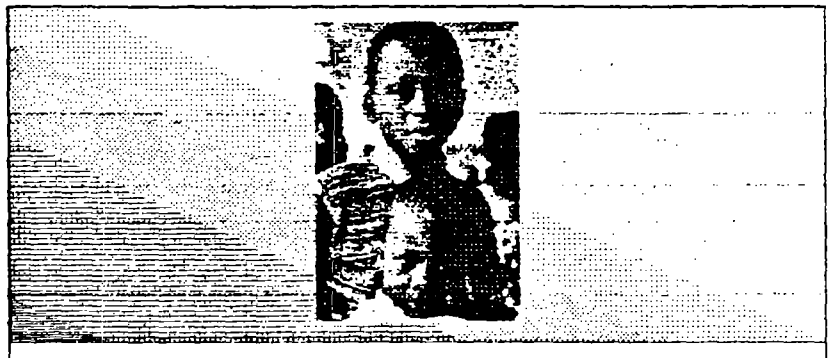
Into the 21st Century:
Designing Care and Protection Programmes For Children Affected by HIV/AIDS

Country Programme Assessment Guide



Into the 21st Century:
Designing Care and Protection Programmes for Children Affected By HIV/AIDS

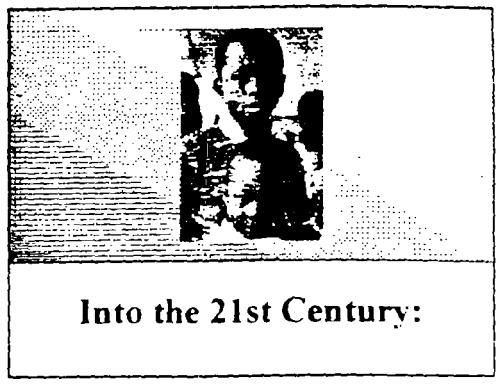
Introduction

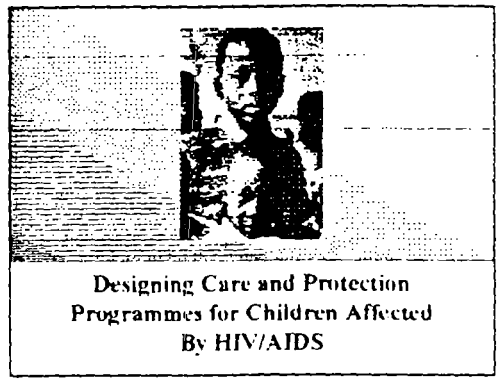
This programme assessment guide has two parts:

1. A written manual (this document)
2. A Power Point presentation.

The two parts are intended to be used together by UNICEF country office personnel interested in conducting a Country Programme Assessment for orphans and other children affected by HIV/AIDS. This guide has been prepared at the request of offices considering the assessment process, and has three aims:

1. To encourage offices to undertake an assessment of activities in their countries;
2. To serve as an introduction for countries undertaking such an assessment prior to the assessment process itself;
3. To use in working with partners participating in the assessment.

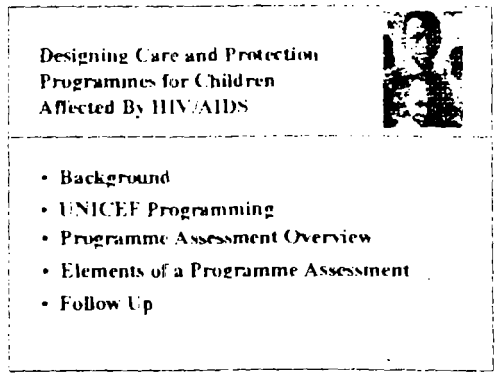




The manual is divided into five sections:

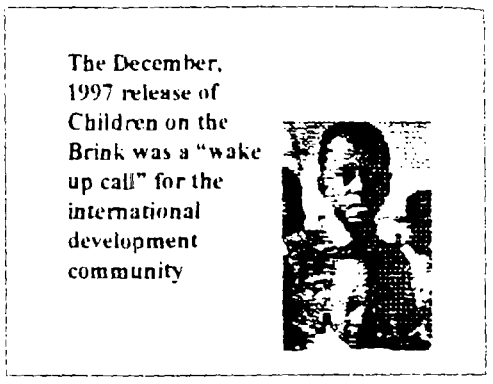
1. **Background** – explains the increasing vulnerability of children due to high HIV/AIDS mortality;
2. **UNICEF Programming** – describes UNICEF's efforts to programme for orphans and other children affected by HIV/AIDS since the late 1980's and its current strategy for programme intensification;
3. **Programme Assessment Overview** – a brief introduction to the assessment process, how it is organized, and what can be accomplished;
4. **Elements of a Programme Assessment** – a discussion of the seven elements of a country programme assessment;
5. **Follow Up** – what can happen after an assessment is completed.

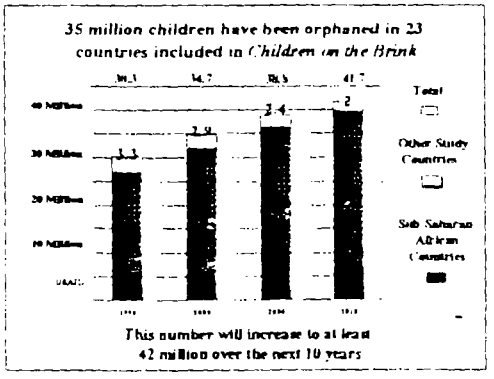
In each part of the written guide, the accompanying slides from the Power Point presentation are shown in the column at right.

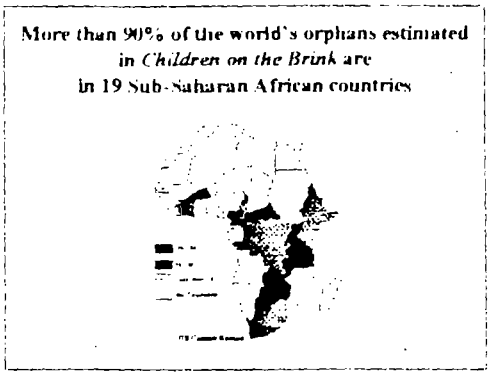


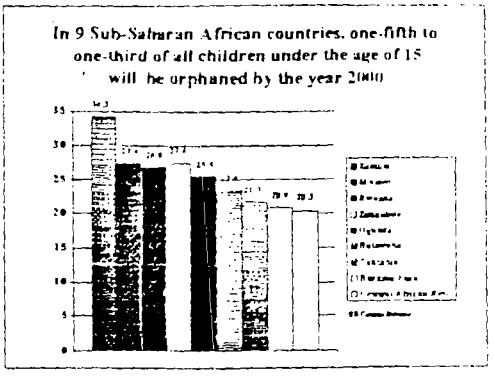
Background

The 1997 World AIDS Day release of ***Children on the Brink*** represented a Awake up call≅ for the international development community on several levels. First, the report estimates that by 2010, there will be nearly 42 million orphaned children in the 23 countries included in the study, 40 million in the 19 Sub-Saharan African study countries alone. By 2000, there will be an estimated 32 million orphans in these 19 countries, largely due to the AIDS epidemic. In eight Sub-Saharan African countries, 20 to 35% of all children under 15 will be missing mother, father, or both parents. ***Children on the Brink*** portrays the scale and urgency of this demographic event, providing a clear picture of the massive impact the pandemic will have on children, families, societies, and economies in Sub-Saharan Africa through the first third of the next century.









The Pandemic

As we approach the end of the century, the AIDS pandemic in Sub Saharan Africa is worse than anyone ever imagined and is getting worse, not better, as had been hoped. HIV infection levels and AIDS deaths in Sub-Saharan Africa continue to grow. In at least four countries, infection levels in the general population are between 20 and 26%, and there are no signs that they are diminishing. **One in four adult Zimbabweans and Botswanans and one in five Namibians and Zambians are infected and will die within the next seven to ten years.**

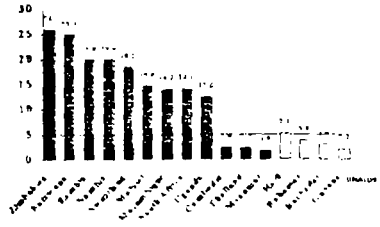
Infection rates are similar in neighboring countries. In Swaziland, the infection rate is 18.5%. In Malawi, Mozambique and South Africa, infection rates in the adult population are 14 to 15 %. Rwanda and Uganda hover between 12 and 13 %. AIDS is now the leading cause of death for people ages 15 to 39 in Malawi, Tanzania, Uganda, Zambia, and Zimbabwe. In countries with recent civil strife, including Angola and Rwanda, infection levels may be higher than reported.

In many countries, including those with high infection rates, some large cities and geographic regions have even higher infection rates than the country average. In Botswana, for example, the infection rate in Francistown was 43 % in 1997. In Beit Bridge, Zimbabwe, 59% of women in antenatal clinics were seropositive, in Masvingo Province, 50% are positive, and in Harare, 32% are positive.

When infection levels become this high, **they will remain high for at least a decade even if there is substantial behavior change**. An analysis of 1996 Zambian serodata shows that if the infection rate in the general population leveled at 19.9% in 1997 – possible because of increasing death rates, not behavior change -- it will remain at 19.9% through at least 2010 because current incidence, or new infections, are high enough to balance AIDS deaths. This, in turn, means that AIDS deaths will not begin to diminish until 2017 or 2020, and that the proportion of children orphaned will remain extremely high through 2030.

Infection levels in other developing regions are as high as those in Africa a decade ago, and with one exception, Thailand, rising. Currently, 1 in 5 of the world's HIV positive men and women are in Asia, a figure which will

Infection Levels are Higher than Ever Imagined



And They Are Worsening

Even if new infections leveled by the year 2000 in Sub Saharan Africa...

Infection rates will remain high through at least 2010

Deaths will not level until 2020

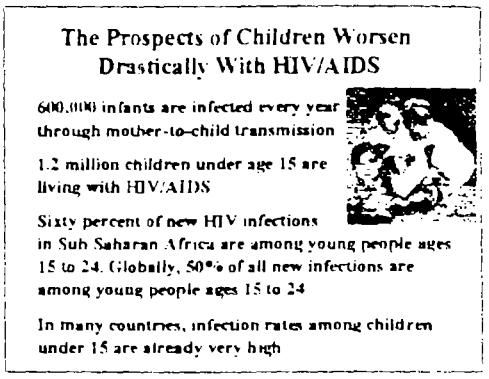
The proportion of children orphaned will be unusually high through at least 2030

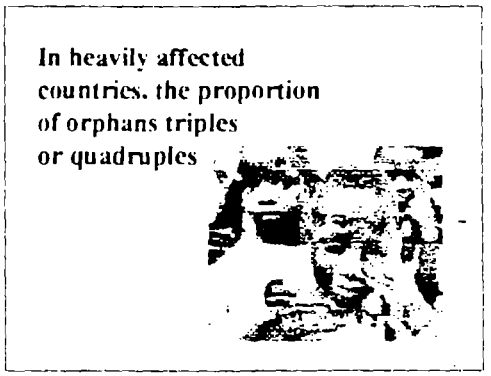
grow to 1 in 4 by 2000. The overall adult HIV rate in Haiti, 5.2%, is as high or higher than some Central and West African countries, suggesting that there is no reason for complacency in the Caribbean region.

