies should be documented so that the information is available to staff of all three organizations.

The capacity building function of CRS was underutilized during the first phase of the Lea Toto project, though the input that was provided by CRS was deemed beneficial by both Lea Toto and CRS. More regular exchange between CRS and Lea Toto would provide Lea Toto with increased technical and capacity building input.

Observations:
Development of a steering committee is recommended, consisting of representatives from Nyumbani, the Board of Directors, CRS, Lea Toto, and USAID. The committee could perform an important role in clarifying administrative and programmatic relationships and providing continued technical oversight to the Program during its second phase. Functions of the steering committee might include:

- Review current technical strengths and gaps among Lea Toto staff and identify requisite qualifications and experience needed to complement current available staff expertise
- Clarify administrative relationships between CRS, Lea Toto and Nyumbani and document procedures for hiring consultants, personnel recruitment and retention, accessing CRS technical assistance, and other financial, administrative and technical decisions.
- Encourage information exchange between Lea Toto and the Board of Directors in order to avail Lea Toto of the potential support of Board Members.

Personnel recruitment and retention: Optimal personnel recruitment and retention of technical expertise among Lea Toto staff is limited by the project's inability to hire staff at market rates. Nyumbani management has explained that this is because Nyumbani's financial stability is weak; its major source of funding is charitable contributions. Even though the project has funding to reimburse personnel at higher rates, Nyumbani representatives feel that this would create discontentment among Nyumbani staff working in other parts of the organization. In addition, Lea Toto is viewed as a short-term project whose funding may not be sustained in the long run. However, the assessment team is of the view that for Lea Toto to attract, recruit and retain competent staff, salaries for key staff positions should be more competitive.

3.4 Monitoring and Evaluation

Lea Toto utilizes a tracking system to monitor a series of process indicators. Progress with regard to these indicators is monitored and included in reports on a regular basis. Lea Toto staff also maintain files on all beneficiaries from which further data is available, though not used for reporting purposes and, therefore, not tabulated nor analyzed. As mentioned previously in the section describing observations related to Objective 1 (physical care of 200 HIV+ orphans), the Program is providing care to many more children and adults than are currently reflected by the indicators.

Current monitoring is limited to process indicators such as the number of children enrolled in the program, the number of CHWs trained and the number of families visited. There is currently no system in place to evaluate the effectiveness of the activities implemented, such as whether caregivers are correctly utilizing medications or whether CHWs are including information learned during training sessions into their community work. In addition, the current indicators concentrate on measuring outputs toward the achievement of Objectives 1 and 2, but are not reflective of outputs that would lead to the achievement of Objectives 3 and 4.

Observations:

Following a re-assessment of the Lea Toto objectives, a monitoring and evaluation plan could be developed through support of a process by which the staff and community members involved in the activities identify information that would be useful to them. Information collected on a regular basis can be used to inform those involved whether they are accomplishing what they have set out to accomplish. Data collected should be simple, practical, and useful. Given an opportunity to analyze this information on a regular basis, program implementers can use the data to inform themselves whether they are "on the right course" toward meeting their objectives or whether there are problems that need to be addressed that might necessitate a re-consideration of program activities. Consideration should be given to identifying "outcome" as well as "output" measures. The latter will inform the staff if they are doing the activities that they set out to do, and the former will inform them whether those activities are, indeed, achieving their objectives. For example, *the number of training sessions* (output) to caregivers will inform the Program that the intended work is being conducted and the *number of caregivers appropriately providing medications to HIV+ children* (outcome) will inform the Program of the success of the training.

Measuring "impact", such as the change in disease progression, would be extremely difficult for the Lea Toto project. For example, the children involved in the program may experience opportunistic infections that are less severe or less frequent, but estimating change with the use of medically-based measurements is likely to be unrealistic. In addition, without a comparison group of HIV+ children, at the same stage of the disease and without LeaToto intervention, the "impact" measured could not be attributable to Lea Toto project interventions. Therefore, it may be more feasible for the Lea Toto monitoring and evaluation plan to limit its focus to "output" and "outcome" indicators.

3.5 Potential contributions to care of OVC

The Lea Toto project provides medical care to HIV-infected children and their families and supports caregivers to care for these children in the community. The evaluation team could identify no documentation of similar programs neither in Kenya nor in other parts of the world. Lea Toto offers a unique model that has the potential to inform efforts that focus on children infected and affected by HIV/AIDS on an international level. Experiences documented and lessons learned will enable other programs to replicate approaches identified by Lea Toto to work best; and it will enable other programs to avoid pitfalls identified by Lea Toto in the process of implementing this groundbreaking effort.

An important aspect of Lea Toto is that it is a community-based activity that was launched by an institution-based program, Nyumbani Orphanage. As the epidemic leaves millions of orphaned and otherwise vulnerable children in its wake, the role of institutional care is continually being revisited. For example, at the XIII International HIVAIDS conference in Durban, South Africa, in April 2000, USAID, UNICEF, and UNAIDS launched a process to develop an international set of principles to guide programming for orphans and other vulnerable children (See Appendix 7 – Principles) . The participatory process and the document that will eventually be produced are intended to accelerate consensus building and provide guidance to sound, effective action at local, district, national and global levels in developing and implementing initiatives to address the needs of orphans and other vulnerable children in AIDS affected areas. While the draft consensus document recommends institutional care only in cases where there is no other option for children, it suggests an alternative model for institutions which involves children's homes that become resources from which to support community-based activities to support children affected by HIV/AIDS in their own communities. Lea Toto embodies the model set forth in the consensus document and, as such, has much to offer in terms of how to make this type of model work in a way that is optimal to meeting the needs of children affected by HIV/AIDS.

Coverage is of primary concern with regard to the role of different types of models of care for children infected and affected by HIV/AIDS. Estimates are that there are over a million orphans as a result of HIV/AIDS and other causes in Kenya. Estimates from 1998 were that 90,000 children were living with HIV/AIDS in Kenya (DCOF, 8/28/99). These numbers do not include other extremely vulnerable children who are neither orphans nor HIV-infected. Resources available to address the needs of these children must be utilized as effectively and as efficiently as possible. The measure of Lea Toto's potential contribution toward making a difference in the lives of the vast number of children in need will depend on its ability to expand its reach. Already, the program has expanded beyond the reach of its parent organization. Whereas Nyumbani is able to support 65 children, at a cost of approximately $US2,300. per child per year*, Lea Toto is budgeted to provide care to 200 children at a cost of $US445. per year*. There is, of course, a vast difference in the type of care provided. Nyumbani is an orphanage that provides excellent and comprehensive care to its residents. Lea Toto can provide only medical and some psychosocial care, but it does offer the advantage of enabling children to continue to live in their communities with family members.

There are a few potential scenarios by which Lea Toto might expand its coverage and, thereby, its contribution to the care of the vast and growing number of children in need in Nairobi, and even possibly, in Kenya.

- The first possibility is to continue running the Program in the same way it is currently running, with Lea Toto staff responsible for managing and implementing activities. Moving into the second phase of activity means that investments have already been made in start-up costs (both in terms of human and capital investments) so that the same amount of funding in the second phase can be used to hire more staff to expand the reach of the program.

- The second possibility is to adopt a more community-focused approach whereby increased community ownership and involvement is fostered. If more of the activities are taken over by community members, some staff members become free to move to other areas of the city to initiate similar activities elsewhere and thereby expand the base of operations and the number of children receiving improved care.

- Another possibility is for Lea Toto to provide consultative services to other organizations to enhance their ability to care for infected children among their beneficiaries. Lea Toto has, in fact, already begun this type of activity on a small scale. One of the orphanages in the area is caring for a number of children, among whom are six HIV-infected children. Lea Toto has trained the staff of the orphanage to care for these children, thus preventing the children from being moved to another placement. There are many organizations providing care to children affected by HIV/AIDS in Kenya. Most, if not all, of these organizations do not have the expertise to

work with caregivers of HIV-infected children who are part of their beneficiary population. Lea Toto could provide training and on-going support to program implementers who otherwise would not be able to address the special needs of these children as part of their community efforts.

The Lea Toto evaluation conducted in May, 2001, was limited to data collected from in-depth interviews, focus groups, observations expressed during a stakeholder meeting, and a review of reports and other available documentation. Based on this information, it is apparent that Lea Toto is providing medical care and psychosocial support to HIV+ children and their families that would not otherwise be available to those beneficiaries. Opinions of interviewees is that children and their families are benefiting from these activities.

Both staff and caregivers involved with Lea Toto report noticeable improvement in the health of children under the care of the Program. However, data is not available to measure the true impact of the activities on the well being of children and their families. Therefore, the extent to which a model of care such as Lea Toto can contribute toward improving the well being of children infected and affected by HIV/AIDS remains unmeasured. Operations research to measure this impact would provide this information. However, until the time that such research is conducted, the contribution of Lea Toto will continue to be measured in terms of the number of children who have participated in activities that are facilitated through the Program.

3.6. Challenges/opportunities, Lessons learned

A major contribution that Lea Toto has to offer toward programming for children affected and infected by HIV/AIDS in Kenya, as well as globally, is to share the lessons learned in the course of implementing this unique model of care. It is important to identify and document what works well and what does not work. During its second phase of operation, Lea Toto will have the opportunity to re-direct its efforts in light of the lessons learned during its first phase. In this manner, the lessons will continue to emerge and will continue to provide a source of learning to programs in other parts of the world. The following are some of the lessons that have surfaced during the first 18 months of Lea Toto project implementation:

Addressing the needs of PLWHA and their families necessitates a holistic and coordinated approach:

Lea Toto chose to work in Kangemi because it was an area, which lacked other interventions focusing on the needs of PLWHA and their families. As the staff continued to enroll beneficiaries and to gain an increased understanding of their needs, they realized that they could not address those needs single-handedly. The following gaps were identified:

- Care and support for children affected, but not infected, by HIV/AIDS;
- Care and support for adults infected by HIV/AIDS;
- Voluntary counseling and testing for HIV/AIDS for adults;

- Income generating activities;
- HIV/AIDS prevention efforts;
- Reproductive health information and services.

Lea Toto, of course, cannot meet all these needs. Efforts to address these gaps would necessitate a coordinated effort to develop and implement a strategic approach involving community members and community organizations that currently work within Kangemi, as well as those that might be able to move activities into the area.

The effect of stigma on program implementation:
There is a great deal of stigma surrounding HIV/AIDS in Kangemi, as in many parts of the world. Focusing exclusively on HIV+ orphans exacerbates the stigma surrounding the Program and results in reluctance of community members to make use of the services provided or to be associated with the Program. Broadening the target of the activity may decrease stigma associated with the Program and thereby increase the number of community members willing to become involved with the Program.

Linking income generating opportunities with care for children:
Lea Toto identified the overwhelming economic needs among caregivers of HIV+ children and attempted to address those needs through four different types of interventions: business training; merry-go-round savings groups; sale of used clothing; and handicraft production. None of these attempts was successful at creating long-term economic opportunities for participants. Given the dire economic environment in the area and recognizing that its own expertise is in health and not economic interventions, Lea Toto recognized that pursuing this course of action would be better addressed through linkage with an organization that specializes in income generating activities.

Community-based versus Community-owned:
Lea Toto is a community-based organization that was developed and implemented by "outsiders" to support community members. As such, it is viewed as a service organization through which community members can obtain needed medical care and other assistance. Community involvement in provision of care to its members is minimal and, therefore, developing sustainable community approaches has been met with little success. However, input from the stakeholders meeting and focus groups facilitated through the Lea Toto evaluation process provided the Program with a better understanding of the potential and the willingness of caregivers to become more actively involved in Program activities and outreach. In addition, though the Program is in an urban setting which offers particular challenges to mobilization due to fragmentation within the community, recommendations from the stakeholders meeting suggested a process to consult more with the community that does exist within Kangemi and to work with the community in a way that responds to its particular nature within Kangemi.

Linking Care and Support with Prevention Activities:

Lea Toto's mandate and expertise do not focus on disease prevention or on family planning education. However, caregivers and family members of the Program beneficiaries who are HIV-negative are at risk of acquiring HIV; those who are HIV+ are at risk of transmitting the disease to others; and pregnancies among HIV+ caregivers occur without access to family planning information. Though disease prevention and family planning are not primary objectives of the Lea Toto project, it would be an important contribution for the Program to link with other projects that can provide reproductive health services to Lea Toto beneficiaries.

3.7 Recommendations

The following recommendations summarize the observations presented in the previous sections and are the result of extensive discussions among the members of the evaluation team, based on observations, interviews, and the stakeholders' meeting.

Continued support to Lea Toto project:

Lea Toto is providing care to 148 HIV+ children and their families and has the potential to extend its coverage to include a larger number of beneficiaries.

The staff of Lea Toto has progressed through the start-up phase and has a great deal of expertise, dedication, and an expanded understanding of how to proceed toward attaining its goal of improved community care in Kangemi.

Therefore: *Continue to provide funding to Lea Toto to support its second phase of operation.*

Targeting activities to HIV+ orphans:

Limiting programmatic focus exclusively to HIV+ orphans:

- Increases stigma;
- Inhibits beneficiary enrollment;
- Limits activities to a small proportion of children identified by the program to be affected by HIV/AIDS;
- Underestimates the impact of the Program on HIV+ children living with a parent (non-orphans);
- Underestimates the impact the Program has on other children who are family members of infected children.