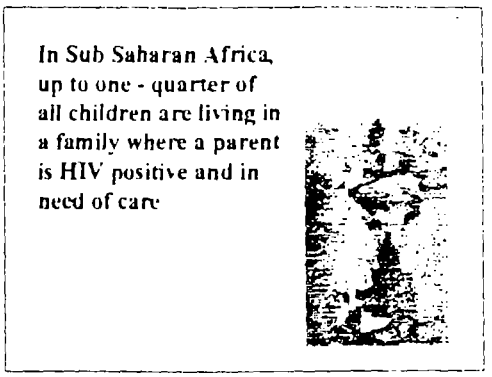
Prospects for Children and Young People in a World with HIV/AIDS

The prospects of children and young people have worsened in many important ways due to the HIV/AIDS pandemic:

1. **600,000 infants are infected every year** through mother-to-child transmission;
2. **1.2 million children and young people under 15 are living with HIV/AIDS**;
3. **Sixty percent of new infections in Sub Saharan Africa are among young people ages 15 to 24**. Globally, 50% of all new infections are in this age group;
4. In many Sub Saharan African countries, **infection rates in this age group are already very high**;
5. In heavily affected countries, the proportion of children and young people under 15 who are **orphans triples or quadruples over pre-infection levels**;
6. In Sub Saharan Africa, up to **one-quarter of all children live in a family where a parent is HIV positive and in need of care**.

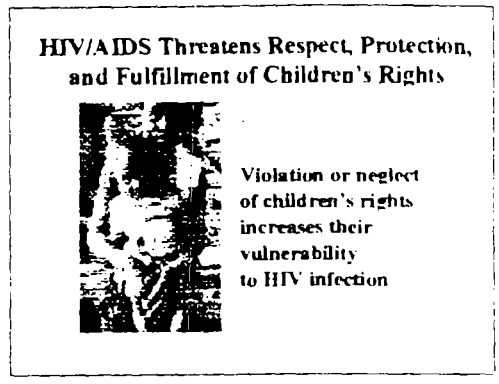




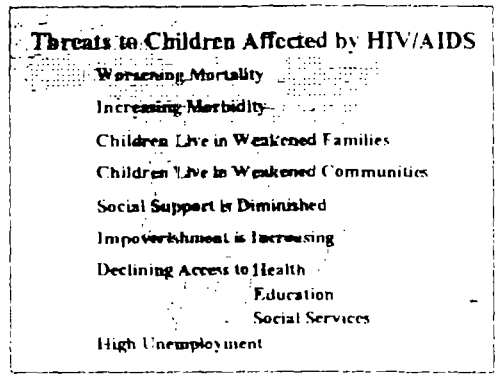


HIV Threatens the Respect, Protection and Fulfillment of Children's Rights

At the same time that the HIV/AIDS pandemic threatens the respect, protection and fulfillment of children's rights around the world, violation or neglect of children's rights increases their vulnerability to HIV infection. The pandemic adversely affects governments, communities, and families in many ways, making it more difficult for them to protect children. Children are threatened in at least seven ways:

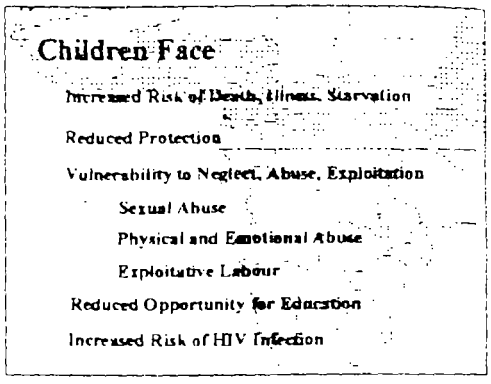


1. **Infant and child mortality** doubles and triples in countries with high rates of HIV infection;
2. **Infant and child morbidity** also increases because children are living with adults infected by HIV or co-infected with tuberculosis, the rates of which are increasing rapidly;
3. **Children and young people live in weakened families** where productive adults have died or are dying, and in families that have accepted the responsibility of caring for children left parentless by the epidemic.
4. The **communities where children live are weakened** by premature adult deaths, increasing twice, three times, or more over levels before AIDS;
5. As a consequence of these changes, **social support** for children and young people **is diminished**;
6. Many **families** whose members are sick with HIV/AIDS **become impoverished**;
7. And **access to health, education, and social services is decreasing** as wage earners fall sick and the disease draws off more skilled personnel and resources;
8. **Unemployment** is high in most Eastern and Southern African countries.



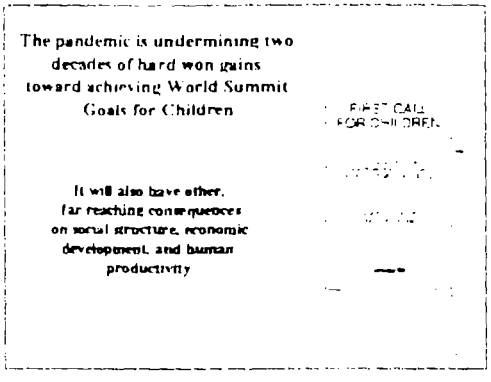
As a consequence of these threats to their well being, **children and young people face**

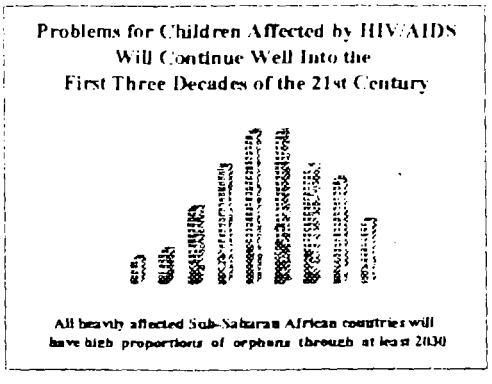
1. Increased risk of **death, illness, and starvation** due to family food shortages;
2. **Reduced protection** as their family members and guardians die;
3. Vulnerability to **neglect, abuse and exploitation**, including sexual abuse, physical and emotional abuse, and exploitation of their labor;
4. **Reduced opportunities for education**, and;
5. Increased **risk of HIV infection**.



The pandemic is undermining two decades of hard won gains in achieving the World Summit Goals for Children, and it will have other, far reaching consequences for social structure, economic development, and human productivity. These effects will be felt well into the first three decades of the next century.

All of these changes have been documented through studies in heavily affected countries. A fuller discussion of them can be found in the UNICEF Power Point presentation, "Children Living in a World with HIV/AIDS", distributed in late 1998 to country and regional offices.





UNICEF Programming

UNICEF was the first global organisation to recognize the problems that would ensue from the growing numbers of children orphaned and affected by AIDS around the globe. In the mid-1980s, it began to develop a strategy of awareness raising and programme development that continues unabated today. In 1988, guided by a report of the Executive Board E/ICEF/1988/L.7, UNICEF carried out a special study of the 10 countries in Central, Eastern, and southern Africa most affected by the epidemic. This study included the first global estimates of AIDS orphans and the first estimates of impact of the disease on infant and child mortality ever presented to the international community, and was published in ***Children and AIDS – An Impending Calamity***.

In 1990, the Executive Board approved a **Global AIDS Interregional Programme** with supplementary funds (E/ICEF/1990/P/L.34), and headquarters staff worked with the Uganda office to formulate a prototype programme for UNICEF offices in Sub-Saharan Africa. The coordination and policy making mechanism created by the programme is still active in Uganda, one of the countries earliest and most severely affected by the AIDS epidemic, and was subsequently adopted by several other UNICEF offices in the region.

The programme provides support to **a voluntary association of national and local voluntary organisations**, that has improved their programming for families and children and act as a policy advocate for these groups and their communities at the national level. This prototype has been a model for most of large scale efforts to assist children affected by AIDS in many other countries.

In 1991, UNICEF convened key partners supporting children and families affected by HIV/AIDS in Sub-Saharan Africa to share views, develop a framework for action, and raise international awareness. Results of this programme were published in ***AIDS and Orphans in Africa***, which described programming in its earliest stages in affected countries. In 1992, UNICEF published ***AIDS: The Second Decade C A Focus on Youth and Women***,

History of UNICEF Global / Regional Support

- 1988 - Children and AIDS – An Impending Calamity
- 1990 - Global AIDS Interregional Programme
- 1991 - AIDS and Orphans in Africa
- 1992 - AIDS: The Second Decade - A Focus on Youth and Women
- 1993 - International Technical Support Group Initiated
- 1994 - Action for Children Affected by AIDS: Programme Profiles and Lessons Learned
- 1995 - ESAR Strategy for Programming to Scale
- 1996 - Child Protection Policy

which described lessons learned from the first decade of the pandemic.

In 1993, UNICEF headquarters instituted **an international Technical Support Group**, with members from six heavily affected countries (Congo, Ghana, Haiti, Malawi, Tanzania, Thailand), with the mission to stimulate programming to scale in the member countries.

In 1994, UNICEF co-sponsored a study of effective programmes in eight countries with WHO , entitled ***Action for Children Affected by AIDS: Programme Profiles and Lessons Learned***. This publication described the range of responses of families, communities, and governments, and the conditions under which each type of programme was most effective.

In 1995, **UNICEF representatives from the East African Region formulated a strategy** to promote programming to scale in the Region's countries. It reiterated UNICEF's commitment to providing sustainable and flexible support to community-based programmes, and recommended that each country conduct a thorough situation analysis and assist national governments in developing policy-level responses. In 1995, UNICEF also convened an international working group on the issue, to review progress in heavily affected countries.

In collaboration with governments and NGOs, **UNICEF continues to support community based care and protection programmes in 24 countries**. With UNICEF assistance, communities in all of these countries have initiated activities such as communal gardens, day care centres, and family counseling to meet the needs of vulnerable children and their care givers and protect their rights.

UNICEF also **supports many governments in strategic activities** to expand the access of orphans and other vulnerable children to basic services and to encourage protection of their rights. These include comprehensive child law review, development of appropriate statutes and judicial mechanisms to prevent sexual abuse and exploitation of children's labour, development of national policy on orphans, fostering and adoption, and policies promoting access of vulnerable children to education. UNICEF also assists with **capacity building in key**

Ministries to expand planning and protection mechanisms for children.

UNICEF produced the first video concerning the impact of AIDS on families and children, ***The Orphans' Generation***, in Uganda. In addition, it assisted in the distribution of three others, ***Neria***, and ***They Are All Our Orphans***, produced in Zimbabwe, and ***Everyone's Child***, produced in South Africa. In addition to efforts geared toward children infected and orphaned by AIDS, UNICEF supports HIV/AIDS prevention programmes among adolescents in many countries.

UNICEF offices in 21 Sub-Saharan African countries have implemented programmes for children and families affected by HIV/AIDS or who have lost families or primary care givers:

East Africa - Burundi, Eritrea, Ethiopia, Kenya, Rwanda, Tanzania, Uganda

Southern Africa - Botswana, Lesotho, Madagascar, Mozambique, Malawi, Namibia, South Africa, Zambia, Zimbabwe

West/Central Africa - Cape Verde, Central African Republic, Chad, Democratic Republic of the Congo, Togo

Several countries in other regions have also implemented programmes, including Brazil, Romania, and Thailand.

New Strategy for Programme Intensification for Families and Children Affected by HIV/AIDS

Period: January 1998 to December 1999

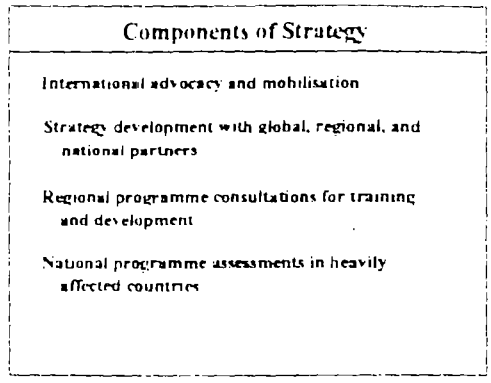
Objective: To expand current programmes in 19 target countries in Sub-Saharan Africa and build capacity for long term, sustained and integrated programming

Partnerships: Unified global strategy with UNAIDS partners (WHO, World Bank, UNDP and UNFPA with UNICEF)

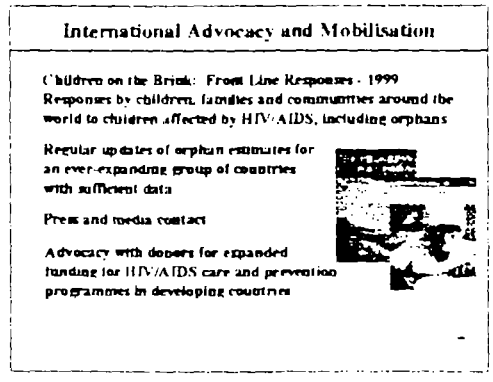
New Strategy for Programme Intensification

Following the World AIDS Day release of ***Children on the Brink***, UNICEF Headquarter=s management team decided to evaluate and intensify its programming efforts in this area, and in January, 1998 undertook **a two-year strategy** to accomplish this goal. Among the objectives of the strategy are to document programming efforts to date, develop tools to intensify programmes, and initiate or expand them to scale in 19 of the most heavily affected countries in the region. Realisation of this goal will require the combined efforts of country governments, non-governmental and religious bodies, UN agencies, donors, and the research community in developing programmes sustainable for the next two to three decades.