Therefore: *Discuss and re-consider if target population must remain exclusively HIV+ orphans.*

Building sustainable community responses:

The current approach to the community does not facilitate community ownership and participation:
Therefore: *Re-consider the community approach to be taken by Lea Toto and provide the technical expertise and support necessary to achieve increased community ownership and involvement of community members – including enhanced coordination and collaboration with community based organizations in Kangemi.* _

Enabling a holistic approach to care and prevention:

Project beneficiaries are in need of care and prevention support beyond that which Lea Toto can be expected to provide.

Therefore: *Initiate strategic planning with potential partners in the community and outside of the community to increase access to:*

- *Care and support for children affected by HIV/AIDS;*
- *Care and support for adults who are HIV+;*
- *Voluntary Counseling and testing;*
- *HIV/AIDS prevention efforts;*
- *Reproductive health information and services.*

Organizational Capacity:

The capacity building function of CRS was under-utilized during the first phase of activities.

Therefore: *Facilitate access by Lea Toto to on-going technical assistance by CRS and reflect this relationship in the wording of the contract guiding the next phase of activities.*

Technical capacity with regard to community mobilization, counseling, and the presence of technical leadership was identified as a weakness of the Lea Toto project.

Therefore: *Assess current Lea Toto staffing and develop a plan to improve technical capacity and provide technical leadership.*

Financial management and reporting:

Lea Toto's current financial reporting system is reliable and efficient.

Therefore: *Decrease monthly submission of source documents, replacing this requirement with periodic on-site third party document reviews.*

Budget:

Budgeting for the first phase of Lea Toto did not have the benefit of technical input because it was a newly initiated activity.

Therefore, *Utilize technical input and recommendations from Lea Toto and CRS staff in developing the budget for the next phase of funding.*

Program management and reporting:

Administrative roles and relationships between Nyumbani, Lea Toto, and CRS are unclear.

Therefore, *convene a steering committee consisting of representatives of COGRI, Nyumbani, Lea Toto, CRS, and USAID whose responsibilities include development of written policies delineating the roles of each organization with regard to administrative, financial and technical decision making.*

There remain gaps in the technical leadership and technical expertise that will be necessary to expand Lea Toto's progress toward its goals and objectives.

Therefore, *Lea Toto and CRS, or the Steering Committee should review technical needs of Lea Toto and develop plan of action to address those needs.*

Monitoring and Evaluation:

Current monitoring and evaluation plan does not address all the Lea Toto objectives and does not utilize a process to identify indicators and collect data that is optimal for utilization by Lea Toto staff.

Therefore: *After the objectives for the next phase of operation have been identified, initiate a participatory process by which Lea Toto staff, in conjunction with community partners and facilitated by CRS, identifies data to be collected on a regular basis that will contribute to monitoring of activities and learning what works and does not work among Program activities. Regularly scheduled, participatory, self-assessments would provide an opportunity for Lea Toto to re-evaluate the effectiveness of its program activities and to identify changes that are needed to achieve the desired objectives.*

3.8 Conclusions / The Way Forward

The needs of children who are infected and otherwise affected by HIV/AIDS are vast; are continuing to grow; and will remain exceptionally high for at least two or more decades. The response must be long-term and it must include a combination of different types of approaches. Lea Toto offers one such approach. As a community-based program that has been initiated and supported by an orphanage, it provides an intervention model that has potential to help to re-define the role of institutions in AIDS affected countries. In addition, the provision of community-based medical care to HIV-infected children and their families is also unique in its focus and approach. Being in the forefront of these types of programs, Lea Toto does not have the benefit of learning from the experience of others who have come before. Instead, Lea Toto's continued growth toward achieving its objectives within Kangemi

will provide lessons to be learned by other organizations that follow in its footsteps.

A focus of the Lea Toto evaluation has been to identify what is working and what is not working. Even more important has been the role of the evaluation team in stimulating discussion about *how to make things work better*. The evaluation team provides recommendations for the next phase of Lea Toto operations. It will be up to the Lea Toto staff, with technical support from CRS, to try new approaches toward meeting their objectives; to continue to assess their progress and modify their activities when necessary; and to share lessons learned with others who have similar objectives in other places.

There is a great deal of dedication and commitment among the staff of Lea Toto, CRS, and Nyumbani. It is this dedication that will be the force that continues to drive their efforts toward their shared goal –improved care and support for the growing numbers of children affected by HIV/AIDS in Kenya.

*NOTE: Cost per child calculations:

Lea Toto: Based on "Project Budget Status and Advance Request Form 3/1-3/31/2001

Options: Could be based on:

1) Total actual costs for 18 months, divided by # children served;
2) Total actual costs, minus car and kitchen (one-time costs only), divided by # children;
3) Total budgeted costs for 2 years, divided by 200 children
4) Total budgeted costs for 2 years, minus car and kitchen, divided by 200 children.

The number in this document represents #4: Total budget ($US253,560) minus car and kitchen ($US75,409) = $US178,151, divided by 200 children = $US890/child/2 years = $US445./child/year.

Limitations to this choice of calculating costs/child: Does not represent ACTUAL costs, rather only budgeted costs; Assumes care of 200 children per year, which is more children than actually served; Does not include costs of drugs, which are currently being paid for by CRS; Does not include number of family members, in addition to the HIV+ children, who are receiving services.

Nyumbani: Calculations based on:

Direct cost per child per year = $US582

Personnel and administration = $US1,725

Total costs per child per year = $US 2,307

This calculation assumes that "personnel and administration" does not include fixed costs such as cars, building construction, etc.

This calculation does not include $US343/child/year spent on education, since Lea Toto does not offer education expenses

This calculation DOES include medication costs, whereas this cost was not included in the Lea Toto calculation, even though medications are provided by Lea Toto.

CARE MUST BE TAKEN WHEN COMPARING COSTS/CHILD FOR Lea Toto and Nyumbani because services provided are so different.. (like comparing "apples to oranges")

1. *Appendix I:* Lea Toto Evaluation Scope of Work (SOW)

INTRODUCTION

In 1999, through a field support transfer to BHR/PVC to Catholic Relief Services (CRS), USAID/Kenya began support to the Children of God Relief Institute[1] to implement a community-based program (known as Lea Toto) in the Kangemi area. Under the program, CRS is helping to strengthen the capacity of the Lea Toto program to help families with HIV positive orphans receive physical care, psychological support and essential medical supplies. The program also hopes to help the Kangemi community, a slum area of Nairobi, identify and establish sustainable community strategies to enable the community to cope with the needs of AIDS orphans. Finally, CRS hopes that this program will improve the organizational capacity of the Lea Toto program to manage community-based support to orphans.

The assessment will review program activities over the project period August 1999 to July 2001. The findings of this assessment will help CRS and Lea Toto to strengthen a second phase of the program.

BACKGROUND

It is estimated that 13.3 percent of the adult population in Kenya is living with HIV/AIDS with the prevalence rate generally higher in the urban areas. One of the impacts of AIDS deaths to young adults is an increase in the number of orphans. It is estimated that the number of children who had been orphaned by AIDS in Kenya by the year 2000 was 850,000 and that this figure will go up to 1.5 million by 2005[2]. These estimates include only children less than 15 years old who have lost either their mother or both parents as a result of AIDS. The number of children made vulnerable by HIV/AIDS is much larger and includes children whose father has died; those who are living with and often caring for a chronically ill parent; those who are older than 15 years old; and children living in households where resources -both financial and psychosocial- are severely strained as a result of caring for ill family members and supporting increased numbers of dependents.

These children often lack the proper care and the supervision they need. The death of one or both parents leads to a number of sociological, economic and psychological problems. Orphans are vulnerable to a number of these problems such as malnutrition, dropping out of school, the loss of physical and social security as well as the lack of parental attention and supervision.

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[1] The Children of God Relief Institute runs the Nyumbani orphanage for HIV positive children in Nairobi. USAID is providing funds through CRS to support the Institute's community based care program known as Lea Toto in a slum area of Nairobi.

[2] Source: AIDS in Kenya, NASCOP,1999

The Lea Toto program targets children who have lost both parents and are HIV positive. There have not been many programs in Kenya dealing with the care and support of orphans living with HIV/AIDS within the community. This assessment will help document some of the experiences and lessons learned over the past two years.

The overall goal of the Lea Toto program is to improve the capacity of the Kangemi community to provide holistic care within the family setting for HIV+ orphans living in these communities.

The following are the objectives through which this goal will be achieved:

- By the end of the project, 200 families with HIV+ orphans will have received physical care and essential medical supplies to alleviate their suffering.
- By the end of the project, psychological and moral support will have been provided to 200 HIV+ orphans and their families.
- By the end of the project the Kangemi community will have identified or established six sustainable community strategies to enable the community to cope with the needs of AIDS orphans.
- To improve the organizational capacity of the Lea Toto Program to manage community based support for orphans.

SCOPE OF WORK

a) Purpose:

USAID/Kenya, in collaboration with CRS and Nyumbani will undertake an evaluation of the Lea Toto program to assess:

- The progress made towards achievement of project objectives.
- The financial accountability and reporting on program funds.
- The current and potential contribution of this type of program to developing sustainable community-based care and support of HIV+ orphans and the families that are caring for them.
- The current and potential role of this type of program to contribute to meeting the needs of the children affected by HIV/AIDS in Kenya.
- Challenges and lessons learned.
- Key areas of focus for the future.

b) Participants and audience for the evaluation

A team composed of a team leader, two USAID/Kenya staff, one USAID/W staff, one CRS staff, one Lea Toto staff and one Nyumbani staff will undertake the assessment and produce an evaluation report. This will be a collaborative review and will draw on views and experiences of health professionals currently working in community-based care of HIV infected and affected people in Kenya. The audience for this evaluation includes USAID/Kenya and USAID/Washington, the Government of Kenya, CRS and Lea Toto.

c) Issues to be addressed by the evaluation team

The following are key issues to be addressed by the evaluation team. The evaluation will include, but not be limited to, the tasks listed as bullets under each of the issues.

- **Achievement of goals and objectives**

  - Assess the contribution of the project towards meeting the needs of the targeted HIV positive orphans in Kangemi and the families in which they live.
  - Assess the extent to which the project developed caretakers' ability to care for HIV positive children.
  - Assess the results of the community mobilization process initiated by Lea Toto to develop and implement strategies to enable the community to cope with the needs of AIDS orphans.
  - Assess change in organizational capacity of the Lea Toto program to manage community-based support for orphans.

- **Financing, management and reporting mechanisms of Lea Toto and of CRS.**

  - Review the effectiveness of current financing mechanisms between CRS and Lea Toto and between CRS and USAID.
  - Review the reporting mechanism from Lea Toto to CRS and from CRS to USAID.
  - Identify the key management issues/constraints affecting financing and implementation of the Lea Toto program.
  - Review the Lea Toto organization structure and make recommendations that can make it more fiscally effective.
  - Review the financial reporting system, the monitoring and evaluation system and make recommendations for change, if appropriate.

- **Current and potential contribution to community-based care of HIV positive children and other children affected by HIV/AIDS**
  - Assess the Lea Toto strategic approach and its potential contribution to community based care of children affected by HIVAIDS.
  - Assess the role of the Kangemi medical clinic in providing services to the Lea Toto program, and its current and potential contribution to addressing problems facing HIV positive children.
  - Assess the process of establishing caregiver groups and how these groups contribute to irriproving support for HIV positive children within the community.
  - Assess the process of community mobilization, the creation of community "safety nets" and the extent to which these activities contribute to community support of HIV positive children.
  - Identify the current coverage of the target population and the potential and cost of scaling up to reach an increased proportion of the target population.
  - Assess the contribution of the project to develop capacity among Lea Toto staff and capacity of the community to contribute to a sustainable response.
  - Review and assess key aspects of the Lea Toto program with the greatest potential for sustainability.

- **Challenges/opportunities and lessons learned**
  - What has been the process to develop and define community participation in the context of the Lea Toto program?
  - What are lessons learned and what are the implications for community-based care of HIV positive children and other children affected by HIV/AIDS in Kenya?
  - What opportunities exist upon which to build a more effective community-based care program for HIV positive children?
  - What are the implications (sustainability? Cost? etc.) of lessons learned by the Lea Toto project for replication of this model of intervention in other communities?
- **What should be the key areas of focus for the future?**

d) Proposed activities of the team

The evaluation team will undertake the following activities:

- ***Meet with USAID/Kenya staff and project staff at CRS, Lea Toto and Nyumbani.*** The team will hold at least two briefing meetings for USAID staff. On arrival, the team will meet with OPH to clarify mission perspectives, activities and priorities on Lea Toto. The team will present proposed organizational plans for undertaking the evaluation. A final briefing will be made near the end of the TDY at which time a draft report will be submitted. Discussions will be held with CRS ,and Nyumbani staff.

  The team will meet with Nyumbani staff and review Nyumbani/Lea Toto reports. Specifically the team will seek an understanding of the referral role Nyumbani plays to HIV+ children referred from Lea Toto and the role of St. Joseph's dispensary in Kangemi with a view to documenting lessons learned.