This strategy has several components:

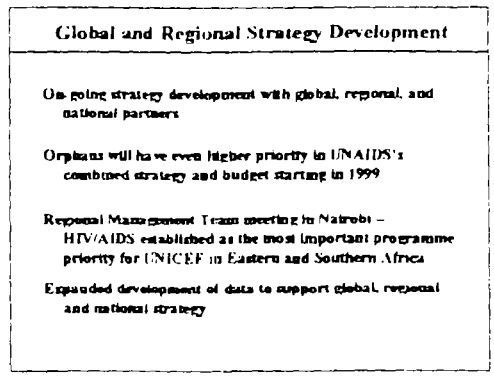


1. **International Advocacy and Mobilisation**. UNICEF and its UNAIDS partners are working to increase public and political awareness of the severe impact that the HIV/AIDS pandemic will have on children and young people. An update to ***Children on the Brink*** will be published in early 1999. ***Children on the Brink: Front Line Responses*** focuses on the work being done by children, families, communities and governments to respond to the needs of children affected by HIV/AIDS. Other publications will follow in subsequent years, and sections of UNICEF's regular ***Progress of Nations*** and ***State of the World's Children*** will highlight the issues of orphans and other children made vulnerable by HIV/AIDS.



UNICEF and its global partners are working to develop **updated estimates of orphans** and other vulnerable children for a wider group of countries as more reliable data becomes available. In addition, raising the awareness of funding agencies and donors will be critical to fund expanded initiatives;

2. **Global and Regional Strategy Development.** Strategy development is an on-going process with global, regional and national partners as the pandemic unfolds around the world. Support for community based responses for care of orphans and other children left vulnerable by the pandemic have had a high priority **in UNAIDS combined strategy and budget**. In mid-November, 1998, UNICEF's Regional Management Team for Eastern and Southern



Africa declared **HIV/AIDS the top regional priority** because of its devastating impact on all sectors in all countries. Strategic development will be an on-going challenge in this critical area because of the overwhelming and cross sectoral impact of the disease.

3. **Regional Programme Consultations.** UNICEF will be hosting regular regional programme consultations to develop programming for orphans and other children left vulnerable by the epidemic. The first was held on October 26 to 28, 1998 in Uganda, and included 73 participants from 12 countries representing community based organisations, non-governmental organisations, governments, church groups, UNICEF offices and other UNAIDS co-sponsors. The objective was **to identify key programming issues and lessons learned** in addressing problems arising from the unprecedented number of children orphaned by the epidemic. Additional consultations are planned in ESAR and WCAR in 1999.

Uganda Programme Consultation

- UNICEF's first regional programme consultation on care and protection of orphans
- Dates: October 26 to 28, 1998
- 73 participants from 12 countries representing community based organisations, non-governmental organisations, governments, church groups, UNICEF offices and other UNAIDS co-sponsor agencies
- Objective: to identify key programming issues and lessons learned in addressing problems arising from the unprecedented number of children orphaned as a result of the AIDS pandemic
- Additional programme consultations planned in ESAR and WCAR in 1999

Six **key strategic interventions** were identified by the consultation:

1. **Political will and commitment** must be expanded and strengthened through awareness raising and education;
2. **Advocacy and social mobilisation** are equally as important to gain the support of families and communities for care and for long term resource mobilisation;
3. **Legal framework and legal review** can help secure the rights of children and their care givers;
4. Governments must establish or strengthen structures for **programming and coordination**;
5. **Poverty alleviation** is critical, and activities are needed at macro and micro levels;

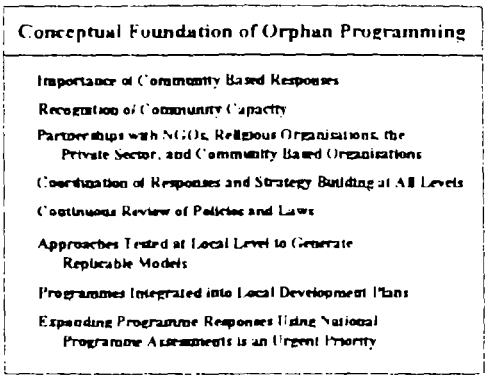
Key Strategic Interventions Identified by the Consultation

- Political will and commitment must be expanded and strengthened
- Advocacy and social mobilisation are needed to expand public awareness of the crisis and mobilise resources
- Legal framework and legal review to secure protection of the rights of orphans and their care givers
- Governments must establish or strengthen structures for programming and coordination
- Poverty alleviation is needed at macro and micro levels
- Family and community care alternatives must be emphasised and supported

6. **Family and community care** are the approaches of choice, and must be emphasised and supported in national strategies.

The consultation also identified **elements of a conceptual foundation** for orphan programmes:

1. **Community based responses** are the most affordable and acceptable approach to care for orphans and children left vulnerable by HIV/AIDS. Institutionnal care is a last resort,
2. **Community capacity and willingness to care** has been documented, but communities must have the resources to sustain mechanisms of care;
3. **Partnerships with community based organisations** are widespread (NGOs, religious organisations, the private sector) and increase their viability;
4. **Coordination and strategy building** are necessary at all levels and increase the vitality of community based responses;
5. Approaches must be **tested at the micro level** and replicated if appropriate;
6. If **included in government development plans**, community based programmes can be stimulated and linked with a wider resource base;
7. **Expanding programme responses** using the comprehensive country programme assessment is an urgent priority for all offices in heavily affected countries.



4. **National Programme Assessments in Heavily Affected Countries.** The final tool for developing and expanding programmes is the country programme assessment. The goal of UNICEF's two-year strategy for programme intensification is to complete assessments in each of the 19 most heavily affected countries in ***Children on the Brink*** by the close of 1999.

Target Countries, Year 1 (proportion of children under 15 orphaned): Zambia (34%), Malawi (27%), Zimbabwe (27%), Uganda (26%), Botswana (23%); South Africa (12%)

National programme assessments in heavily affected countries

Year 1
(% Children < 15 Orphaned)

Zambia (34%)
Malawi (27%)
Zimbabwe (27%)
Uganda (26%)
Botswana (23%)
South Africa (12%)

Year 2 Target Countries (proportion of children under 15 orphaned): Rwanda (27%), Tanzania (22%), Burundi (16%), Ethiopia (15%), Lesotho (14%), Kenya (12%), Burkina Faso (21%), Central African Republic (20%), Cote d'Ivoire (19%), Congo (17%), Democratic Republic of the Congo (16%), Cameroon (12%), Nigeria (8%)

In addition, several other countries, including Swaziland, Mozambique, and Namibia, are likely to have large orphan populations and are interested in assessments in 1999.

National programme assessments in heavily affected countries

Year 2
(% Children < 15 Orphaned)

Rwanda (27%)
Tanzania (22%)
Burundi (16%)
Ethiopia (15%)
Kenya (12%)
Burkina Faso (21%)
Central African Republic (20%)
Cote d'Ivoire (19%)
Congo (17%)
DR Congo (16%)
Cameroon (12%)
Nigeria (8%)
Mozambique
Namibia
Swaziland

In 1998, six programme assessments were completed: Botswana, Malawi, Uganda, South Africa, Zambia and Zimbabwe.

Programme assessments have been completed in six Eastern and Southern African countries:

Botswana, Malawi, South Africa, Uganda, Zambia and Zimbabwe

Programme Assessment Overview

Each of the participating countries hosted a two-person assessment team from UNICEF headquarters for 5 to 10 days. In future programme assessments, this team will be augmented where possible by consultants from the region who have participated in programme assessments in other countries in the region or who have special expertise in orphan programming. With this approach, a cadre of skilled experts can be built in the region to sustain programming over the next several decades.

Country Programme Assessments

Each of the participating countries hosted a two-person assessment team from headquarters for 5 to 10 days.

The team helped country staff assemble and review information on the status of orphans and care givers, policy, and programmes.

The team presented findings to in-country members. Subsequently, the reports were used by four countries to develop proposals for additional funding.

In the completed assessments, the team helped country office staff assemble and review information on the status of orphans, care givers, policy, and programmes. At the end of the two weeks, the draft report was presented to in-country partners. Subsequently, the reports were used by four countries to develop proposals for additional funding.

All of the countries reported that the exercise was extremely useful in helping them **focus on their programming strengths and weaknesses, and develop strategies for programme expansion**. The first six assessments have been distributed widely and are available on disk.

Many other countries have requested assistance in completing their own assessments. This manual encapsulates the procedures used in the first six assessments so that countries can initiate similar processes in the near future with the headquarters assessment team or with experts of their own choosing.

A country programme assessment has six **objectives**:

1. To review **programme coverage** for orphans and other children affected by HIV/AIDS;
2. To appraise programming **strengths and weaknesses**;
3. To **build strategy** in collaboration with our partners (government, NGO, private sector) to improve programmes and expand coverage;
4. To **initiate or expand programming**;
5. To initiate or expand **policy review** related to children affected by HIV/AIDS;
6. To develop **funding proposals** for programme expansion.

Objectives of a Country Programme Assessment

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Since these are fairly generic, they can easily be tailored to the special needs of the country conducting the assessment. Typically, the programme assessment consists of **three phases**:

1. Country office staff gather background documents and research;
2. The assessment team, including country office staff, conducts the assessment, lasting about two weeks. It includes interviews, focus groups, site

Phases of a Country Programme Assessment

I. Country office staff gather background documents and research reports.

II. The team, including country office staff, conducts the assessment, lasting about 2 weeks. It includes interviews, focus groups, review of documents and data, and preparation of a draft report. This report is presented by the team to in-country partners.

III. Staff reviews results with partners, decides on programme initiation or expansion, and develops funding proposals if needed.

visits, review of documents, and preparation of a draft report. This report is presented at a debriefing with partners;
3. Staff reviews the results with partners, decides on programme initiation or expansion, and develops funding proposals if needed.

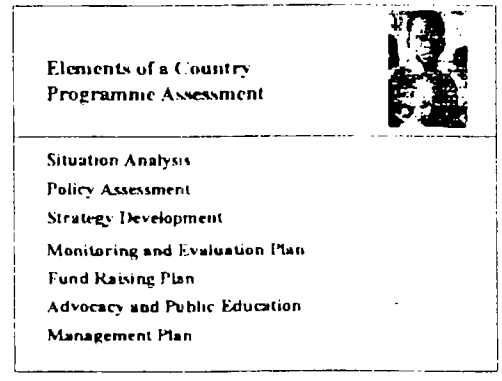
The programme assessment is as much a process as it is an analytical document. It is an opportunity for advocacy and education. For this reason, it helps to use outside consultant(s) because:

1. A person from outside the country can ask "stupid" or "innocent" questions, and raise difficult issues with impunity;
2. Someone from outside the country can describe what other countries are doing;
3. Someone from the outside can be the reason to call partners together for briefings, debriefings and strategy sessions.