- ***Review relevant documentation.*** The team will review the CRS/Lea Toto project studies, status reports and other documents. In addition, the team will review USAID HIV/AIDS strategy documents and other reports related to community-based programs in Kenya.

- ***Meet with stakeholders.*** The team will collect information through interviews, discussions or focus groups with key stakeholders, including, but not limited to community leaders, National AIDS Control Council staff, MOH, other USAID-funded agencies working in HIV/AIDS such as IMPACT and COPHIA.

- ***Make site visits.*** The team will meet with project staff, health workers, and families at Kangemi.
- ***Stakeholders' workshop.*** A one-day meeting with stakeholders will be held to present findings of the evaluation and to provide a forum for discussion that will feed into the recommendations of the report.

The outcome of this assessment will be an evaluation report. The team will be responsible for completion of the evaluation report synthesizing findings and recommendations. The team leader will be responsible for completing the report on time and submitting it to OPH.

The final report should include the following sections:

I. Executive summary
II. Background
III. Summary of key issues
IV. Conclusions
V. Recommendations
VI. Annexes

e) Level of effort

The level of effort will be as follows:

Desk review	2 days
Team briefing/orientation	2 days
Interviews/discussions in Nairobi	4 days
Planning Stakeholders meeting	1 day
Stakeholders' meeting	1 day
Completion of written report	3 days
Total number of working days:	13 days

f) Administrative and logistical arrangements

- ***Relationships***. The team leader will report directly to the Chief, Office of Population and Health. The team leader will work closely with the OPH's Technical Advisor in AIDS and Child Survival, Child Survival Program Officer, and other OPH staff. As necessary, supplementary guidance will be provided by the Executive Officer, USAID/Kenya.

- ***Completion of deliverables***. The contract will be considered successfully completed when the team leader submits to USAID/Kenya the document described in III-D, terms of reference. Two paper copies of the final document shall be delivered to the Chief, OPH. In addition, the team leader will submit an electronic copy of the entire document in Word on a 3.5" diskette. This document must be submitted no later than two weeks after the completion of the stakeholders meeting.

- ***Office space and equipment.*** CRS will provide office space for the assessment team
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2. *Appendix 2*: Lea Toto Evaluation Team Members

1.	Linda Sussman	USAID Washington
2.	Jane Muita	UNICEF
3.	Yvonne Ferguson	CRS
4.	Wamuyu Manyara	CRS
5.	Caroline Masterly	Lea Toto
6.	Nicholas Make	Nyumbani
7.	Joseph Indigo	USAID Kenya
8.	Victor Masbayi	USAID Kenya

3. *Appendix 3*: Methodology

The Evaluation team consisted of eight members (see Appendix 2 – Evaluation team members), representing Lea Toto, Nyumbani, CRS, UNICEF/Kenya, USAID/Kenya and USAID/Washington and took place between April 30 and May 11, 2001. All participants were actively involved, and consensus was sought and achieved for joint action taken by the team.

The process began with a meeting of the team to:
- Identify team member expectations and
- Identify potential interviewees

Questionnaires development occurred through brainstorming sessions and were based on:
- Team member expectations for the evaluation; and
- SOW objectives.

All interviews were conducted by at least 2 team members. Interviews included:
- Individual interviews
- Focus groups (Caregivers; CHWs; Lea Toto staff)
- Stakeholders meeting (May 10)

The financial and management assessment included a review of:
- Lea Toto and Nyumbani's organizational structure;
- Accounting systems
- Procurement regulations;
- Personnel and travel policies
- Non-expendable procedures
- Budgeting and cost controls
- Reporting procedures.

Daily meetings of the evaluation team were held at 4:00 p.m. to:
- Share daily information
- Identify interviewees
- Plan and determine logistics for team interviews
- Develop and review Questionnaires
- Develop evaluation document outline
- Discuss evaluation findings, especially issues related to:
    - Lea Toto programming
    - Constraints and Options for future programming
    - Management and budget issues

4. *Appendix 4:* List of Interviewees

Lea Toto:
- Caroline Matsalia, Assistant Program Manager
- Joseph Kamau, Program Director
- Susan Ngugi, Social Worker
- Ruth On'garo, Nurse
- Dr. Aluvaala, Doctor
- Focus group with Lea Toto staff

CRS:
- Wamuyu Manyara, Project Officer – AIDS unit
- Yvonne Prempeh-Ferguson, HIV/AIDS Manager
- Jean Marie Adrian, East Africa Regional Director
- Jane Mumo, Financial officer
- Judy Ojwang, Finance Manager

Nyumbani
- Nicholas Makau, Program Manager
- Father D'Agostino, Nyumbani Director
- Protus A. Lumiti, chief Manager
- Sister Theresa, Matron
- Sister Mary Owens, Treasurer
- Dr. Maringo, Board member and baseline survey consultant

Community Beneficiaries/Partners
- 3 Focus Groups with Caregivers
- 2 Focus Groups with Community Health Workers (CHW)
- Attended CHW training session

Community Opinion Leaders:
- Fr. Emannual, Assistant Parish Priest-St. Joseph Church
- Mr. Karanja, Kangemi Chief's Office
- Mr. Mbutia, Kangemi Chief's Office

Community Organizations
- Francis Nelegwa, Clinical Nurse, St. Joseph Dispensary
- Sr. Sarah, Nurse, St. Joseph Dispensary
- Anne Owiti, Director, Kicoshep
- Mr. Julius Kaberere, Deputy Director, Kenya Alliance for Advancement of Children (KAAC)
- Ruth Wangare, Training and Counseling, KAAC
- Annastacia Muli, KWEC

Government
- Karen Ogoti, Children's Department
- Muthoni Mwithiga, NAAC
- NASCOP (meeting cancelled by NASCOP)

USAID: Dana Vogel
- Neen Alrutz
- Cheryl Sonnichsen
- Victor Masbayi

5. *Appendix 5:* Stakeholders Meeting Held May 2001.

(a) Introduction

A stakeholder meeting was held with 24 participants. The organizations represented at the meeting included the Nyumbani Orphanage, Progress 2000, USAID, CRS, St Joseph's Parish, UNICEF, NACC, Family Health International-IMPACT, Pathfinder International-COPHIA and, Lea Toto.

(b) Purpose of the meeting

The purpose of the meeting was to share findings of the assessment with stakeholders and hear from them how some of the key challenges to program implementation could be addressed.

Four key challenges had been identified by the assessment, and stakeholders were asked to discuss these in four groups. The four issues were community mobilization and ownership; targeting HIV+ children vs all vulnerable children; disclosure and acceptance and the role of programs targeting HIV + children in addressing OVC's.

(c) Group Reports

Group 1: *Challenges and strategies in mobilizing communities and developing ownership in an urban setting*

The group discussed and presented what they saw as community mobilization strategies that have worked for other programs and suggested that these could be applied to Lea Toto. These were listed as follows:

- Participatory urban appraisal/focus groups.
- Community involvement in mapping and peer education.
- Organizing around a specific purpose e.g. money-making venture.

The group also discussed how to mobilize the community in transient populations and concluded that one should organize around existing social groupings e.g. religious, tribal, merry-go–rounds etc.

The group concluded that technical inputs such as exchange visits, technical assistance through CBOs, and formalizing relationships with district, locational and government departments are necessary to conduct this process.

Participants who had used these strategies in other programs proposed that in an urban setting such as Kangemi a lack of social cohesion and trust due to movement of people can be a key problem and that a strong referral network is necessary. Further, a two or three year project is too short to ensure community mobilization and that community mobilization should be done through local CBOs.

The group concluded that while community ownership and involvement in an urban slum where poverty is pervasive can be difficult to achieve, one should build on existing programs; e.g. merry-go-rounds and church networks. Financial Participation should be encouraged no matter how small and a capacity to handle funds should be developed.

Partners can assist in this process of community mobilization by making resources and technical assistance available.

Group 2: The challenge of targeting HIV+ children vs. all vulnerable children.

This group discussed and agreed that the characteristics of vulnerable children would include:

- Child under 18 living near high-risk situation
- Orphan – partial, total, virtual
- Child affected by AIDS
- Either parent sick/ailing
- Child head of a household
- Child soldier/prostitutes/laborers
- Exploited/abused children
- HIV + child
- HIV negative child

The group also discussed and listed the needs of vulnerable children as follows:

- Education
- Health care
- Nutrition
- Love and support
- Recreation
- Security
- Legal protection
- Socialization /good parenting
- Shelter, food, clothing

The group concluded that HIV+ children would have all these needs as well as acceptance of their sero-status and special medical care due to compromised immunity.

The group discussed and listed advantages and disadvantages of focusing only on HIV+ children.

Advantages	**Disadvantages**
Ability to provide specialized care	Targeting may lead to more stigma
More access to target group	Slow community mobilization
Efficient use of scarce project resources	
Encourages acceptance of HIV+ children	
Ability to build support for one another	
Advantages of expanding support to OVC	**Disadvantages of expanding support to OVC**
Easier community mobilization	Inadequate resources to meet the needs
Increased number of children participating in the project	More complex targeting in heterogeneous groups
	Harder to monitor
	Potential for abuse of services

This group recommended targeting HIV + children but for Lea Toto there is a need for stronger linkages, collaboration, and partnership. The group also recommended that that Lea Toto program needs more prevention and BCC programming and better empowerment/capacity building of the community (including enabling environment, fund raising mechanisms etc).

Group 3 Stigma attached to disclosure and acceptance

The group concluded that stigmatization is due to the fact that HIV/AIDs is associated with sexuality, loose morals and that there is a lot of distortion and misconception about HIV/AIDS. It was suggested that health workers focus on changing the message by giving hope and avoiding sentences like " Break the silence".

Strategies that can increase acceptance were listed as follows:

- De-segmenting the community as appropriate
- Targeting people at their own personal level
- Using an education approach
  - Address feelings and fears
  - Personal contribution
  - Encourage knowledge of HIV status
- Promote VCT to become community based (services to be available at all levels).
- Encourage post-test clubs
- Encourage those testing positive to go public
- Skills building
- Provision of support
- Integrate provision for basic immediate needs into wider program (empowerment to meet one's own needs.
- Promote collaboration and create linkages

Group 4: The potential role of programs targeting HIV + children in addressing OVC's.

The group identified different types of organizations i.e. those that operate in a rural setting; institution based types; fundraising organizations; community based prevention types in an urban setting; those that provide technical support and partnerships. The group felt that programs targeting HIV+ children could make a contribution to OVC in general by being a source of information, stimulating passive contributors and helping to develop a capacity for information and support. Some key strategies to achieve this could be encouraging active participation of local teams in networking and sharing information through existing structures such as churches, welfare associations and women's groups and developing linkages with other organization working in OVC.

To mobilize communities and share information organizations could use publications such as newsletters, journals, websites, network news, evaluations findings as well participating in forums.

6. *Appendix 6*: Lea Toto Evaluation Questionnaires

A. *Questionnaire for Lea Toto, CRS, Nyumbani*

1. Meeting the needs of HIV+ children in Kangemi families:

What are the needs of the children in general in Kangemi?
What services, other than Lea Toto, are available for vulnerable children in Kangemi?
What is the magnitude of HIV among children in Kangemi?
What are critical needs of HIV+ children?
What services are available to other children that are also available to HIV+ children?
Were they there before Lea Toto? Are they new? When did they begin in Kangemi?
What needs are being addressed through Lea Toto activities and how
How are children and families identified and prioritized to participate in Lea Toto activities? (get criteria for inclusion)
How many children have been reached with:
medical, clinical, nutritional care, referrals for further management
How has the well being of HIV+ children and their families changed as a result of Lea Toto (what is the documentation for this change?)
What are the Constraints (financial, human capacity)?
Recommendations

2. Development of caregiver ability to care for HIV+

How were the children being cared for before caregivers came into place?
Data (profiles) who are the caregivers of these children?
What are their characteristics?
How are they identified?
What Lea Toto is doing for caregivers and why?
What would Lea Toto like do that they are not doing now?
Are there other stakeholders working to strengthen the capacity of the caregivers
With regard to caregiver groups, describe:

- The objectives of the caregiver groups (written and stated);
- The process by which caregiver groups have been established;
- Current status (coverage, meeting frequency, etc);
- Specific activities of the groups;
- External support received to caregiver groups;
- Internal resources that members contribute;
- The impact of these activities on the support of HIV+ children - both directly and indirectly;
- Degree to which the groups have achieved their objectives

Constraints
Recommendations

3. Results of the community mobilization process

Describe the goals and objectives of community mobilization process
Describe the approach used in mobilizing the community
At what level has the community been involved in the mobilization process?
What are the outcomes of the community mobilization?
What are the specific sustainable strategies that have been identified as a result of community mobilization
Which of the strategies have been implemented? (get supporting documents)
Challenges to community mobilization process
Challenges to implementation of strategies
Given an opportunity how would they do it differently?

4. Organization capacity of Lea Toto to manage community support for orphans

Describe the Lea Toto funding prior to USAID funding, including the objectives and geographic area covered.
What is the current status of the non-USAID funded outreach program?
What is the relationship with the USAID-funded project?