Elements of a Programme Assessment

A country programme assessment has **seven essential elements**:

1. Situation analysis
2. Policy assessment
3. Strategy development
4. Monitoring and evaluation plan
5. Fund raising plan
6. Advocacy and public education
7. Management plan



The table of contents from the Botswana report is typical of the six country reports:

Table of Contents

IV. Incorporation in UNICEF/ Botswana Programming

V. Expanded Programming

VI. Funding Development

VII. Support for Programme Development

VIII. Best Practices and Lessons Learned

IX. Summary of Recommendations

Appendices

The first two elements of a country programme assessment, the situation analysis and policy assessment, can be conducted simultaneously, and the results brought together for a strategy development session with partners. As you can see from the Table of Contents above, findings from these two elements were presented in Sections II and III of the report for Botswana: "The Situation of Orphans and Care Givers", and "The Status of the Response".

Situation Analysis

The first part of the country programme assessment is the situation analysis. There are **three major areas** to consider in the situation analysis:

1. **Children, Families, and Communities**
2. **Services and Responses**
3. **Safety Nets**

Three major areas in a situation analysis

Children, Families and Communities	Services and Responses	Safety Nets
Numbers	Characteristics	Adoption/Fostering
Location	Location	Stipends
Education	Sponsorship	Public Assistance
Health	Networks	Health Services
Women's Status	Collaboration	Education System
		Social Welfare

As in any situation analysis, the aim is to overlay a picture of the location and needs of vulnerable children, families and communities with a picture of services and safety nets available to assist them to determine where significant gaps exist.

To compare
the location and needs of children
and
the location and provision of
services and safety nets
to determine where significant gaps exist

Some facts to gather on the service populations include:

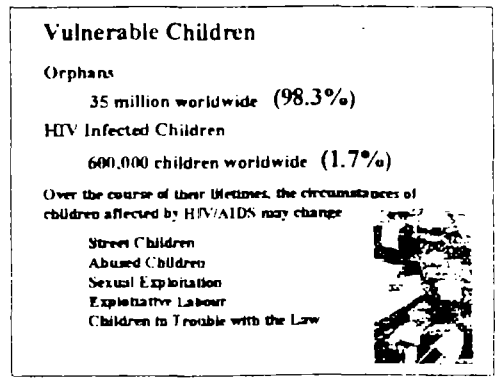
Children, Families, and Communities

Numbers
Proportion of children orphaned
Location
Needs for education, health and protection by age and sex
Guardian's status
Women's status
Poverty

- Numbers
- Proportion orphaned
- Location
- Needs
  - Education
  - Health
  - Protection
- Guardian's Status
- Women's Status
- Poverty

Although the emphasis is on orphans, you will want to collect information on all vulnerable children:

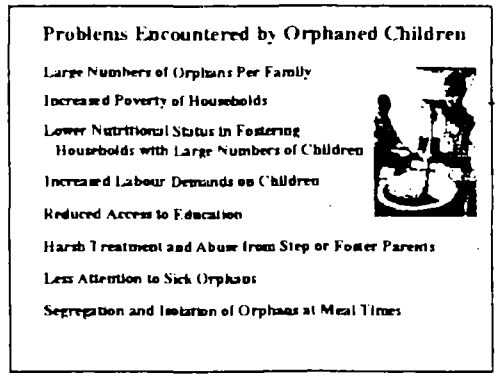
Orphans
Street Children
Child Abuse
Sexual Exploitation
Exploitative Labour
Children in Trouble with the Law



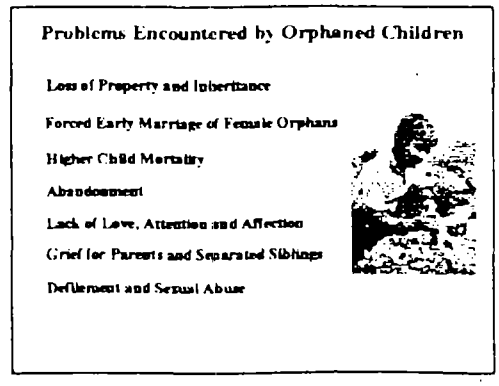
Children often move between these categories in response to stress and loss of a care giver's protection. In the first six countries assessed, estimates for these categories were often not of consistent quality.

Finally, while a great deal of concern is expressed for HIV positive children, globally they represent only 1.7% of children affected by HIV/AIDS, while orphans represents more than 98% of affected children.

The **problems encountered by orphaned children** reported in Sub-Saharan African countries are many:

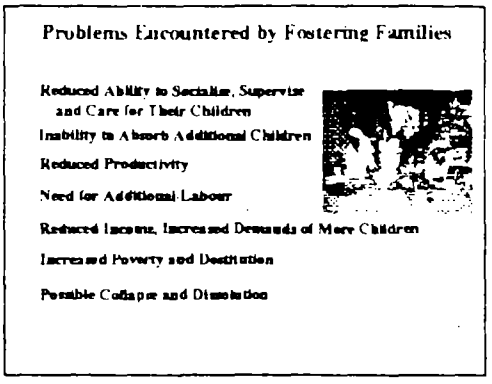


Large numbers of orphans per family; increased **poverty of households**; **lower nutritional status** in fostering households with large numbers of children, shown by research projects in several countries; **increased labour demands on children** because of loss of productive adults; **reduced access to education** by orphans compared to biological children, a consistent finding in countries in Africa, Asia, and Latin America and the Caribbean; **harsh treatment and abuse** from step or foster parents; **less attention and care provided to orphans** than biological children when they are sick; **segregation and isolation of orphans at meal times**; **loss of property and inheritance**; **forced early marriage** of female orphans by families as a way to reduce the burden of children; **higher mortality** than biological children; **abandonment**; **lack of love, attention and affection**; **grief for** parents and separated siblings; **defilement and sexual abuse** of both male and female children.



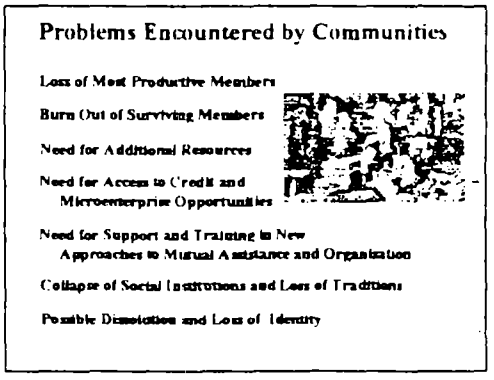
Problems faced by fostering families include:

Reduced ability to **socialise, supervise and care** for their children because there are fewer adults and more children in fostering households; **inability to absorb additional children**, even when they are wanted, because of poverty and lack of access to resources; **reduced productivity** of the household because of loss of productive members and loss of remittances when non-resident members fall sick or die; the often-unmet **need for additional labour** that the family cannot afford to hire; **reduced income** as members fall sick, coupled with increased need with more foster children; **increased poverty and destitution**, experienced by families affected by AIDS as a result of cost of medical treatment, funerals, and care for additional children. Finally, AIDS affected families face the possibility of **collapse and dissolution**.



Problems **encountered by communities** as they develop community based programmes of care include:

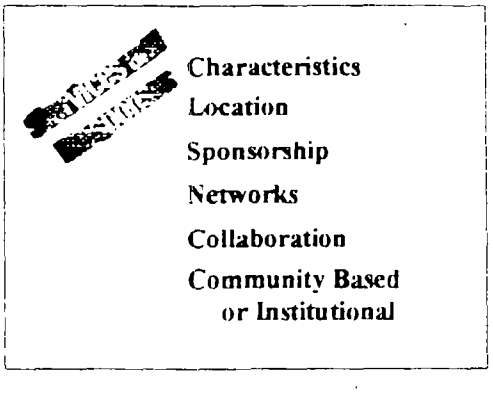
Loss of **members in the most productive age groups**; **burn out** of surviving members trying to care for additional children with fewer adults; **need for additional resources** as dependency ratios grow; need for **access to credit and microenterprise opportunities** to earn more income for support of children's basic needs; need for **support and training in new approaches to mutual assistance and organisation**. Communities even face **collapse of social institutions and loss of traditions** and possible dissolution and loss of identity when a sufficiently large proportion of their population dies.



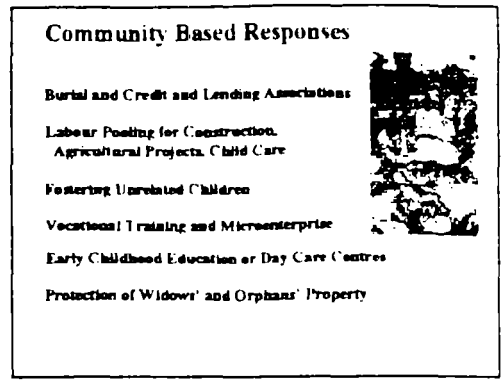
Services and Responses

Data on services and responses needed for planning purposes include the following:

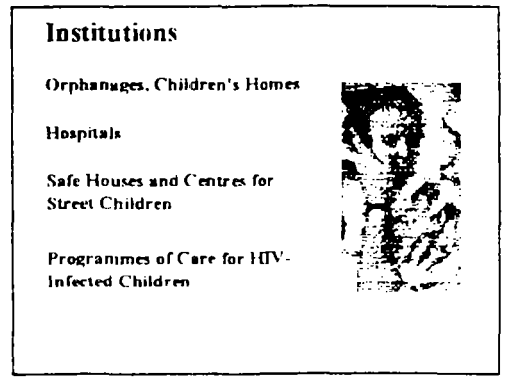
Characteristics
Location
Sponsorship
Networks
Collaboration
Community Based or Institutional



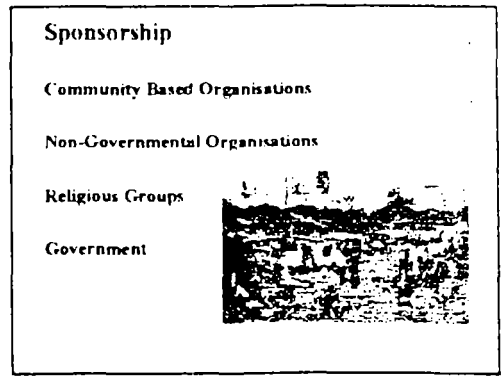
Community based responses, are found in all heavily affected countries and take a variety of forms. Most common are **burial associations**; credit and lending **groups** to help widows cope with loss of income; **pooling labour** in communal gardens, construction of shelters for orphans, agricultural projects, income generating projects, and child care; **fostering of unrelated children**, including supervision of cluster foster care and child headed households; **early childhood education or day care centres**; and **protection of widows' and orphans' property** against claims by family members and others.



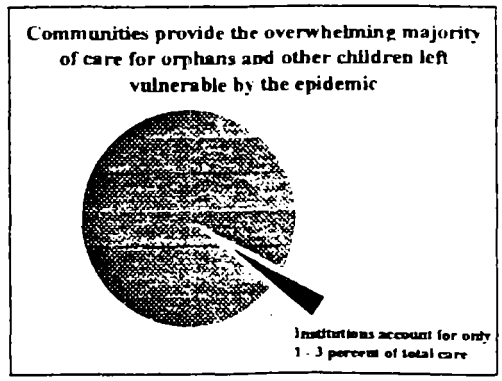
Institutional care takes the form of orphanages and children's homes; hospitals, where HIV infected children are sometimes abandoned; safe houses and centres for street children; and programmes of care and adoption for HIV-infected children.



Sponsorship for community based and institutional care can come from community based organisations; non-governmental organisations, either local, national, or international; religious organisations; and from government.

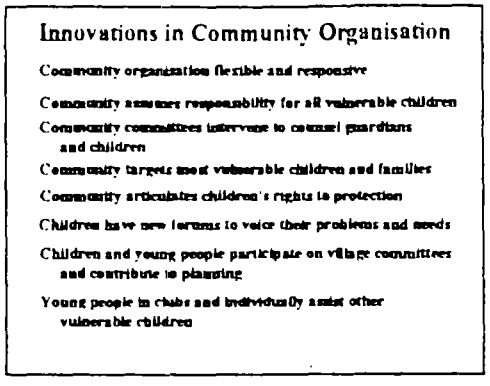


Community based programmes account for the overwhelming majority of all care children left vulnerable by the epidemic. **Institutional care is usually adequate for only 1 to 3 percent** of all children because orphans were commonly cared for in families and communities prior to the AIDS epidemic. In many countries, orphanages were intended to care for only infants and the youngest of children because after the age of 3, other relatives could provide support. While the emphasis



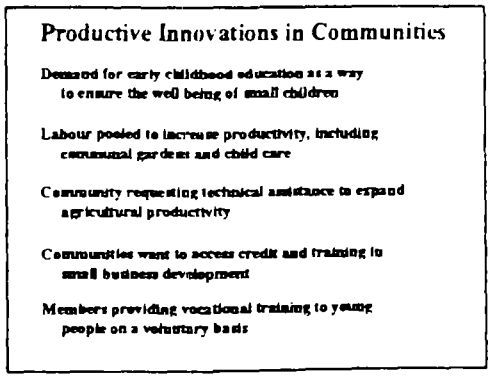
is on community based support mechanisms, information on institutional care is needed because it can be used to document the need to develop support for community based services. Also, institutions are needed for children with no other means of support.

In the countries visited during the first six programme assessments, many **positive innovations in community based organisation** were seen. First, communities were showing themselves to be **flexible and responsive** to the needs of families and children affected by HIV/AIDS. Many communities were **assuming responsibility for all vulnerable children**, and helping families with large numbers of children to the fullest extent possible. Community orphan committees intervened to assist guardians who were having difficulties caring for children, and also **provided counseling** to harsh step or foster parents to help them adjust to the needs and demands of their additional responsibilities.



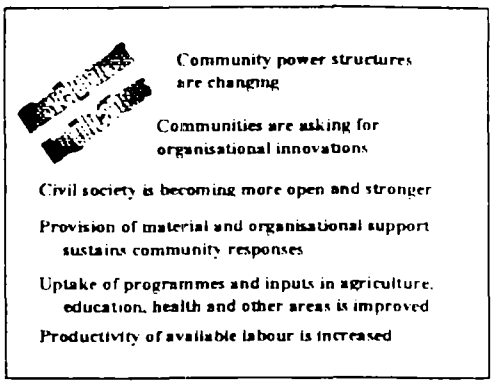
Community committees **registered vulnerable children and families** for assistance, and **targeted those most in need** of support. Community committees were more aware of children's needs and problems as a result of their new programmes, and **could articulate children's rights to protection**. Community orphan committees provided children with **forums to voice their problems and needs**, and to receive counseling and guidance. In some countries, children and young people **were participating on the orphan committees**, contributing skills in record keeping, counseling, and planning. **Young people in Anti-AIDS Clubs "adopted" vulnerable children**, providing them material and emotional assistance where possible.

Communities were also exploring **innovations to increase their productivity** as availability of labour declined due to AIDS deaths. Demand for **early childhood education** was increasing because communities understand it as a way to ensure the well being of small children in an efficient manner. **Labour was pooled** in gardens and child care, and communities were asking **for technical inputs to increase agricultural productivity**. Communities are also seeking **access to credit and microenterprise training** to increase their incomes through small business development. Members often volunteered to provide **vocational training** to orphans and other vulnerable children, passing on skills in tailoring, carpentry and other ventures.

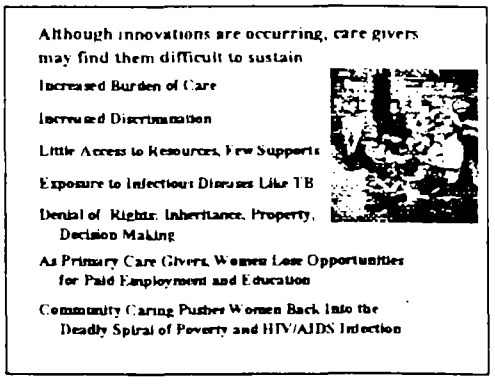


These changes have many positive development implications:

1. **Community power structures are changing**, leaving more room for the participation of women and young people;
2. Communities are **seeking organisational innovations** useful to other programmes;
3. **Civil society is becoming more open and stronger** as communities are trained in self-governance and mutual assistance through these programmes;
4. **Provision of material and organisational support can sustain community responses**. A study in Malawi found that communities that were refusing to adopt or maintain additional orphans were willing and able to absorb more children if these were provided;
5. Changes in the community increase members' **acceptance and uptake of development programmes and inputs** in agriculture, education, health and other areas;
6. As a consequence, the **productivity of available labour was increased**.



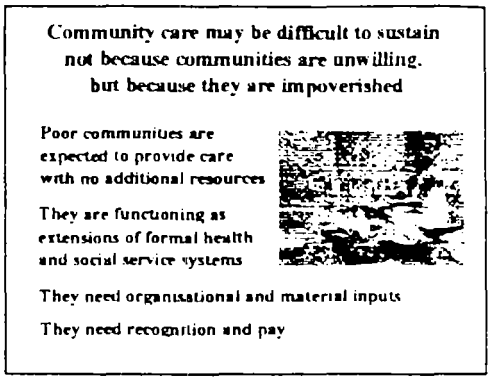
However, **care givers find innovations difficult to sustain** as more children are orphaned and the burden of care increases. Families and children affected by HIV/AIDS are still suffering from considerable levels of **discrimination**, even in heavily affected countries, particularly if government and other officials do not acknowledge the epidemic. In most cases, communities find they have **little access to resources and few supports** to sustain their programmes, leaving them discouraged about the ability of their efforts to keep up with demand for care.



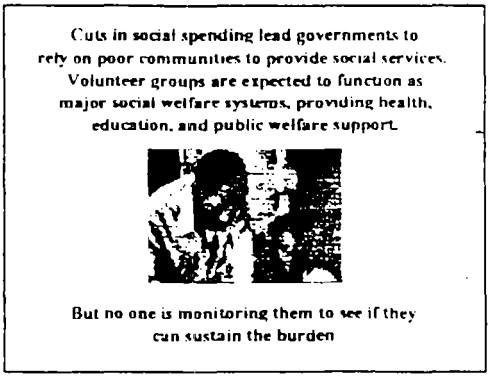
In many families, **HIV-negative care givers are exposed to HIV and other infectious diseases like tuberculosis** when they provide care to HIV-infected members. Tuberculosis rates are rising four and five times in heavily infected countries, even among HIV-negative children. Families, particularly widows and orphans, suffer from **denial of their rights to inheritance and property**, and to **decision making about their future**.

As primary care givers, **women lose opportunities for paid employment and education** outside the home. In South Africa, women were especially sensitive to this, and vocal about seeking government support so they did not get pushed back into a **deadly spiral of poverty and HIV infection.**

Community care may be difficult to sustain not because communities are unwilling, but because they are impoverished. Economic adjustment programmes in developing countries have often pinched the poor and have thrown more families into poverty. Despite this, poor communities are expected to provide care with no additional resources. Communities are functioning as extensions of formal health, education, and social services systems on a voluntary basis. Communities receive little organisational and material inputs, recognition, or pay for the services they are providing.

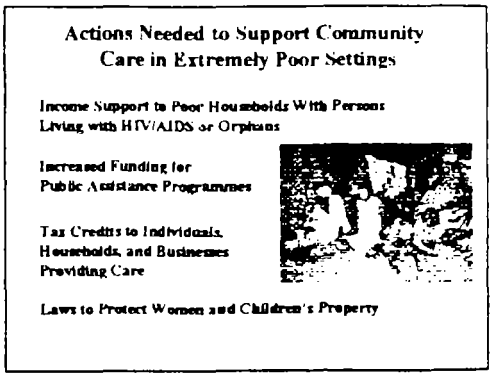


Cuts in social spending in most developing countries lead governments to rely on poor communities to provide social services. Volunteer groups are expected to function as major social welfare systems, providing health, education and public welfare support. But in many cases **no one is monitoring them** systematically to see how long they can sustain the burden or if they are being effective at what they undertake.



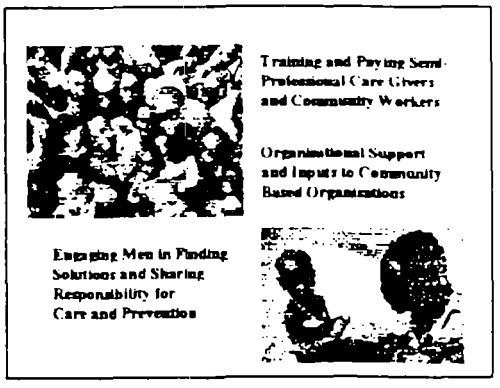
Many **programme and policy actions are needed to ensure communities do sustain the burden**, including:

1. **Income support to poor households** with persons living with HIV/AIDS or orphans. While this is legally provided in many of the countries visited during the initial programme assessments, budgetary constraints mean that few actually receive benefits;
2. **Increased funding to public assistance programmes** would see that this is possible;
3. **Tax credits to individuals, households and businesses** that provide care would also stimulate a broader response;
4. Few countries have passed **laws protecting the property of widows and orphans**, although most have programmes to encourage the writing

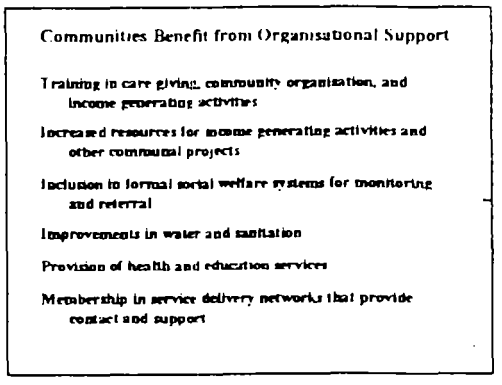


of wills. In some countries, communities take informal local action to protect these vulnerable groups;

5. South Africa was exploring the possibility of **paying semi-professional care givers and community workers** as part of their formal social welfare system so that the unpaid contributions of volunteers would be acknowledged and rewarded;
6. **Organisational supports and material inputs to community based organisations** are proven to sustain community responses;
7. Finally, **engaging men more directly at all levels in finding solutions and sharing responsibility** for care and prevention is critical both to stem the spread of HIV and in the development of equitable systems of care.



Communities benefit from organisational support, which takes many forms:



1. **Training in care giving, community organisation, and income generating activities** increases the quality of services provided to children and the overall skill levels of the communities where they reside;
2. **Increased resources for income generating activities and other communal projects** can stimulate greater participation and benefit and also ensure their sustainability;
3. **Inclusion in formal social welfare systems** for monitoring and referral will improve the quality of these services and help to see that children and families in need of specialised support will not "fall through the cracks";
4. **Improvements in water and sanitation** reduce labour demands on affected families and on community members who want to help;
5. **Expanded provision of health and education services** can increase access for orphans and their families and make sure these services are provided equitably to orphaned children;
6. **Membership in service delivery networks** can provide communities with moral and material inputs and increase recognition for their contributions.

Service delivery networks were found in all the countries in which programme assessments were conducted. They commonly include government networks, hospital home care services, religious organisations, and networks created by non-governmental organisations. These networks are often hierarchical, forming efficient distribution systems for programmes, supplies, or ideas. Commonly, there is an array of services in a geographic area provided by organisations with different sponsorship. Government, NGO, and church-related groups may have **geographic coverage data** in their national offices, but this should be verified.