Since the beginning of the USAID funding, describe changes and current level of:

Human resources (compare current human resources to that identified in the proposal)

Infrastructure

Management capacity
Space/ Equipment
Technical capacity

Since USAID funding, how has the program changed?
Are there any differences in types of services, difference in coverage?

With regard to reporting by Lea Toto...:
- What is the accuracy?
- Timeliness
- Quality of content

5. Financial Reporting

(a) Purpose of the grant and how it will be achieved
(b) Grant date and PACD
(c) Amount obligated and disbursed to date

The purpose of the assessment is to report in writing on the acceptability of the accounting system and records, personnel organization, and controls in place at (Grantee) in regard to USAID grant funds.

Methodology
Test the fitness of: (a) the source documentation used to bill USAID, (b) Grantee's personnel and their capabilities in regard to managing the grant funds, and (c) documented evidence of internal controls put in place to govern the use of the funds, for example, procurement procedures and check approval authorities. In addition, check compliance with the terms of the grant agreement and, assess progress made in implementing the program in relation to time and funds expended.

If conditions are found to be unacceptable at the offices of the Grantee, then the Mission must consider suspending the payment of grant funds until corrections, as prescribed, are made.

Detailed Assessment Steps

I. Organizational Set-up

The assessment objective here is to document and evaluate the control environment; and the capacity of the Grantee's personnel to implement its program and manage USAID funds.

(1) Determine the names, titles and responsibilities of all the registered officials. Which of these officials have overall responsibility for the day-to-day running of the organization?
(2) In regard to personnel, obtain an organization chart and other written procedures to show the responsibilities and reporting lines for the Grantee. In regard to the Finance Department, document the number of staff, their qualifications/experience, and reporting lines. Determine whether accounting duties are adequately segregated. For the whole organization, determine whether there are written job descriptions.
(3) Obtain information on the physical location of the office, contact address and phone numbers.

II. Financial Management System:

The assessment objective for this area is to confirm the existence of an internal control system that ensures a separate and accurate accounting for USAID funds; collects or prepares and files source documentation of all payments and receipts; safeguards assets; and produces accurate reports on time and in the required format.

(1) Ensure that (Grantee) maintains an up to date cashbook/bankbook and general ledger for USAID funds.

(2) To confirm the completeness and accuracy of the equivalent of (amount in $) disbursed to (Grantee), ensure that all receipts from USAID were promptly recorded in the cashbook and then banked intact. Trace these amounts to the bank statements. Also, trace the cashbook totals for the respective months to the general ledger.

(3) To confirm the validity and accuracy of payments, select a sample made up of different expense categories, including large and small amounts, and ensure that:
   (a) A pre-numbered and approved voucher supports each payment;
   (b) Duties in the payment process are segregated such that different stages are handled by different people and then approved by the supervisor, or the designated official.
   (c) Support documentation exists for each payment voucher; amounts paid and other details in the pay records match the source documentation; and
   (d) Each paid voucher is stamped "PAID" to avoid duplication.

(4) Confirm the existence of the following controls in regard to the recipient's banking procedures:
   (a) A separate bank account is maintained for USAID funds;
   (b) A monthly bank statement is received and a reconciliation between the cashbook and the bank statement performed on a monthly basis;

   (c)Each bank reconciliation is approved in writing by a supervisor and the supervisor follows up to ensure reconciling items are cleared in succeeding months;
   (d) The checkbook is in the custody of a responsible official;
   (e) The names of the authorized signatories for the bank account are minuted; and
   (f) Tests of cancelled checks (if available) show that appropriate signatories and pay data are on these checks.

(3) To confirm the accuracy of the banking system select a number of bank reconciliation's and:

(a) Verify the reconciling items by tracing them to the cashbook and ensuring that they don't appear in the bank statement and vice versa;

(b) Trace all transactions from the cashbook to the bank statement for 2 or 3 months. Ensure that all transactions that do not appear in the bank statement, and vice versa, are shown as reconciling items;

(c) Check the footing and cross-footing of the cashbook for the months selected in (a) above and trace the totals for each month to the general ledger; and

(d) Consider the need to obtain confirmation of the current bank balance direct from the bank.

III. Procurement and Travel Procedures

The assessment objective is to confirm whether the Grantee's procurement and travel advance/reimbursement procedures satisfy USAID requirements.

(1) Select a sample of large procurements from the cashbook and:

(a) Determine whether competitive procedures were applied and whether there was segregation of duties in the whole process;

(b) Review supporting documentation and ensure that proper payment procedures were followed;

(a) For instances where the vendor is one of the Grantee's officials or a related party, determine the circumstances behind the procurement;

(b) assess the reasonableness of the amounts paid and discuss with the Grantee's officials as appropriate; and

(e) discuss any frequent and large procurements especially if they are always from the same source.

(2) To determine whether the travel and vehicle operations procedures result in reasonable and allowable costs in line with applicable cost policies; include a sample of this expense category in test II (3) above and confirm that:

(a) Payments were for official travel and were duly approved in advance;

(b) Payment procedures agree with those detailed in test II (3); and

(c) Travel advances were approved in advance and liquidated in a timely manner.

III. Reporting

The assessment objective is to ensure that the Grantee complies with relevant grants, laws and regulations

(1) Confirm compliance by reviewing reports submitted by the Grantee including the one for the period ended (date of latest period) .

(2) Alternatively, determine reasons for non-compliance.

(3) Select a sample of these financial reports and agree all amounts back to the source documents. This test can be achieved by using the same 2 or 3 months that were tested in step II, 5 (b) above.

(4) Ensure the reports are submitted in the agreed format and in a timely manner.

IV. Audit

The assessment objective is to ensure compliance with the grant requirement for an annual audit. Review the audit clause in the grant agreement and determine when/if audit is indicated.

Determine whether the Grantee is making arrangements for this audit. Who are the auditor's? Are the auditor's on RIG/A/N's list of approved auditors for the recipient-contracted programs. Inform the Grantee of the procedures involved in the conduct of such audits; the review issuance of the audit reports; and the follow-up of audit recommendations .

V .Program Results

The assessment objective is to have a general idea of whether the Grantee is making progress in achieving the outputs contained in the grant agreement.

The grant agreement contains a detailed list of outputs that the Grantee is expected to achieve by the end of the grant period and which are expected to be in certain stages of completion during the life of the grant. Document the grant date, the PACD and disbursements to date. Through discussions with Grantee officials and a review of relevant documentation, determine whether, in relation to the level of disbursements and implementation period, the Grantee has made reasonable progress in achieving program results.

Who is responsible for financial reporting at CRS; Lea Toto

Describe the process for writing financial reports among Lea Toto staff to CRS;
Describe the process for reviewing Lea Toto financial reports by CRS staff;
Describe the process for writing financial reports among CRS staff to USAID;

Describe the process for reviewing CRS financial reports by USAID staff.

What is the agreed upon financial process of reporting
* Get copies of document(s) describing this process
Are there verbal agreements for reporting that are different than those documented
If so, describe opinions of those involved

Describe compliance to the financial reporting process described above
* Get copies of all reports
Describe opinions of those involved

Analyze contents of written reports for:
Compliance with process described in documents
Compliance with process agreed upon verbally
Clarity
Transparency

What is working
What is not working
Recommendations

Management/Supervision

What is the current relationship between Nyumbani & Lea Toto?

What are the relationships between Nyumbani & Lea Toto with regard to:
Program decisions;
Financial decisions;
Supervision of staff and activities;
Provision of support and facilitation to Lea Toto in implementation;
How clear are these relationships

Describe communication process between Nyumbani & Leatoto and CRS and USAID
Is the relationship between Nyumbani & Lea Toto facilitative of the Lea Toto work?
What is the future vision for this work?

What is working
What is not working
Recommendations

Technical support

Answer with respect to:
USAID providing TA to CRS;
CRS to Lea Toto
Nyumbani to Leatoto
Lea toto to Community

What technical support is needed
How is the need determined
Who determines the need
How is it being met:
    What type of technical support is provided
    How often?

Constraints
What works (get documentation describing technical support provided)
What does not work
Recommendations

Monitoring and Evaluation

Describe written monitoring and evaluation plan
    * Get M&E plan
    How was the M&E plan developed?

Is there an effective MIS in place?
If not, how do you track activities?
Who collects the data?
How often?
Who reviews it?
Who aggregates it and puts it into a document?
Who uses the data?
Confirm the monitoring plan given to the evaluation team

Measuring impact
Is it being measured?
How? With what accuracy? validity?

What are other possible ways of measuring impact in the future?
When was the baseline data collected?
When were the results received?
To what extent were key partners (CRS, Lea Toto, and the community) involved in developing the instrument?
How have the baseline results been used?
How do you plan to move from baseline to M & E?

IN Conclusion…
Is this a worthwhile program?
What are the unexpected outcomes
-Good outcomes
-bad outcomes (Have they been addressed. If so, how?) Should the program be sustained?
If so, what would it need to be sustained?
How to sustain it?

Lea Toto model
What are the barriers to HIV+ children accessing Leatoto?
What is the role of stigma?
What feeds into or decreases stigma?
What is the advantage to HIV+ children of targeting them in Particular?

Questionnaire to the Focus Group

Introduce the purpose of the focus group
Thank participants for participating

Background information

What has been your work as a CHW in the community?
(i.e. do you work with another organization? Doing what?)

Do you know people living with HIV/AIDS?
Do you know children living with HIV/AIDS?
(explain)?
In your work with other organizations, have you found people living with HIV/AIDS in the community?
If so, what has been your involvement with them?

How did you learn about Lea Toto?

What is your current connection with Lea Toto?
How do you work with them?
How do they work with you?

Do you get benefits from Lea Toto?
If so, what are they?

For CHWS already working with Lea Toto:
Since you have begun to work with Lea Toto, how has your work in the community changed?

To focus group leaders..... you will probably not reach the end of this package of questions

10 *minutes before the end of the focus group... come back to this page to finish....*

Finishing Up the focus group:

How do you think the well being of HIV+ children and their families has changed as a result of Lea Toto?

Give 10 minutes to the group to express other ideas, concerns, observations, etc.

Identifying the Needs and Resources available to:
Children in general in Kangemi
Children affected by HIV/AIDS
Children who are HIV+:

What is the magnitude of orphans in Kangemi, in general?
A lot? A little? Explain
What is the magnitude of children affected by HIV/AIDS?
What is the magnitude of HIV+ orphans?

What are the needs of the children in general in Kangemi?
Do those differ for children affected by HIV/AIDS?
If so, how?
What are the specific needs of HIV+ children?

How are these needs addressed by the community?
Extended family? Neighbors? Siblings? No support? Etc?

What programs/services, other than Lea Toto, are available for vulnerable children in Kangemi?
Which of these might also be available to HIV+ children?
Other than Lea Toto, what help can HIV+ children get in Kangemi?

Do you think that other types of children would benefit from the Lea Toto activities? If so, who would most benefit and how?

How to increase reach of Lea Toto

What are the methods that Lea Toto can use to reach more groups with information?

How do you think Lea Toto could reach more children?
Are you a member of an informal or an organized group of people?
If yes, how might Lea Toto link up with that group?

Community involvement

Do you feel that Lea Toto is responding to a community felt need or *not?*
What is the attitude about HIV+ children in the community?
What is the capacity of the community to care for HIV+ children?
What is the role of the community in Lea Toto activities?

What could Lea Toto do to help make it easier for community members to volunteer to work with Lea Toto program?

Community Mobilization:

What community structures could facilitate community mobilization around the issue of HIV affected and/or infected children?

Who are the key persons who could help in that process?

How do you think Lea toto could work with the community to increase the community's ability to care for HIV+ children?
To increase HIV prevention?

If Lea Toto had another location closer to where caregivers are living, that was also open to the community during weekends or evenings, .
Would this be an advantage? If so, how
Or a disadvantage? If so, why? ...

Acceptance of CHWs by Lea Toto been

In the Lea Toto program, CHWs are not well accepted by households with HIV+ children;
Why do you think this happens?
What can be done to increase acceptance of CHWs by families of HIV+ children?

Stigma:

What is your perception and experience with people who are HIV+

How does the community treat people living with HIV/AIDS?
What about children who are HIV+?
Why do you think some people in the community react negatively to people living with HIV/AIDS? (Facilitator, try to get out where the negative perceptions are coming from?)

Do you think HIV+ children should get free health care?
Why, or why not?
Is there a need for a specific health center for HIV+ children?
Why or why not?
What are the biggest barriers to providing care of the HIV+ child and the child's family?
i.e. economic? No money?
The attitude that the children will die early anyway?
Insufficient information and knowledge about how to care for them?
Fear that other people will find out that the child is HIV+?

Economic situation and potential for change in Kangemi

What are the economic activities in Kangemi?
What do you do for income?
Are there strategies that can support people to increase the economic situation of families with HIV+ children?
How are families who have an family member with HIV currently?
Economically and otherwise?

Attitudes toward Lea Toto:

How do you feel about the home visits conducted by Lea Toto?
Do you have suggestions about how Lea Toto may be more effective?
Do you have concerns?
What has been the reaction of other CHWs to your involvement with Lea Toto?

Finishing up the focus group:

How do you think the well being of HIV+ children and their families has changed as a result of Lea Toto?