Service delivery networks should be encouraged because they play vital roles in member education and training, quality assurance; long term programme development; resource access and allocation; organisational development; and monitoring and evaluation.

Service Delivery Networks in Malawi

- Government Network, organised through the District Orphan Technical Subcommittee
- Christian Hospital Association of Malawi
- Religious Organisations
- Non-government Organisations

Additional Networks in Zimbabwe

- Child Welfare Forums as part of formal government social welfare system
- Commercial Farmers' Network

Additional Network in Botswana

- Private Sector Employers

Roles of Service Delivery Networks

- Member education and training
- Quality assurance
- Long term programme development
- Resource access and allocation
- Organisational development
- Monitoring and evaluation

Availability of Safety Nets

Safety nets in the form of cash grants and stipends or services were provided by law to vulnerable populations in most of the countries visited during the initial programme assessments. These included:

Adoption and fostering stipends provided to families caring for children up to the age of maturity, 18 in most Eastern and Southern African countries;

Public welfare assistance grants provided to needy and vulnerable families, including those caring for AIDS patients, single mothers, disabled persons, and the elderly;

Services through health, education and social welfare systems, including primary care for mothers, children and for persons with infectious diseases; free schooling for all children or for orphans; and stipends and material assistance through social welfare for needy children and families.

SAFETY NETS

Cash and services are often provided to vulnerable groups under the law in many developing countries

Adoption and Fostering Stipends

- Provided to guardians for children up to 18 years of age

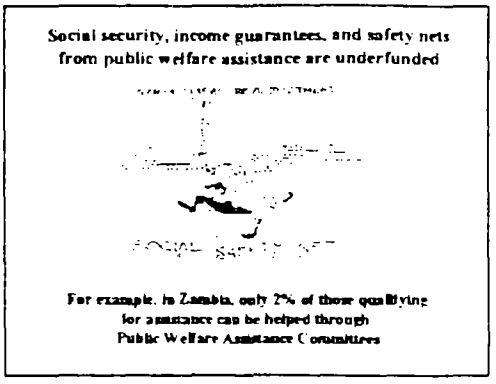
Public Assistance Grants

- Grants to single mothers
- Grants to persons living with HIV/AIDS as part of assistance to the disabled

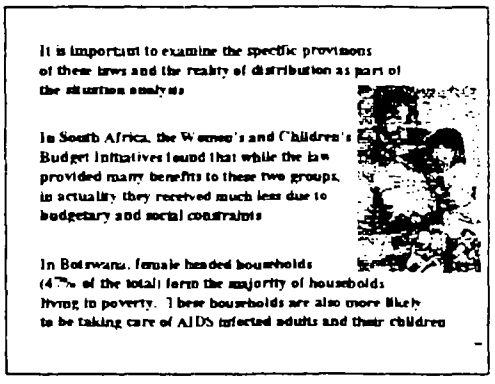
Health, Education and Social Welfare

- Basic services provided by law to vulnerable groups including persons with HIV/AIDS, STDs or TB, and to young children and mothers

Several of the countries assessed had public assistance mechanisms in place that provided stipends for needy children and families. However, **their coverage was very poor because they were insufficiently funded** to meet the needs of an expanding group of poor households. Health services may provide a way to monitor the status of vulnerable children, as may education centres, particularly those for the very young. It is, of course, important that someone be watching out for the welfare of the very youngest and most vulnerable children, but in most countries assessed, the holes in safety nets were very large.

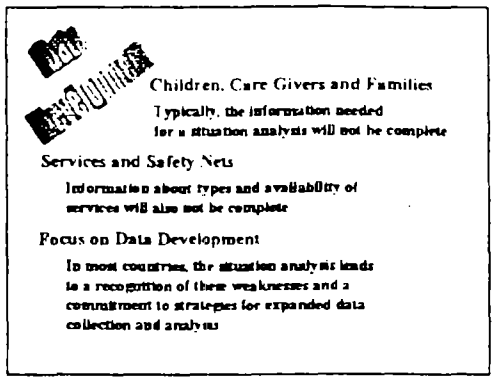


As part of a programme assessment, it is important that **the specific provision of these laws and the reality of the distribution of their benefits be analysed**. In South Africa, the Women's and Children's Budget Initiatives found that while the law provide many benefits to women and children, in actuality, they were limited by budgetary and administrative constraints. In Botswana, female headed households (47% of the total) form the majority of households living in poverty. These households are also more likely to be taking care of AIDS infected adults and their children. A WHO study of AIDS patients in home care in Botswana found that their most important need was food, which they couldn't afford because their entitlements were inadequately budgeted and funded.



Data Development

Typically, the information needed on children, care givers, and their families for the programme assessment will not be complete. **National data or estimates for orphans** and other vulnerable children was limited, unavailable or outdated in the majority of the first six countries where assessments were done. Prior to the AIDS epidemic, these groups were not a major concern to governments, and so little effort was made to collect information. Data on the **geographic distribution** of vulnerable children and on the **distribution of services** was also quite limited in most of the countries completing the first programme assessments.



As a consequence, in most of the countries assessed, the situation analysis lead to a recognition of these weaknesses in data systems and to a commitment to **strategies for expanded data collection**.

At the national level, **censuses** are the best source of data on orphans, followed by USAID-**sponsored Demographic and Health Surveys** (DHS). For regions and localities, some communities have initiated registrations or enumerations of orphans or other vulnerable children. **Vital registration** systems are often limited. For some special populations, such as people employed on commercial farms, data might be available from the employer or group.

In some countries, **special surveys or estimates** had been made by universities or for poverty monitoring and alleviation. Several of these were quite extensive, and were a valuable resource for current data on children and families. Orphan estimates might be made by the National AIDS Control Programme or through special studies by churches, NGOs, or community groups.

Data on orphans have been collected in the **national censuses** of several countries, including Kenya, Uganda, Tanzania, Zimbabwe, and Malawi. Censuses have the widest geographic scope of any data and 100% coverage, although their data are typically "thin" in that not many details are collected and household level analysis has not been done. Where possible, it is critical to encourage country officials to collect data on the orphan status of children during the next round of census taking, on or after the year 2000. This is not difficult to do if undertaken early because it can be demonstrated that the problem is of critical concern to national policy makers, and that many other governments are already collecting such information in their censuses. Also, the additional data collection needed is minimal to determine whether the parents of children enumerated are living. One disadvantage to census data is that marginalised children or families, such as street children or homeless populations, may not be fully enumerated by census takers.

Demographic and Health Surveys are conducted in many African countries every two to four years with the sponsorship of USAID. The household schedules from these surveys usually indicate if a child's parents are living or dead. Until recently, however, only households with child-bearing-age women (15 to 49 years old) were included, which means that orphaned children, many of whom reside on their own or with elderly guardians, were excluded. For this reason, orphan estimates made using

Sources of Data

National Data
- Censuses
- Demographic Health Surveys

Regional or Local Data
- Registrations and enumerations of orphans
- Vital registration systems where available
- Surveys of special populations, such as commercial farms

Special Surveys in All Sectors

Orphan Estimates
- National AIDS Control Programme
- Special Studies

National Census Data

Advantages:

Many countries, including Kenya, Tanzania, Zimbabwe, Malawi and Uganda) collected orphan data on 1990 and earlier censuses

Censuses have the widest geographic scope of all data sources and 100% coverage, but little depth of data

All governments are encouraged to include orphanage on Year 2000 censuses

Disadvantage: Marginalised children (street children, homeless children) and families with impermanent residences may be underrepresented

Demographic Health Surveys

Advantages:

Conducted every two to four years in selected countries

Recently revised to sample all households with children 5 and under

Will include families headed by children and the elderly

Will collect health, immunization, nutrition, education and other data on all children in the household

Samples are nationally and regionally representative

Disadvantage: Marginalised children and families are less likely to be included

DHS surveys taken prior to 1999 underestimate the proportion of children orphaned by about half.

In 1999, DHS instruments and procedures were revised to include all households with children under 5 years of age regardless of the presence of a care giver or guardian. DHS surveys will now include households headed by children or elderly guardians. Also, health, immunisation, nutrition, education, and other data will be collected on all children in the household, whereas formerly this data was collected on biologically related children only. DHS are not complete count surveys, but their samples are usually nationally and regionally representative. Unfortunately, coverage of marginalised children and families may also be limited for the same reasons it is in censuses.

Registrations and enumerations of orphans and other vulnerable children collected by local authorities and communities is a popular way to mobilise communities for action. Typically, community members are trained to collect, analyse and maintain their own data, which may serve as the basis for targeting assistance to vulnerable children and families. Communities must gain experience with using and maintaining data, and typically it must be linked to some kind of assistance.

Regional or Local Data

Advantages:

- Registrations or enumerations by local communities to identify vulnerable children and families stimulate local action and concern
- Communities collect and analyse their own data
- Registrations serve as the basis for targeting assistance by communities
- Difficult to maintain unless communities perceive their value and receive assistance
- Data can be more complete and detailed than a national survey

Disadvantage: quality is highly variable and must be validated by a national survey or census

Data from these sources are usually more complete than census or DHS data, but care must be exercised in using the data because it is often highly variable. Two neighboring communities in Malawi reported 50% and 6% of their children to be orphaned, a difference more likely to be a reflection of the communities' perception of vulnerability than demographic reality.

Malawi and Uganda both **undertook national orphan registrations** in the early 1990's, and both reported that their experience was "disastrous":

1. The registations were **too costly** to administer on a national basis;
2. The registrations raised **false expectations** for assistance by communities;
3. The numbers produced were **wildly variable and unreliable** as a basis for national orphan estimates;
4. **Registrations could not be maintained or updated** because communities saw no advantage or result to doing so.

Why Malawi and Uganda's National Orphan Registrations Were "Disastrous"

- Too costly to administer on a national basis
- Raised false expectations for assistance in communities
- Numbers produced were unreliable and variable among communities
- Registrations could not be updated or maintained because communities saw no concrete results

What They Now Recommend

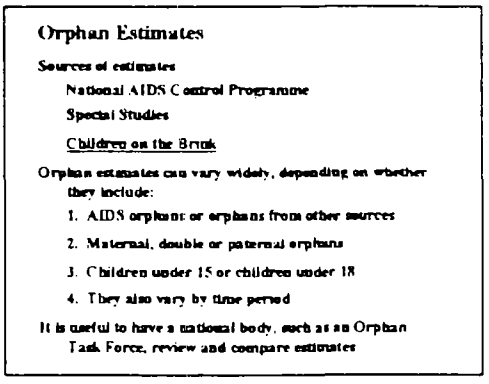
- Small area or pilot registrations for specific assistance programmes
- Local registrations by Village Orphan Committees

Both countries abandoned the effort, and they now recommend registrations in small areas or pilot registrations for specific assistance programmes. They also recommend local registrations by village orphan committees rather than data collection by a regional or national authority.

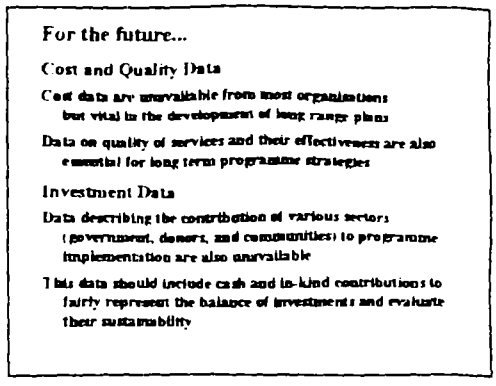
Orphan estimates may come from one or several sources, including the National AIDS Control Programme, special studies, or from ***Children on the Brink***. These can vary widely for any given country, depending on whether they include:

1. **AIDS orphans** or **orphans due to all causes** of death;
2. Orphans who are **maternal** (mother dead), **paternal** (father dead), or **double** (both parents dead). Maternal and double orphans are estimated from maternal deaths, and these estimates are most common. However, as a rule of thumb, paternal orphans are often as numerous as maternal orphans, and in many cases are in fact double orphans because they are abandoned or their mothers die soon after their fathers.
3. **Children under 15** (the demographic cut off) or **children under 18** (the legal cut off);
4. Orphan estimates also vary by **time period**. ***Children on the Brink*** includes the only projections of orphans through 2010.