Give 10 minutes to the group to express other ideas, concerns, observations, etc.

Questionnaire to the Focus Group Care

Introduce the purpose of the focus group
Thank participants for participating

Background information:
How did you learn about Lea Toto?

What is your current connection with Lea Toto?
How do you work with them?
How do they work with you?
What kinds of benefits do you get from Lea Toto?

To focus group leaders .... you will probably not reach the end of this package of questions.. 10 minutes before the end of the focus group come back to this page to finish....

Finishing UD the focus Group:

How do you think the well being of HIV+ children and their families has changed as a result of Lea Toto?

Give 10 minutes to the group to express other ideas, concerns, observations, etc.

Identifying the Needs and Resources available to:
Children in General in Kangemi
Children affected by HIV/AIDS
Children who are HIV+:

What is the magnitude of orphans in Kangemi, in general?
A lot? A little? Explain
What is the magnitude of children affected by HIV/AIDS?
What is the magnitude of HIV+ orphans?

What are the needs of the children in general in Kangemi?
Do those differ for children affected by HIV/AIDS?
If so, how? What are the specific needs of HIV+ children?

How are these needs addressed by the community?
extended family? Neighbors? Siblings? No support? Etc?
What programs/services, other than Lea Toto, are available for vulnerable children in Kangemi?
Which of these might also be available to HIV+ children?
Other than Lea Toto, what help can HIV+ children get in Kangemi?

Do you think that other types of children would benefit from the Lea Toto activities? If so, who would most benefit and how?
How to increase reach of Lea Toto

What are the methods that Lea Toto can use to reach more groups with information?

How do you think Lea Toto could reach more children?
Are you a member of an informal or an organized group of people?
If yes, how might Lea Toto link up with that group?

Community involvement

Do you feel that Lea Toto is responding to a community felt need or not?
What is the attitude about HIV+ children in the community?
What is the capacity of the community to care for HIV+ children?
What is the role of the community in Lea Toto activities?

What could Lea Toto do to help make it easier for community members to volunteer to work with Lea Toto program?

Community Mobilization:

What community structures could facilitate community mobilization around the issue of HIV affected and/or infected children?

Who are the key persons who could help in that process?

How do you think Lea Toto could work with the community to increase the community's ability to care for HIV+ children?
To increase HIV prevention?

If Lea Toto had another location that was closer to where caregivers are living, that was also open to the community during weekends or evenings,
Would this be an advantage? If so, how
or a disadvantage? If so, why?

Acceptance of CHWs by Lea Toto beneficiaries:

In the Lea Toto program, CHWs are not well accepted by households with HIV+ children;
Why do you think this happens?
What can be done to increase acceptance of CHWs by families of HIV+ children?

Stigma

Facilitators, this question is only for the HIV negative group:
What is your perception of people who are HIV+

Continue in all groups with the following questions:
How does the community treat people living with HIV/AIDS?
What about children who are HIV+?
Why do you think some people in the community react negatively to people living with HIV/AIDS? **(Facilitator, try to get out where the negative perceptions are coming from?)**

Do you think HIV+ children should get free health care?
Why, or why not?
Is there a need for a specific health center for HIV+ children?
Why or why not?
What are the biggest barriers to providing care of the HIV+ child and the child's family?
i.e. economic? No money?
The attitude that the children will die early anyway?
Insufficient information and knowledge about how to care for them?
Fear that other people will find out that the child is HIV+?

Economic situation and Potential for change in Kangemi

What are the economic activities in Kangemi?
What do you do for income?
Are there strategies that can support people to increase the economic situation of families with HIV+ children?
How are families who have a family member with HIV currently coping?
Economically and otherwise?

Attitudes toward Lea Toto:

How do you feel about the home visits conducted by Lea Toto?
Do you have suggestions about how Lea Toto may be more effective?
Do you have concerns?
What has been the reaction of your neighbors?
Would you be willing to have a volunteer from the community come to your home to visit and help you?
If yes, what would be most helpful for a volunteer to do?
If not, why not?

Finishing up the focus group.

How do you think the well being of HIV+ children and their families has changed as a result of Lea Toto?

Give 10 minutes to the group to express other ideas, concerns, observations, etc.

Questionnaire to the Community (5/2/01)

What are the needs of the children in general in Kangemi?
What services, other than Lea Toto, are available for vulnerable children in Kangemi?
What is the magnitude of HIV among children in Kangemi?
What are critical needs of HIV+ children?
What services are available to other children that are also available to HIV+ children?

Are you aware of Lea Toto and its programs?
How did you learn about Lea Toto?
What needs are being addressed through Lea Toto activities and how?
Do you know any children who benefited from Lea Toto?

What kind of benefits?
Do you know of how many children have been reached by Lea Toto with: medical, clinical, nutritional care, referrals for further management? Many? A few?
How do you think the well-being of HIV+ children and their families has changed as a result of Lea Toto?
Are there other types of children who would benefit from the Lea Toto activities?

What is the magnitude of the problem of orphans in Kangemi, in general?
What is the magnitude of the problem of children affected by HIV/AID5?
What is the magnitude of the problem of HIV+ orphans?
What are the unmet needs of HIV+ children in Kangemi?
Do you feel Lea Toto is responding to a community felt need or not?
Are members of Kangemi likely to volunteer in Lea Toto activities to support HIV+ children?
If not, why not?
What can Lea Toto do to help make it easier for people to volunteer?

How do you think Lea Toto could reach more children?
Are you a member of an organized group?
If yes, how might Lea Toto link up that group?
What are the methods that Lea Toto can reach more groups with information?
What is the attitude about HIV+ children in the community?
What is the role of the community in Lea Toto activities?
What is the capacity of the community to care for HIV+ children?

What community structures could facilitate community mobilization? around the issue of HIV affected and/or infected children?
Who are the key persons who could help in that process?
How do you think Lea Toto would work with the community to increase the community's ability to care for HIV+ children?
To increase HIV prevention?

In the Lea Toto program, .CHWs are not well accepted by households with HIV+ children; i.e. Why do you think that is true?
What can be done to increase acceptance of CHWs by families of HIV+ children?
How is Kangemi community organized?
What are the economic activities in Kangemi?

Are there strategies that can support people to increase economic stability? If so, give examples
How are the families infected with HIV+ coping? Economically and otherwise?

STIGMA:
What is your perception of people who are HIV+? (PLWHA)
Do you know PLWHA ?
Do you know children living with HIV/AIDS?
How does the community treat people living with HIV/AIDS?
How about HIV+ children?

Why do think some people in the community react negatively to PLWHA?
Why do think people treat them differently if they are HIV+?
Do you think HIV+ children should get free health care? Why and Why not?

What are the biggest barriers to providing care for the HIV+ child and the child's family?
Economic? No money?
The attitude that the children will die anyway?
Insufficient information and knowledge about how to care for them?
Fear that other people will find out that the child has HIV?

There will be four (4) discussion groups that will discuss some of the programmatic challenges around Children Affected by AIDS.

Kindly enlist in of the groups that covers a topic in which you are particularly interested or could make a significant contribution towards.

A maximum of seven (7) participants per topic will be allowed.

The topics of discussion are:

Potential contribution of an activity that focuses on care and support to HIV + children to the well-being of children affected by HIV / AIDS in Kenya

How to encourage disclosure and acceptance by the community

Targeting HIV+ children versus Orphans and Other Vulnerable Children (OVC)

Challenges and strategies in mobilizing communities and developing community ownership in an urban setting.

Topics

Challenges and strategies in mobilizing communities and developing community ownership in an urban setting. (Victor)

What are the strategies that participant organizations have applied
Which worked? Which did not work?

In a community with a transient, unrelated population, how do you Immobilize them for a common cause.

What technical inputs are required to conduct this process

What were the main problems that they encountered?
And how they overcame them?

In a slum area where poverty is pervasive, how much community ownership and involvement can be realistically expected?

For the organization mobilizing the community, what role should they play in facilitating the process? Financial resources? Technical resources?

Targeting HIV+ children vs Orphans and Vulnerable Children (OVC)

Based on your experience and giving examples from your own activities:

What would be the advantages of L T continuing a focus on only HIV+ children and their families?

What would be the disadvantage

What would be the advantages of L T focusing on OVC, of which HIV+ children would be included?

If L T would focus on OVC, then how would they prioritize and select target population?

How do you address the needs of their families?

How to encourage disclosure and acceptance by the community

One of the major challenges to the L T and other programs targeting PLWHAs is that once they have been diagnosed as such there is fear.

What strategies have you used or observed within the community that increase acceptance of PLWHA?

What strategies have you used in your programs that have encouraged disclosure of sero-status ? at family level? (women's disclosure to partner) At community level?

Is there evidence in your programs that provision of support such as medicine, food, etc. increase willingness to disclose? And ultimately reduces stigma?

How to effectively handle the psycho-social needs of the HIV+ child, including the when and how to disclose their sero-status to them.

LT, working in a relatively low prevalence area, find people reluctant to associate with an HIV/AIDS program for fear of stigma and they are also reluctant to allow community volunteers into their homes because of concern about revealing their sero-status and being ostracized. What strategies are being used to overcome these barriers?
Potential contribution of an activity that focuses on care and support to HIV+ children

What is your organization doing now to address the specific needs of HIV+ children?

Would it be appropriate for L T to use its comparative advantage to support other organizations working with vulnerable children to increase their capacity to meet the needs of HIV+ children in their programs?

What are the strategies that L T could use to build the capacity of the community to support HIV/AIDS+ children?

How far should L T go in providing support to the rest of the family?
i.e. care of parents, siblings
And for how long after the child dies?
Realistically, how much community ownership can be expected from a program that focuses on HIV+ children?
How does a program such as L T contribute to the support of children affected by AIDS in Kenya?

7. *Appendix 7*: Principles for Programming (Draft 2- October)

DISCUSSION PAPER

Principles to Guide Programming for Orphans and other Vulnerable Children

This document aims to accelerate a process to build consensus on guiding principles for an expanded response to children and adolescents affected by HIV/AIDS. This effort is grounded in and driven by the firm conviction that children living in AIDS-affected communities have the right to protection, appropriate care and support. They have the right to protect themselves from becoming infected with HIV, and must not be forced into situations where they face risks of infection with HIV or other sexually transmitted diseases. Children have the right to grow up without taking sole responsibility for households, and they have the right to information, education and health care.

The global community has a moral responsibility to protect, respect, and fulfil these rights for all children and adolescents affected by HIV/AIDS. As articulated in the Convention on the Rights of the Child (CRC), nations are responsible for ensuring that children are not simply objects of decision-making, but rather active subjects with a meaningful role in decisions affecting them. The rights of children infected with HIV, and all other children who are made vulnerable by AIDS should be carefully considered when determining their needs in the context of HIV/AIDS.

The needs of children and adolescents affected by HIV/AIDS are vast and growing. Societies are confronted with a generation of children growing up without adequate adult role models and without adult support and protection. Children and adolescents who are malnourished, undereducated and marginalized represent a grave threat to security, stability and markets in heavily AIDS-affected countries. While the challenge of ensuring their safety, well being and development is daunting, the risks of a generation without family support, education, and opportunities are too great to be ignored.

All evidence indicates that this crisis is growing worse at an alarming rate. Even if HIV rates are significantly stabilised in the near future – an unlikely prospect in most areas - the number of orphans will continue to increase and remain very high for decades.

The global community needs clear principles to guide collaborative action for orphans and other children and adolescents affected by HIV/AIDS. This document is being developed through a participatory process intended to expand and enhance the global response by identifying such principles and building consensus around them into a broad vision of what can and should be done. It aims to expand and strengthen the circle of partners who will take up the

responsibilities to make this vision a reality. The current draft reflects the experience of many organisations and experienced individuals, but it is being distributed with the intention of soliciting even greater participation in its development.

The principles that result from this process are intended to serve as a resource to guide sound, effective action at local, district, national and global levels in the development and implementation of initiatives to address the needs of vulnerable children and adolescents in AIDS affected areas.

HIV/AIDS, orphans and other vulnerable children and adolescents

The HIV/AIDS epidemic has rapidly evolved from a health crisis into a development crisis with profound social and economic ramifications.

- HIV/AIDS primarily affects young adults in the prime of life. Around half of all people who acquire HIV become infected before they turn 25, and typically die before their 35th birthday.

- The orphans left behind when these adults die are becoming a generation of marginalized young people, forced to care for sick adults, siblings and even entire households on their own, with little experience of living in stable family environments.

- The loss of able adults critically impacts economies through lost productivity, labour, expertise, and increased health care and death-related costs. In the most severely affected countries, AIDS is reversing decades of investments in health, education and human resource development.

Statistics

- 18.8 million people around the world have already died of AIDS, 3.8 million of them children.
- 34.3 million are currently HIV infected.
- The most recent UNAIDS/WHO estimates show that in 1999 alone, 5.3 million were newly infected with HIV.
- The number of children under the age of 15 who have already lost their mother or both parents to AIDS is estimated to be 13.2 million by the end of 1999.
- Estimates project that the number of children under the age of 15 who will have lost one or both parents from all causes, including AIDS, in a sample of 34 severely affected countries, will be 40.3 million by the year 2005 and 44.2 million by 2010.