It is therefore important to determine what types of orphans are being included in an estimate and to make careful comparison of orphan estimates. They can then be presented to a national body or steering committee for review so official consensus is established. The many reasons for including paternal orphans in national estimates are described in ***Children on the Brink***. All countries are encouraged to include paternal orphans in their estimates.



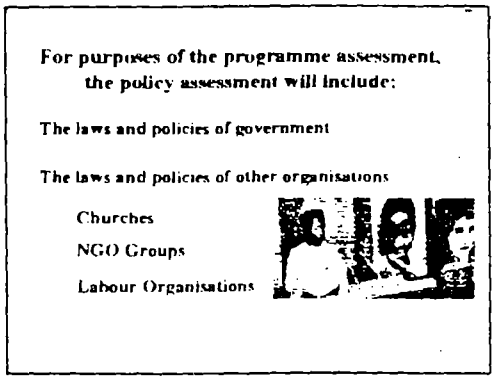
For the future, **cost and quality data** will be important to collect. At present, both are usually unavailable from most organisations, but vital in development of long range plans and strategies. Data on quality of services and their effectiveness can also be critical for chosing between alternative forms of care and developing strategies for improving long term programming.



Investment data describes the contribution of various sectors to orphan care. It is important to estimate the voluntary contributions of families and communities in order to appreciate their commitment, value their work, and persuade policy makers to support their efforts. One way to do this is to estimate the cost of maintaining all orphans in institutions, or to estimate the cost of paying a substitute care giver in the home were it possible to hire one. This data should include both cash and in kind contributions in order to fairly represent the balance of investments and evaluate their sustainability.

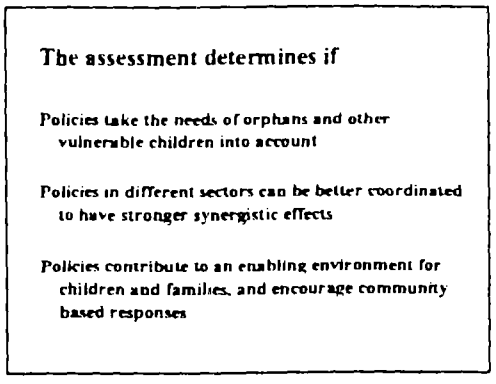
Policy Assessment

Only one of the six countries assessed had a specific **national orphan policy**. All five others were reviewing laws relative to orphans and other children made vulnerable by the epidemic. A thoroughgoing policy assessment will include both the laws and policies of government and those of other organisations, including churches, NGO groups, and labour organisations.

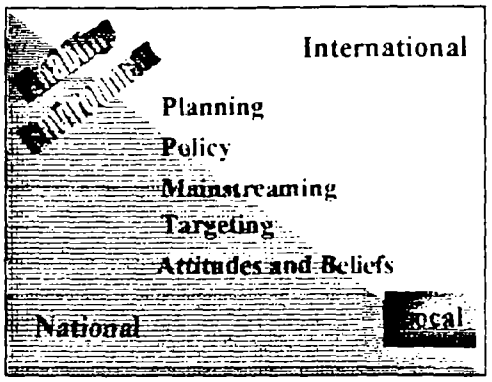


The policy assessment determines if:

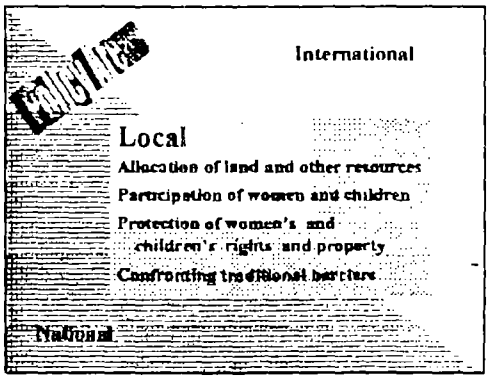
1. Policies **take the needs of orphans and other children left vulnerable by the epidemic into account**;
2. Policies **in different sectors** can be better coordinated to have **stronger synergistic effects**;
3. Policies contribute to an **enabling environment** for children and families and encourage community based responses.



The **enabling environment** implies that actors at the international, national and local levels are committed to assist orphans and other children affected by HIV/AIDS. These actors review and adjust their planning, policy development, mainstreaming, programme targeting, and -- most importantly -- their attitudes and beliefs to determine how well they assist all children that are vulnerable. A thorough-going policy review will include the following areas:



Local Policy Review



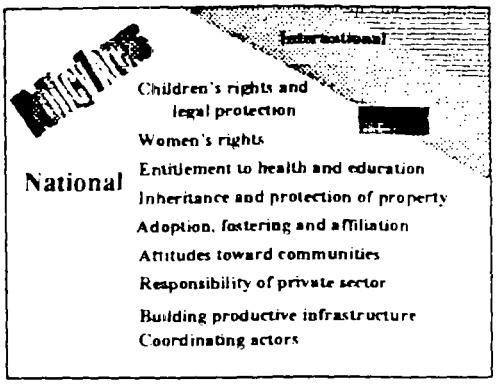
Allocation of land and other resources –Do local policy makers allocate land to communal gardens or shelters for children, or to NGOs that provide services to children? Do they encourage sharing of resources to the weaker members of the group? Are local policy makers concerned that children have access to education and health services and do they seek innovative ways to allow the poor or disenfranchised full use of local services?

Participation of women and children – Do local policy- making bodies encourage the participation of women, children, and young people, of guardians and orphans, so that the needs of these groups are articulated and better understood? Do they participate on a decision making level?

Protection of women's and children's property -- Do systems of tenure protect widows and orphans or child headed households from loss of their property to relatives or other opportunists? Are there credit associations to help families with limited resources maintain their resources? Do community leaders seek small business opportunities to assist these groups?

Confronting traditional barriers – What is the attitude toward widow inheritance? How is mistreatment of step children viewed? Does the community accept responsibility for all vulnerable children and intervene when guardians are harsh or abusive?

National Policy Review



Children's rights and legal protection – Review of laws and policies in all sectors and monitoring of their administration to ensure that the rights of all children are respected, protected, and fulfilled is critical. The review will consider the Convention on the Rights of the Child and the National Programme of Action for Children. It includes the definition of sexual maturity, age of marriage and defilement, and children's access to resources without adults

Women's rights – Increasing women's rights under the law to entitlements and protection is an important step in ensuring the protection and well being of their children. Studies have shown that women who retain their property and land are more able to meet the needs of the orphans dependent upon them

Entitlement to health and education – Entitlements for orphans, especially very young ones, to health care and education, must be sufficient to ensure their access to these services. They may be the only safety nets a child has. In addition, the reality of access may be more limited than policy makers intend due to budget restrictions, discrimination, or insensitivity to the special problems of these children and their families.

Inheritance and protection of property – Since this area is systematically weak in all heavily affected countries, policy makers need to demonstrate their commitment to equity and their intent to see it realised through legal and judicial action and public education.

Adoption, fostering and affiliation – In many African countries, laws for adoption, fostering and affiliation, and the definition of orphans (establishing and enforcing paternal responsibility) are outdated. In addition to revising these laws to accommodate the rapid need for expanded services, public education programmes are also needed to encourage families to care for additional children. Families may need grants or other fiscal support to be able to maintain children. Policy makers need to understand the long term fiscal ramifications of failure to support family and community care at the earliest stages.

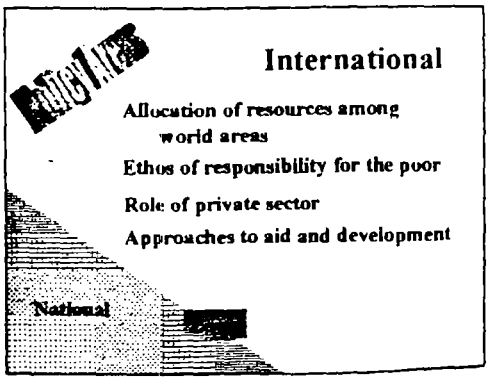
Attitudes toward communities – Community innovation, altruism, and self determination in the face of the AIDS epidemic are often overlooked or underrated both by government and non-governmental organisations. Community abilities need respect and support through training and development. NGOs and CBOs may need special support and better definition through the law.

Responsibility of the private sector – In many countries, large private sector employers need support in developing responsible plans for care of HIV/AIDS affected employees, their spouses and children. Adequate insurance and death benefits are minimal; however, in several countries commercial employers are taking the lead in developing additional care and protection programmes for widows and orphans.

Building productive infrastructure – Increased labour demands on households and children can be reduced through the development of water and sanitation services in AIDS affected communities. Such changes allow widows to provide more adequate care or seek outside employment, support increased agricultural production, and will allow more children to remain in school. Communities seeking technical assistance to increase their productivity in agriculture or in other small businesses, if assisted, can continue to maintain their children despite losses of productive adults.

Coordinating actors – A national body dedicated to the protection and care of orphans can help to conduct reviews of policy areas, stimulate public awareness and response, and rationalise delivery of benefits by coordinating services in local areas. This can be established under the responsible ministry, but should include all public and private sector partners.

International Policy Areas



Allocation of resources among world areas. Current allocation of development resources may need reexamination given the variable impact of the AIDS pandemic among world regions. More priority may be needed for heavily affected countries.

Ethos of responsibility for the poor. The threat of AIDS has made it ever more difficult to ignore the growing maldistribution of wealth in the world. More effort must be

made to inform the world public of the interactions of AIDS and poverty and to encourage expanded foreign aid and debt forgiveness.

Role of the private sector – Many private sector companies have global connections. The international policy of these firms can govern national choices for employee benefits and problem solving regarding social issues.

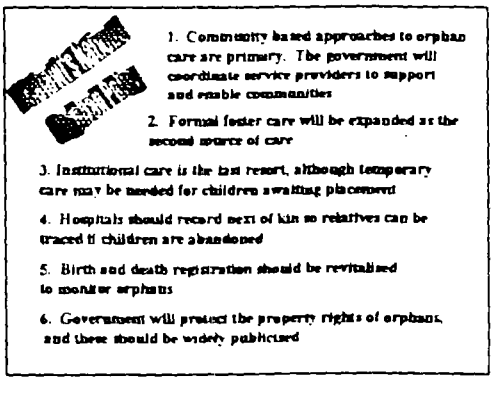
Approaches to aid and development – Since the pandemic will condition economic response over the next several decades, more study is needed of the positive effects which can be drawn from growing community inventiveness and interest in technical innovation. In addition, donor agencies need to examine their policies in other sectors to accommodate the impact of AIDS on other development programmes.

Malawi's National Orphan Policy

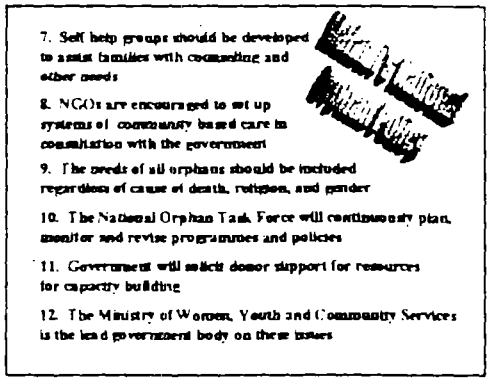
Malawi was the first country in the region to create a National Task Force on Orphans (NOTF). The body was established in 1991 within the Ministry of Women, Youth and Community Services, and includes national and district government representatives from the MOWYCS, the Ministry of Health through the NACP, key NGOs and Community Based Organisations (CBOs), and major religious bodies in Malawi.