Children orphaned by AIDS and children and adolescents made vulnerable by HIV/AIDS, constitute a significant portion of the global AIDS emergency. UNAIDS estimates that by the end of 1999, 13.2 million children had lost their mother or both parents to AIDS[3]. However, these children are only a portion of those who are seriously affected by HIV/AIDS. There are millions of children whose parents are ill; many of these children have become primary care providers for their parents, neighbours and relatives. There are millions more children and adolescents whose fathers have died because of AIDS. There are those living in

[3] Report on the global HIV/AIDS epidemic, June 2000, Geneva: UNAIDS

households where the financial and emotional capacity is over-stretched as a result of caring for an increased number of children and other dependants; those who live in communities heavily affected by the AIDS epidemic; those who are themselves living with HIV/AIDS; and those whose day-to-day lives put them at high risk of HIV infection.

While more than 90% of children orphaned by AIDS to date are in sub-Saharan Africa, the number of orphans is increasing and will continue to increase in other regions. Though prevalence has remained low in many countries in Eastern Europe and Central Asia, incidence is rapidly escalating. The same is true for the Caribbean and Central America. In comparison with the rates of HIV infection in sub-Saharan Africa, those in the general population of Asia are low; the prevalence among 15-49-year-olds exceeds 1% in only three countries – Cambodia, Myanmar and Thailand.

But prevalence rates alone do not tell the whole story in Asia. China and India jointly account for more than a third of the world's population. In these countries, even low prevalence rates result in large numbers of HIV infected people. In India, for example, there were 3.7 million people living with HIV/AIDS at the beginning of the millennium – more than in any other country in the world except South Africa.

The development of guiding principles

The impact of AIDS on children and adolescents and on their families is so vast that only a broadly inclusive, collaborative effort can effectively mitigate it. We all must *strengthen and reinforce our resolve to put aside individual and organizational agendas and piece together a network of responses that will match the scale of the impact.* Communities that have developed effective responses, based on sound principles, need to be recognized in order for national, regional and global learning from this experience to be expanded and accelerated.

More than fifteen years of action against HIV/AIDS has demonstrated that decreasing incidence and mitigating the epidemic's impacts, including on children and adolescents, must be nationally driven, as much as possible, from the highest levels of government. Programmes focussing on children and adolescents need to be in place in more than one government ministry. Prevention and mitigation efforts must involve all sectors of government; civil society, including religious organizations, non-governmental organizations, community groups and associations of people living with or affected by HIV/AIDS; the private sector; international organizations; donor governments; and individual citizens. The front line of response to HIV/AIDS is the affected individuals, families and communities. Mechanisms must be developed to channel resource directly to those who need them and can use them effectively at the community level. There is an urgent need to provide stronger and broader political, financial and technical assistance at all levels.

Much has already been learned from current responses to the impacts of the HIV/AIDS epidemic on children and adolescents. However, efforts have remained fragmented and of small scale relative to the magnitude of the problems caused by the epidemic. The challenge to consolidate these experiences and lessons learned from around the world and to develop mechanisms for scaling up responses is great. The development of common principles to guide collaborative action is intended to generate wider and stronger partnerships and commitments to an expanded response to orphans, and other children and adolescents affected by HIV/AIDS. Their needs demand that we do so. Their rights are a framework that indicates what must be achieved.

The price to be paid if we do not respond adequately to this challenge will be paid not only by the most vulnerable children and families, it is a price we and succeeding generations will pay in underdevelopment, social instability, and lost potential. This is a test of our humanity and our intelligence. We cannot afford to fail.

The following four sections discuss:

1. Human rights as a framework for analyzing the impact of HIV/AIDS on children and the
   response to the epidemic;
2. A strategic approach to action
3. Proposed principles and approaches to guide programming for strategic action, and;
4. The importance of collaboration and networking.

This document is offered as a starting point for discussions among stakeholders at the local, district, national and international levels. The principles and recommendations herein will remain open for revision, in order to reflect the ongoing dialogue and incorporate lessons learned from experience.

Human rights as a framework for analyzing the impact of HIV/AIDS on children and the response to the epidemic

Human rights-based approaches have increasingly been recognized as essential to the success of HIV prevention and care programs, including those working with children and adolescents. Governments have committed themselves to respecting, protecting and fulfilling human rights by ratifying human rights treaties, such as the Convention on the Rights of the Child. In addition many NGOs utilize human rights as a programming framework. The interrelationships between the protection, respect, and fulfillment of rights and situations posed by the HIV/AIDS pandemic provide both dangers and opportunities for children and adolescents. At the Committee on the Rights of the Child Theme Day 1998:

Children Living in a World with HIV/AIDS Peter Piot, Executive Director of UNAIDS, said:

> *What is needed now is to expand the relationship between current children's rights initiatives and HIV/AIDS prevention and care efforts. Promoting the Convention on the Rights of the Child, as well as other human rights treaties, is one step in that direction.*

At the same event, Mary Robinson, UN High Commissioner for Human Rights, noted:

Infants, young children and adolescents are all confronted with a serious challenge to their human rights contained in the Convention on the Rights of the Child as a result of the [HIV/AIDS] pandemic; at the same time, the Convention provides an essential and powerful framework for preventing and combating the spread of AIDS among children and adolescents and avoiding their being adversely affected by the disease and its consequences. Human rights approaches to programming are not only a matter of doing the right thing (i.e. a good, positive outcome for children and adolescents), but of doing it the right way (i.e. a concern for process, participation, ownership, and sustainability).
Fundamental Principles from the Convention on the Rights of the Child
The Convention on the Rights of the Child includes four general principles, which underpin its provisions and offer guidance for their implementation. These principles are:

- Non-discrimination;
- The best interests of the child;
- Survival and development; and
- Opinion and participation.

These four guiding principles highlight the nature of the relationship between children and human rights, in that children are rights holders and active participants in their own lives, while at the same time in need of special protection because they are vulnerable.

Guidance Provided by the Convention on the Rights of the Child

The United Nations Convention on the Rights of the Child, which has been ratified by more countries than any other international instrument, specifies standards to that should be given particular attention when addressing the situation of children affected by HIV/AIDS:

Article 3 includes the provision that the "best interests of the child" shall be a primary consideration in matters concerning children;

Article 5 recognizes the responsibility of members of the extended family, community, or legal guardians to provide for the child in a manner consistent with his or her evolving capacities;

Article 8 concerns the right of a child to preserve his or her identity, including name and family relations;

Article 12 recognizes a child's right to be heard in any proceedings that concern him or her;

Article 18 recognizes the responsibility of the State to support parents and legal guardians in their child-rearing responsibilities and to develop services for the care of children;

Article 19 concerns the protection of children from abuse, neglect, maltreatment, or exploitation;

Article 20 concerns the responsibility of the State to provide special protection for a child deprived of his or her family environment;

Article 21 addresses safeguards regarding adoption;

Article 24 recognizes the right of children to the highest standard of health and access to health services;

Article 25 concerns the periodic review of the situation of a child who has been placed in care;

Article 27 recognizes the right of children to an adequate standard of living;

Article 28 concerns the right of every child to education;

Article 32 addresses the protection of children from economic exploitation; and

Article 34 concerns the protection of children from sexual exploitation and abuse.

A Strategic Approach

Developing effective interventions to mitigate the devastation HIV/AIDS causes among children and families requires giving careful attention both to the problems on a human scale, what happens to parents, children, and orphans' guardians, and to the massive scale and decades long future impacts of the HIV/AIDS. Establishing programs that significantly improve the lives of individual children and families affected by HIV/AIDS is challenging, even with enough resources, organizational capacity, and compassion. Vulnerable individuals and households can be identified, health services can be provided, school expenses of orphans can be paid, food can be distributed, and supportive counseling can be provided. Such interventions meet real needs, but the overwhelming majority of agencies and donors that have responded so far have paid too little attention to the massive scale of the problems that continue to increase with no end in sight. Since programs to date have reached only a small fraction of the most vulnerable children in the countries hardest hit by AIDS, the fundamental challenge is to develop interventions that make a difference over the long haul in the lives of the children and families affected by HIV/AIDS at a scale that matches the magnitude of their needs.

The starting point for effective responses to the impacts of the pandemic on children is recognizing that families and communities are the first line of response to HIV/AIDS. Whether outside bodies intervene or not, families and communities are going to be dealing with the impacts of HIV/AIDS, often with great difficulty. Consequently, interventions by governments, international organizations, NGOs, religious bodies, and others will have significant, sustainable impacts on children's vulnerability and well being to the extent that they strengthen the ongoing capacities of affected families and communities to protect and care for vulnerable children. Building family and community capacities is not enough, but it must be the foundation for addressing the impacts of HIV/AIDS on children.

Children on the Brink 2000 has presented a strategic framework to help shape an effective, collaborative response to the impacts of HIV/AIDS on children and families:

1. *Strengthen the capacity of families to cope with their problems.*
2. *Mobilize and strengthen community-based responses.*
3. *Strengthen the capacity of children and young people to meet their own needs.*
4. *Ensure that governments protect the most vulnerable children and provide essential services.*
5. *Create an enabling environment for affected children and families.*

Proposed principles and approaches to guide programming

1. Strengthen the caring and coping capacities of families and communities

In nearly all areas heavily affected by HIV/AIDS, the first line of response to protect the rights and address the needs of children is extended families. Families show remarkable creativity and dedication in coping with the impacts of HIV/AIDS. However, the scale of the pandemic is causing enormous strain on the traditional coping mechanisms of the extended family, eroding its capacity to care for those suffering from or left behind by HIV/AIDS. In many areas, communities have organized, formally or informally, to support especially vulnerable children and households. Families and communities are the primary social safety nets, and, to the extent possible, their capacities must be strengthened to minimize the number of children and adolescents who slip through them onto the street. Supplemental assistance and support services are needed, but they will be overwhelmed if families and communities are allowed to collapse. Programmes should affirm and reinforce family and community responses to the crisis. Efficient systems need to be developed and strengthened to monitor the status of vulnerable children in the community, and to identify and mitigate exploitation and abuse.

2. Increase and strengthen community care rather than institutional care

In many areas of the world, orphaned children have traditionally been cared for by members of their extended family. In some areas, religious communities and foster families also provide care. In AIDS-affected areas there are increasing stresses to the capacity of extended families and communities to provide care, yet in most cases institutions are not an appropriate alternative. Institutions, such as orphanages, generally do not adequately meet key developmental needs of children, such as consistency of care, especially for younger children. In addition, when children grow up without family and community connections, they are cut off from the support networks they will need as adults, as well as the opportunities to learn the skills and culture that children learn in families and in their communities.

Economically, institutional care is also not financially feasible for large numbers of children. The financial resources needed to support institutional care for a single child could assist scores and even hundreds of children if used effectively to support a community-based initiative. In communities under economic stress, increasing the number of places available in institutions has often led to more children being pushed from family care to fill those places, where the material standards are seen as being higher than families can provide. This increases the scale of the problem and consumes resources that could do more if directed towards strengthening family and community capacities to care for vulnerable children. Institutional care can be helpful in some cases where there is no other option, as an interim solution while a fostering situation is arranged. Children in such situations should be reintegrated into the community as soon as a reliable caregiver can be identified.

One alternative model for institutions has involved transformation of children's homes into community-based resource centres that help families support children in the community. Such centres provide day care for foster parents or parents in need of relief; support groups; counselling; training in parenting skills; skills training programmes for older children, and a variety of other forms of support. There are many other forms of care: economic strengthening of households and communities, group foster homes, school-based services, etc...

All children in affected households (i.e. with chronically ill caregivers/parents) should participate in decision-making processes regarding fostering. This is integral to memory approaches, which try to help HIV-positive parents give their children the support they need and to prepare for the future. Through this process inheritance rights are less likely to be violated.

3. Enhance the capacity of families, communities, and local groups to respond to the psychosocial needs of vulnerable children and adolescents

HIV/AIDS undermines then often destroys the fundamental relationships considered ideal to healthy family life and child development. Children affected by HIV/AIDS suffer anxiety and fear during the years of parental illness, then grief and trauma when a parent dies. Less tangible than the material problems children suffer, these psychosocial problems are rarely addressed in programmes, although they are frequently of concern to staff and can have serious long-term impacts on children and adolescents. A child's progression through basic developmental stages is jeopardised if HIV-related illness reduces and then ends a parent's capacity to provide consistent love and care. Development is also jeopardised if HIV/AIDS causes social isolation, stigma, and discrimination or otherwise disrupts the experiences normal within a child's community. If developmental needs are not fulfilled, a child may have difficulty relating to a care provider or other people and may demonstrate behavioural or psychological problems.

Children's psychosocial problems are often compounded by silence. In many cultures it is taboo to discuss an impending death for fear of making it happen. Also, fear of being stigmatized leads some families to deny that an illness is related to HIV/AIDS or to forbid discussion of it. In this climate of silence, children's fears and questions about their own future are neither acknowledged nor discussed. After the death of a parent, children's grief is compounded if siblings are separated to live in different households or if new step-parents or guardians fail to provide nurturing care. Such losses can cause invisible wounds that may never heal.

Enabling a family to cope more effectively with the material problems they face is a major step towards helping them deal with psychosocial problems, but it is not enough. Effective measures to address psychosocial needs do not require separate programmes. They should be incorporated into other activities to benefit children and families affected by HIV/AIDS. They should involve community-owned efforts to promote the psychosocial well-being and social integration of vulnerable children and adolescents in general, as well as efforts to reach out to and provide emotional support to individuals who are isolated, withdrawn, or showing other signs of distress. A particularly appropriate response at the household level is for an ill parent and his/her children to develop a memory book with important family information and plans for the children's future.

4. Reduce stigma and discrimination

From its earliest stages, the HIV/AIDS epidemic has been accompanied by fear, ignorance, and denial, leading to stigmatization of and discrimination against people with HIV/AIDS and their families. Because of their status as orphans or affected by HIV/AIDS, many children and adolescents also experience stigma and discrimination, often made worse by the increased poverty they experience as a result of the death of one or both parents. Stigma and discrimination increase the pain and suffering already experienced by those who are affected by HIV/AIDS, and often threatens the effectiveness of prevention and mitigation efforts. Fear of being identified as a person living with AIDS often keeps people from seeking treatment and care, discussing prevention, changing unsafe behaviour, and supporting care for people with HIV/AIDS and their families. Specific efforts to address and reduce stigma and discrimination must be an integral part of prevention and mitigation activities.

5. Foster linkages between HIV/AIDS prevention activities and efforts to support vulnerable children and adolescents

Children orphaned or otherwise affected by HIV/AIDS can also be at higher risk of HIV infection. It is imperative that support to children and adolescents affected by HIV/AIDS include a prevention component. There is evidence to suggest that programs that focus on care for vulnerable children and care for people living with HIV/AIDS can be especially effective in promoting HIV prevention. Providing care for children and/or adults affected by HIV/AIDS has the potential to stimulate a more realistic assessment of personal risk among community members and a better understanding of potential consequences for themselves and their families. Many caregivers have subsequently begun to actively promote prevention messages as a result of their familiarity with the effects of the disease and recognition of the urgent need to prevent additional sickness, death and orphaning. Prevention messages that are conveyed by a family member, friend, or acquaintance are likely to have a greater impact on the recipient than messages conveyed by an unknown outsider.

Meeting needs and building family and community capacity can help prevent the spread of HIV. Hopelessness and sense of powerlessness are two of the biggest obstacles to effective prevention efforts. Enabling young people to gain more control over their lives and to develop hope for a worthwhile future increases the likelihood that they will chose behaviours that will enable them to avoid HIV infection. Furthermore, gaining such control often enables adolescents to act on their choices. Programmes to protect the rights and assist children and adolescents affected by HIV/AIDS should consider either including prevention activities or linking to prevention-oriented programmes.

6. Foster linkage between home-based care and support to children/adolescents

HIV/AIDS has an impact on all members of household – infected adults, non-infected adults, adolescents and children. However, programmes that target children affected by HIV/AIDS are often undertaken in isolation from those that provide care to people living with AIDS. Support for home care of people living with HIV/AIDS is often done with a focus solely on the people who are ill. There are limited examples of care initiatives that have included these two complementary activities. By promoting care for HIV/AIDS-affected adults, programmes are effectively assisting their children, and vice versa.

Linking the two types of activities also takes advantage of the cost savings that can be achieved by integrating care for children and adults within a single approach, rather than using two different approaches, structures, and/or programmes. In addition, integrated programming more effectively responds to the reality that the vulnerability of children in HIV/AIDS-affected households begins long before the death of the child's parent(s) and continues after their death.

Children whose parents are ill as a result of AIDS experience the psychosocial distress of seeing a parent approach death, as well as the economic deterioration of the household that often accompanies chronic illness of the person who is the primary source of income. Integrating attention for children into the provision of care for those who are infected by HIV/AIDS facilitates earlier identification of these children and earlier action to assist them. Therefore, where possible, it is advisable to link programmes of care and support for people living with HIV/AIDS and those that focus on the needs of children and adolescents who are affected by the disease, either by integrating them into a single intervention or by linking these related interventions to maximize co-ordination and complementarily.

7. Target communities where HIV/AIDS makes children vulnerable, not "AIDS orphans"

Responses to protect, respect, and fulfil the rights of children affected by HIV/AIDS should not single out "AIDS orphans". Instead, programmes should direct services and community mobilization efforts towards communities where HIV/AIDS is significantly increasing the vulnerability of children and adolescents. Targeting specific categories of children can lead to increased stigmatization and discrimination and increased harm to those children. In addition, problems start for children and adolescents long before a parent dies because of AIDS. The psychosocial distress and economic problems typically begin with awareness of HIV infection or illness. Within communities that are not adequately meeting their children's needs, assistance should be directed to the most vulnerable children and households, regardless of the specific cause of their vulnerability. Generally, it is the people who live in these communities, rather than an outside agency, who are in the best position to determine who is at greatest risk and what factors should be used to assess vulnerability. Many community-based responses to children affected by HIV/AIDS have developed effective systems to identify and prioritize the children/adolescents most in need. In those communities in which such an approach has not yet been developed, the process to develop representative, participatory systems should be encouraged and supported.

8. Give particular attention to women and girls

Much of the burden of caring for people living with AIDS and of orphans falls to women. When illness strikes a family or children are orphaned, very often it is the girls who are forced to drop out of school, care for younger siblings, and take on adult tasks. The laws of some countries seriously affected by HIV/AIDS do not allow women to own property or widows to inherit land. Men must assume greater responsibility in providing care. Laws and policies should be changed to ensure and protect basic rights of women and girls. Water and sanitation development and interventions to reduce demands on firewood for cooking are needed and will benefit women and girls. Efforts to ensure vulnerable children can remain in school should give particular attention to girls.

9. Involve children and adolescents as "Part of the Solution"

The CRC defines the rights of all persons below age 18 or the legal age of majority. Interventions to address the needs of children affected by HIV/AIDS should be developed with attention to the risks and needs of infancy through adolescence. Interventions should include emotional, economic, educational and social support, as well as health promotion. Children and adolescents are important and valuable resources and should be involved in such interventions mitigating the impact of the disease in their communities. They can be an essential "part of the solution" - providing support to each other, to younger children, and to those who are ill as a result of HIV/AIDS, as well as influencing behaviour change among peers and within the community.

Actively acknowledging and supporting the potential contribution of adolescents in efforts to improve their own lives and the lives of others – children and adults – can build self-esteem, efficacy and can encourage them to adopt safer behaviours, as well as cultivate concrete skills that can contribute to future self-support. The involvement of young people in providing psychosocial support is a way of engaging them in care activities. Such involvement increases "caring solidarity," which may lead towards preventive behaviour changes.

Providing psychosocial care for orphans and affected children is an entry point to HIV prevention and care and can be seen as an innovative HIV prevention strategy, at the same time as a much needed service. Adolescents should be involved and consulted to the extent possible in the design and implementation of mitigation and prevention efforts. The elderly, often grandparents, should also be recognised as key figures in all responses.

10. Accelerate learning and information exchange

Response to the impacts of the HIV/AIDS pandemic is still at a developing stage. Knowledge and practice in the field are constantly evolving. Governments, donors, NGOs and community groups need better information about the most effective ways to intervene and how to achieve quality coverage that addresses the massive scale of needs. Future efforts to use wisely the resources that are available must incorporate lessons learned from current efforts through systematic monitoring, evaluation, and research. Commitment is needed to identify the types of rights-based approaches that are most effective, efficient, and sustainable; to identify the conditions under which they are most appropriate; and to share lessons learned with local and with global partners in this effort. In addition, it is through linkages and networks, cross-site visits and other methods that support exchange of information that programmes have the opportunity to learn from each other's successes and failures. Examples abound of model programmes that have contributed to the development and implementation of successful activities in other areas.

11. Strengthen partnerships at all levels and build coalitions among key stakeholders

The impact of HIV/AIDS on children, their families, and their communities is far too large and complex to be addressed without the co-ordination and collaboration of stakeholders at local, national, and global levels. Resources that could be used to respond to these impacts, often scarce even in the best of times, are being severely depleted by the expanding crisis. No single action or actor can effectively address these impacts on its own. Consequently, programmes to assist children and families affected by AIDS must seek to involve government, NGOs, community- based organizations, religious bodies, donors, business, and others in broad initiatives of community action. By working together, they can bring enough effort and resources to bear on problems to make a difference. Good examples of such collaboration may be observed among the many grassroots groups and impoverished communities

that have come together to use their own resources to support orphans and other vulnerable children.

12. Develop multisectoral, mutually reinforcing programming strategies

HIV/AIDS interventions have typically fallen into such categories as "prevention," support for "home-based care," and "orphans programs." Organisations and government agencies tend be organised around specific professional capabilities, but the HIV/AIDS-related problems that children and families are struggling with do not divide themselves into such boxes. They are complex and interrelated and cannot be addressed adequately by any single professional discipline. Families and communities, leaders and organizations need to develop and maintain holistic, integrated programme approaches and interventions and develop partnerships among organisations and groups so their collaborative responses respond to needs effectively. Integration also means cross-sectoral reponses, between health, education, economic growth, agriculture and other sectors.

13. Ensure that external support does not undermine community initiative and motivation

It is vital that interventions with AIDS affected children and communities take into account the long-term nature of AIDS-related problems. HIV infection today will have direct impacts on children and adolescents 15 to 30 years from now. The indirect impacts experienced by children and adolescents, such as increased aggravated poverty, reduced opportunities, decreased nurturing and support, and increased morbidity and mortality are much wider than HIV/AIDS-related illness and will extend for decades into the future. Interventions developed today must respond to the need for wide-scale, long-term efforts that address both the direct and indirect impacts of AIDS on children and adolescents.

There is serious concern in some areas that new, donor-driven efforts will take the place of local efforts and that donor support will not continue over the long-term. Large amounts of funds or material assistance can change the nature of the humanitarian motivations that drive local efforts. This becomes a problem if the external assistance ends, or if local organizations shift programmatic focus due to donor-driven funding conditions and priorities. While there is need at the community level for funds for basic supplies such as food, medicine, shelter and school fees, this support must be paired with efforts, including training and technical assistance in organizational development and resource mobilization that will enable participants to continue to make a difference after shorter-term funding is no longer available.

When donors or organizations are prepared to provide limited amounts of support for many years, it is possible to develop effective, ongoing partnerships with community-owned groups whose commitment is not based on the availability of outside assistance. Central to the provision of external support must be the recognition that families, communities and the children themselves are at the front line of the response, demonstrating enormous capacity to care for and support vulnerable children and adolescents in AIDS-affected areas. It is imperative that governments, donors, non-governmental organizations (NGOs) and religious organizations focus on strengthening and supporting these ongoing efforts of families and communities. Community ownership of support efforts is of paramount importance.

14. Scale up and scale out

The most critical challenge currently facing organizations seeking to assist AIDS-affected children and adolescents is that of developing responses to problems on the same enormous scale as they are occurring. Millions of children have already been orphaned by HIV/AIDS; tens of millions more will lose one or both parents to the pandemic in the first decade of the twenty-first century. Tens of millions more children will be in circumstances requiring special protection measures. While it is reasonable to believe that the international community will make substantially more resources available to assist these children than are currently allocated, resource levels will still be far lower than required.

Each organisation involved in programming must carefully consider how to use its limited resources to ensure that quality care and support is provided to the highest number of AIDS-affected children/adolescents possible. Programmes should be designed and developed to benefit as many children as they can (scaling up) and effective approaches should be adopted and adapted by organizations in other areas (scaling out). All groups concerned with health, safety, well-being, education and economic development must recognize and respond to the problems the pandemic is causing among children and families, and they must actively seek ways to undertake a set of interventions that make a lasting positive difference in the lives of those in greatest need.

International NGOs need to resist implementing their own "top down" programmes and initiatives. They should focus on capacity strengthening of local NGOs and community-owned organizations so that they can be effective facilitators of community owned programmes.

Recommendations for strategic action

While no single intervention will make a substantial impact on the full range of economic and psychosocial problems posed by HIV/AIDS, combinations of activities can make a difference. Some candidate actions for an effective response are shared in this section.

1. Family and community levels

1.1 Develop and implement programmes to help HIV-positive parents fulfil their roles as long and as well as possible.

1.2 Enable children, whose parents are ill, to express their fears and concerns about their parents' illness and their own future. Encourage parents to talk to their children about the illness and plan together for the future (succession planning).

1.3 Strengthen the capacity of existing community-owned responses. Assist extended families and communities in providing consistent support to children and adolescents.

1.4 Draw on traditional ceremonies and local cultural practices and knowledge to address grieving and promote social integration.

1.5 Train teachers to recognize and respond supportively to withdrawn or disruptive behaviour or changes in academic performance that can result from distress over the illness or death of a parent.

1.6 Encourage and support communities to conduct psychosocial support activities, such as structured recreation, art, cultural and sports activities that provide life skills to enable orphans and other vulnerable children and adolescents to integrate socially, build confidence, trust, and self-esteem.

1.7 Organize regular home-visiting for orphans and children whose parents are ill.

1.8 Provide counselling services for children who are not responsive to community-based interventions.

1.9 Systematically mobilize and support community-owned responses to the needs of children and families affected by HIV/AIDS, with emphasis on the greater involvement of people living with HIV/AIDS.

1.10 Support community ownership as a key to sustaining effective responses by ensuring that communities are able to identify their greatest concerns and respond to these, rather than to an externally defined agenda. There is a need to facilitate community care processes and plan the supportive role of NGOs at the onset.

1.11 Target social assistance to families in need, not just those grappling with AIDS, as a way of ensuring equity and discouraging discrimination against orphans and others affected by AIDS.

1.12 Ensure that interventions benefit as many vulnerable children and adolescents as possible, given the limited resources available.

1.13 Identify, implement, and evaluate models for scaling up and scaling out community approaches.

1.14 Ensure monitoring and evaluation to maximize project quality and coverage.

1.15 Encourage activities that engage and empower adolescents to ensure they are part of the solution.

1.16 Encourage co-operative problem-solving and support information exchange among communities.

1.17 Incorporate HIV prevention and care for children and adolescents affected by AIDS into related community development programmes

1.18 Encourage information exchange, and actively develop collaboration among stakeholders to maximize the impact of limited resources. Facilitated program to program visits, or study tours, are good practice for information exchange

1.19 Utilise monitoring, evaluation, research, and information exchange to generate Lessons Learned and Good Practices.

1.20 Increase women's access to credit, income-generating activities and property, including land. In many cases, such action will require changing laws and policies regarding inheritance and property ownership.

1.21 Enable vulnerable children to return to and/or stay in school.

1.22 Enable caregivers and child household heads access to guardianship funds.

1.23 Increase young people's and caregivers' access to microenterprise and vocational training and credit.

1.24 Protect the property and inheritance rights of widows and orphans.

2. National level

Advocacy and social mobilization

2.1 Actively combat discrimination. Raise the visibility of AIDS while combating shame and stigma.

2.2 Raise public awareness of the nature of the crisis and mobilize resources locally and internationally.

2.3 Encourage the full participation of communities in all aspects of the response to HIV/AIDS. Ensure that people living with HIV/AIDS and those caring for them are involved at every step – including in planning, implementation, monitoring and evaluation.

Policy reform

2.4 Undertake analysis and reform of relevant national policies. Comprehensive strategies are needed to guide national policies involving children and adolescents affected by HIV/AIDS. These strategies define the role of government and other stakeholders supporting the coping capacity of individuals, families, and communities, and providing essential protection through laws, policies, and action.

2.5 Develop priority national policies in support of HIV prevention and mitigation of the impact of AIDS. Focus on protecting younger children and girls and on providing young people with *effective* education on HIV/AIDS and on related reproductive health issues. Encourage effective prevention programmes involving peer educators.

2.6 Mobilize widespread support for the struggle against AIDS and establish frameworks linking efforts of government and civil society including religious organizations, non-governmental organizations, the private sector and communities.

2.7 Ensure access to education for both girls and boys, especially for girls, by introducing specific measures such as subsidies, scholarships and the provision of alternative avenues for high-quality education, such as community schools.

2.8 Reform the education sector to respond better to the needs of orphans and their communities. Traditional approaches to education need to be altered to make schools more participatory and responsive to the everyday needs of students and more relevant to their lives. It is essential that schools help students acquire skills that can enable them

to make informed decisions and avoid risks. Teacher training and support is pivotal to this effort.

2.9 Reform the health sector to emphasize HIV prevention and the expansion of quality health care services that can address the needs of children and communities affected by AIDS.

2.10 Introduce and enforce laws that realize the rights of children and women, emphasizing the best interests of the child. Focus on child protection issues such as child abuse and rape, children in commercial sex work, exploitative child labour, juvenile justice, and children and women who lack secure tenure and are denied property ownership.

2.11 Reform social welfare in countries with higher HIV prevalence to focus on community mobilization towards enabling local social safety nets rather than dealing with individual case-work style interventions.

2.12 Identify, analyse, refine, and monitor the implementation of a range of policies, regulations, and laws that impact children affected by HIV/AIDS. Key aspects to consider include:

- Enactment and enforcement of laws ensuring women the right to own property;
- Universal birth registration
- Protection of the inheritance rights of orphans and widows;
- Protection of children against neglect and abuse (physical, sexual, and emotional);
- Prohibition of exploitative and harmful child labour;
- Availability and accessibility of social welfare support;
- Regulation of institutional facilities caring for children;
- Elimination of barriers to vulnerable children continuing their education;
- Improved access to quality education and information about sexual and reproductive health;
- Protection and support for street children.

2.1.3 Prohibit discrimination in health care, schools, employment, or other areas based on actual or presumed HIV/AIDS serostatus.

2.1.4 Regulate and support the placement and guardianship of children who lack adequate adult care.

Monitoring and evaluation

2.2 Identify, assess and document successful community-based initiatives with a view to expanding them into effective national or inter-country programmes.

2.3 Monitor the impact of HIV and AIDS on children and families at all levels and use the information gathered to take targeted actions.

2.4 Equip communities to monitor the local impact of the epidemic, facilitate action and evaluate interventions.

2.5 Establish supported surveillance sites for ongoing orphan reporting to have quality data from selected sites and use demographic projections for national figures.

2.6 Facilitate access of minors heading households to funds and other state social safety nets.

3. Global level

3.1 Build consensus on the urgency to address the impact that AIDS will continue to have on children, adolescents, families, communities, and the broader societies in which they live.

3.2 Increase commitment among governments, donors, the private sector and international organizations to act comprehensively and quickly to mitigate the impacts of AIDS on children, adolescents, and their families.

3.3 Build consensus on principles and approaches to support the development and implementation of initiatives that will increase the well-being of children and adolescents, based on the need for large-scale, sustainable efforts that recognize the vast numbers and long-term effects of increased proportions of orphans and vulnerable children and adolescents in AIDS-affected areas.

3.4 Support the development of networks to facilitate the sharing of technical and financial resources at global, regional, national and local levels.

3.5 Promote consideration of the needs of children and adolescents affected by HIV/AIDS, and the impact of their vast numbers, in the development and implementation of HIV/AIDS prevention and mitigation efforts at global, regional, national and local levels.

3.6 Ensure that development programmes in all sectors, especially in countries heavily affected by HIV/AIDS, give attention to the rights and special needs of orphans and vulnerable children and the long-term impact of vast numbers of children and adolescents affected by AIDS on current and future development.

3.7 Reinforce the spirit of true collaboration as all concerned unite to meet the challenges of the AIDS pandemic. The impact of HIV/AIDS on children and adolescents and on their families is so vast that only a broadly inclusive effort can begin to mitigate its impact effectively. We must strengthen our resolve to put aside individual differences and forge

a common commitment to undertake an unparalleled global response to a crisis of unprecedented magnitude.

The importance of coordination and networking

There are great many challenges to improve networking and strengthen collaboration of existing efforts and build on them at local, district, national, and international/global levels. Diverse priorities and uneven relative capacities for programme delivery and management vary greatly in different settings. Programming experience makes it clear that co-ordinating efforts is often not effective without mechanisms that bring together the key partners on a regular basis to define and review the programme implementation plans, along with sharing experiences based on the ground realities, obstacles, and opportunities.

In order to achieve larger-scale programming, good practice programmes need to be adapted and scaled up. Key factors that have the potential to substantially contribute to such programme expansion include government support; national level advocacy by leaderships; multi-sectoral partnerships (including government, United Nations agencies and NGOs); capacity building/staff and partner training; youth and community participation; and financial stability. The International Partnership against AIDS in Africa (IPAA) could serve as an ideal mechanism to strengthen expanded responses in that region, while other mechanisms need to be identified elsewhere.

Enhanced collaboration and networking among individuals, community groups, front-line NGOs, religious organisations, private sector, governments, associations of people living with HIV/AIDS, and other societal actors working with and for children, adolescents, and HIV/AIDS can and will make a difference in promoting the rights of the child as a solid framework for responding to and mitigating the impact of the HIV/AIDS pandemic[4]

[4] For more information and linkages to a broad range of networks and websites of interest visit:
http://www.usaid.gov/pop_health/caba
Children affected by AIDS network and Archive (USAID and Synergy Project) http://www.unaids.org/
Joint United nations Program on HIV/AIDS
Http://www.unicef.org/ United Nations Children's Fund

8. Appendix 8: Fulfilling commitments– Internationally agreed upon goals and targets to orient our work

1. The World Summit for Children, 1990

Lead UN agency: UNICEF
(Reference: E/ICEF/2000/13 – Emerging issues for children in the 21st century: Preparatory Committee for the Special Session of the General Assembly for follow-up to the World Summit for Children in 2001, 30 May-2 June 2000, New York)

- The 2001 UN General Assembly Special Session should re-affirm the goals set in 1990 but should also recognize that further action is required, particularly against HIV/AIDS, recognizing that HIV/AIDS is one of the new and greatest threats to the future of children.
- The AIDS pandemic has had a tragic impact on efforts to fulfil children's rights and has greatly affected the trajectory of human development in the 1990s.

Preparations for the Special Session should include opportunities to provide inputs and recommendations for further action based on agreed specific goals and targets for children and adolescents affected by HIV/AIDS.

2. The International Conference on Population and Development, Cairo 1994 and the review undertaken last year after 5 years – Cairo +5

Lead UN agency: UNFPA
(Ref: A/S-21/5/Add.1 - Key actions for the further implementation of the Programme of Action of the International Conference on Population and Development, 2 July 1999)

- The review called for intensified action in many areas of reproductive and sexual health including prevention of HIV/AIDS.

- Establishment of benchmarks on HIV/AIDS prevention – to reduce vulnerability of HIV/AIDS infection, at least 90% of young men and women, aged 15-24, should have access by 2005 to preventive methods (such as female and male condoms, voluntary testing, counselling, and follow-up), and at least 95% by 2010. HIV infection rates in persons 15-24 years of age should be reduced by 25% in the most affected countries by 2005 and by 25% globally by 2010.

3. The World Summit on Social Development, Copenhagen, 1995 – Review of implementation and achievements – 26-30 June 2000, Geneva, Switzerland

- The AIDS epidemic has been a major obstacle to achieving the goals of the Copenhagen Summit in 1995. AIDS is clearly an unprecedented and catastrophic development crisis undermining social development achievements in basic services, particularly primary health care and education.

- The sixth of the 10 commitments made in 1995 sought to promote and attain the goals of universal and equitable access to quality education, the highest attainable standard of physical and mental health, and access of all to primary health care – i.e. quality basic education and primary health care. To do so, it is imperative to take measures at the national level to enable all women and men, including young people, to protect themselves against HIV infection, to mitigate the adverse social impact of the epidemic and to counteract the increase in poverty and widened social and economic inequalities which have resulted from the HIV/AIDS epidemic.

- Under Commitment 7, seeking to accelerate the economic, social and human resource development for Africa and the least developed countries, 25 African countries most affected by HIV/AIDS were encouraged to adopt time-bound targets, such as targets for reducing infection levels among young people by 25% by 2005 in countries severely affected by AIDS, and globally by 2010.

4. Organization of African Unity (OAU) Seminar on Strategies to Support Orphans and Vulnerable Children Affected by HIV/AIDS – April 2000, Algiers

The seminar adopted a "Common Position and Plan of Action on Strategies to Support Orphans and Vulnerable Children Affected by HIV/AIDS.

The 5 thematic recommendation areas included detailed points addressing:

1) Breaking through denial and inaction
2) Strengthening legal and policy protection for affected families
3) Strengthening the capacities of vulnerable children and families
4) Building capacity of government and communities
5) Establishing a broad social alliance to slow the rate of infection and provide care and protection to affected communities

This draft document should complement the above-mentioned resolutions, goals, and recommendations pertaining to orphan, other vulnerable children and adolescents.

9. Appendix 9: Proposed process for developing a consensus on Principles of collaboration for realising the rights of children and adolescents affected by AIDS (or other title)

Output

UNICEF/UNAIDS/USAID and other lead international organizations (i.e. Francois-Xavier Bagnoud Center for Health and Human Rights, PLAN International, Save the Children, World Conference on Religion and Peace, AFXB, Salvation Army, CARE and others) and regional groups widely circulate this draft document containing proposed principles, approaches and actions, in an effort to continue an inclusive, participatory process to build consensus and commitment to action and to guide collaborative and expanded responses to orphans and children affected by AIDS. The document produced through this participatory process will be submitted to a wide range of partners for their endorsement. It will serve as a resource document for setting and fulfilling global political commitments and translating these into collaborative action at international, national, district and community levels.

Timetable

July — Durban Conference: a list of workshops and sessions on orphans and children, adolescents and young people affected by AIDS was compiled. A discussion paper was presented for feedback and consensus on further action needed and concrete next steps.

August-October — Feedback requested regarding recommendations for agreed upon principles and approaches. Draft 2 produced for wide consultation/review.

November — Review and input at UNICEF-Zambia/USAID regional workshop on orphans and vulnerable children

December — Draft document will be presented at the African Development Forum for review by African Governments in the framework of the International Partnership Against AIDS in Africa (IPAA)

February 2001 — A consultation will be held to finalise the document.

March-April 2001 — Final edit, printed and distributed as UNAIDS document with all contributing organizations listed.