Members of the National Task Force, in consultation with advisors from the Ugandan government and NGOs, developed APolicy Guidelines for the Care of Orphans in Malawi and Coordination of Assistance for Orphans≡ in 1992. Malawi was a pioneer in this regard, and few if any other countries have specific orphan programme and coordination guidelines The guidelines are simple and brief, and are often used by the government as programme development guidance for community groups interested in developing orphan care programs.:

1. **Community based approaches** to orphan care are primary. The government will coordinate service providers to support and enable communities;
2. **Formal foster care** will be expanded as the second source of care;



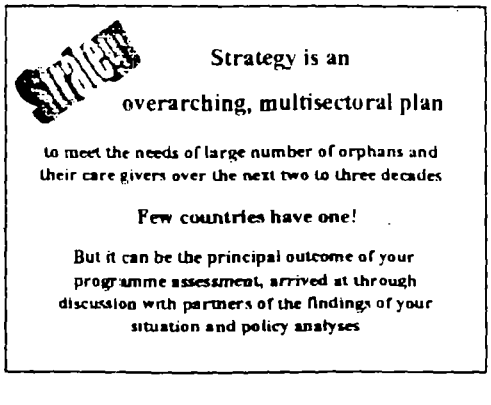
3. **Institutional care** is the last resort, although temporary care may be needed for children awaiting placement;
4. Hospitals should **record next of kin** so relatives can be traced if children are abandoned;
5. **Birth and death registration** should be revitalised to monitor orphans;
6. Government will protect the **property rights of orphans** and these should be widely published;
7. **Self-help groups** should be developed to assist families with counseling and other needs;
8. **NGOs** are encouraged to set up systems of community based care in consultation with the government;
9. The **needs of all orphans** should be included regardless of the cause of death, religion, and gender;
10. The **National Orphan Task Force (NOTF)** will continuously plan, monitor and revise programmes and policies;
11. Government will solicit **donor support** for resources for capacity building;
12. The Ministry of Women, Youth and Community Service is the **lead government body** on these issues.



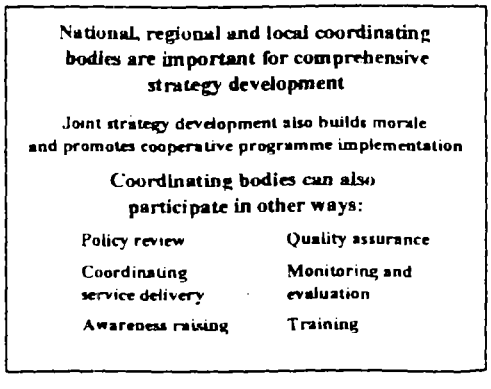
NOTF is committed to continuing review and update of these policy guidelines, and related areas of responsibility of the Ministry.

Strategy Development

Strategy is an overarching, multisectoral plan to meet the needs of large numbers of orphans over the next two to three decades. Few countries have it! Ideally, as in Malawi, it would be generated by a central coordinating body that includes all the players -- government, NGO, UN bodies – following presentation of the results of the situation analysis. A working strategy may be the principal outcome of your programme assessment, what you come to when you discuss your findings with a large group of partners.



National, regional, and local coordinating bodies are important for comprehensive strategy development. Joint strategy development can build their morale and promote



cooperative programme implementation at all levels Following strategy development, coordinating bodies can also conduct policy review, coordinate service delivery, integrate their findings and activities into local development plans, monitor and evaluate programme implementation, review programme quality, and provide training.

Most of the countries that have completed programme assessments have joint coordinating bodies. **Malawi**'s National Orphan Task Force implements programmes thorugh the District AIDS Coordinating Committees and and Village Orphan Committees, and organises multisectoral planning that includes NGOs and religious groups. The findings of the District AIDS Coordinating Committees are included in District Development Plans.

Malawi's National Orphan Task Force
- Implements programmes with District AIDS Coordinating Committees and Village Orphan Committees
- Organises multisectoral planning and includes NGOs
- Activities are included in District Development Plans

Zimbabwe's National Child Welfare Forum
- Part of formal social service system
- Has branches in each region
- Each branch has affiliates at area and local level

In Uganda, planning for all vulnerable children is the responsibility of the District Development Committees
- Each district has a Plan of Action for Children
- Fund raising is done at the local level using national taxation mechanisms

Zimbabwe has a National Child Welfare Forum with branches in all regions, many districts, and in villages organised for community care. The Child Welfare Forums are incorporated into the formal government social welfare system so that they can refer especially difficult cases and so that their work can be monitored and improved by social welfare officers with formal training. Social welfare officers provide communities with organisational assistance when they wish to develop orphan committees.

In **South Africa**, the government's pilot for orphan care in the KwaZulu-Natal region, the Children in Distress Project (CINDI), has a steering committee that coordinates local services provided by community based organisations, NGOs, government social welfare officers, hospitals and home care agencies. **Botswana**'s local development structure includes child welfare committees, but these have not been fully mobilised concerning assistance to orphans. **Zambia** has local coordinating committees that include all public and private sector players. They coordinate assistance, develop referral mechanisms, and systems to identify needy children and families.

Uganda had an active national coordinating body, but its responsibilities have been devolved to the District level. District Development Committees create plans of action for children and also have the responsibility to raise and allocate tax monies for their implementation.

Classically, **a strategy works to cover gaps in coverage by geographic area or programme type, building on data from the situation analysis**. The strategy would probably be linked with **goal setting** for coverage of community based programmes and State safety nets (by age, location, vulnerability), and for well being of children and care givers (health, nutrition, school enrollment).

Strategy development is linked with goal setting for the well being of children

A strategy works to close gaps in coverage by geographic area or programme type, building on data from the situation analysis

Questions you can ask yourself in the course of a programme assessment, while preparing for the strategic development phase, include:

What is the country's strategy for taking care of large numbers of orphans over two to three decades? Does the country have a strategy? Is it multisectoral? Is there a body charged with formulating strategy? Is there a body that should take the leadership role?

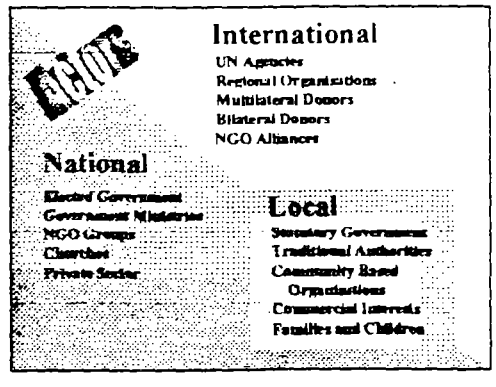
What is the UNICEF office's plan to work with partners to formulate such a strategy? What are the barriers to developing strategy with partners? What should the strategy contain? Does it have a time horizon? What are the responsibilities of various actors? How will orphan assistance programmes be mainstreamed over time?

The strategic orientation is development, not charity

Formal recognition of community care as primary is necessary, coupled with sufficient assistance so communities do not reach the stage of exhaustion and burn out

How is coordination accomplished by the national policy body? How are regional activities coordinated? What mechanisms exist for local coordination? How is the participation of children, young people, and women encouraged?

Formulation of strategies should include all international, national and local actors. Following development of the strategy, each group can assume appropriate responsibilities to see that it is implemented:



International bodies raise awareness, expand resources, provide technical assistance;

National bodies assemble and distribute resources equitably, define policy areas, and manage donors;

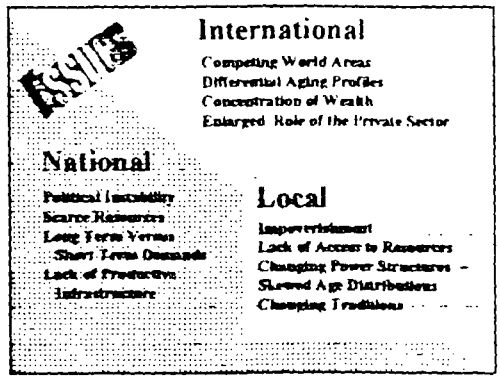
Local bodies may be charged with protection of children, provision of support for families, and developing community based resources and organisations.

Strategy implementation can be hindered by a variety of issues at each level:

International – competing world areas with differential aging profiles, concentration of wealth in more developed regions, and an enlarged private sector with less responsibility to the State;

National – political instability, scarce resources, long term versus short term demands and needs, and lack of productive infrastructure;

Local – impoverishment, lack of access to resources, changing power structures, skewed age distributions with large numbers of dependent children and elderly, and changing traditions.



Key Planning Considerations

In developing strategy, the responsible body can match responses with characteristics of the orphan problem:

1. The problem will have **a 20 to 30 year life**, so responses must be viable over the long term;
2. **Large numbers of children** are involved, which means that solutions must be large scale, integrated or mainstreamed, community based, low cost and sustainable;
3. The AIDS pandemic makes **children extremely vulnerable** in many ways, so any strategy must have provisions for protection and care high priority;

Key Planning Considerations

The Problem...	The Response Must Be
Has a 20 or 30 Year Life	Long Term
Involves Large Numbers of Children	Large Scale, Integrated, Community Based, Low Cost, Sustainable
Extreme Vulnerability of Children	Include Provision for Protection and Care

4. The **size of the problem is predictable** from long term orphan estimates, so it is possible to plan for a corresponding scale of programmes and inputs;
5. Also, **needs of orphans are predictable by age group**, so that the programme will have a fairly standard design in the provision of basic services;
6. **Impact is measurable** through standard indicators of child health and well being, so programme success can be measured and its design adjusted through time.

Key Planning Considerations	
The Problem...	**The Response Must Be**
Predictable in Size	Plan Programme Scale and Inputs
Predictable Needs by Age Group	Predictable Programme Design
Measurable	Determine Success and Adjust Programming

A national implementation strategy needs to recognize that in the short term (3-5 years), a national orphan programme requires **investment in programme-specific services** to:

1. Organise national, regional and local coordinating committees;
2. Catalyse community organisation;
3. Develop networks of service providers;
4. Undertake legal review and policy changes;
5. Develop data collection, modeling and research capabilities;
6. Establish a monitoring and evaluation system;
7. Develop public and policy maker awareness
8. Undertake fund raising for expanded programming.

Programming needs to be vertical and focussed until the ground work for long term response is made. It may take 10 years or longer to pass through the initial organising stage because of multisectoral involvement. Even then, a country may wish to maintain a national body for advocacy, on-going monitoring, and policy and programme development.

Over the long term (5-10 years), implementing agencies should **integrate family and community support programmes into mainstream programmes** in health, education, agriculture, water and sanitation, the key sectors determining a country's progress in meeting the World Summit goals.

Demographic Changes

The AIDS epidemic is producing **radical changes in the population structures of communities and countries** due to increased adult and child deaths and illnesses. This means that the number of children will be much lower than currently projected by many official sources, and the aged population will be proportionately larger.

Demographic Changes and National Development Planning

The AIDS Epidemic Causes

Increased adult deaths and illnesses

Increased child deaths and illnesses

Changing dependency ratios

This means that

The number of children will be much lower than currently projected by most official sources

The aged population will be proportionately larger

Each of these demographic changes has implications for implementation of strategies in all sectors. For example, the number of school facilities needed may be much lower than currently projected. Skilled labour and trained personnel in all sectors will be reduced in numbers. Although these changes are easy to predict, few governments are including them in their long term development plans.

Each of these demographic changes has implications for implementation of strategies in all sectors.

For example, the number of school facilities needed may be lower than currently projected. Skilled labor and trained personnel in all sectors will be reduced in numbers

Few governments are including these considerations in their long term development planning.

Aggregate estimates of long term programme needs are not available in most countries. Most governments have not made long range projections of gross sectoral needs that may be increased by the orphan situation. These would be helpful in mobilising donor assistance. It is difficult for planners to describe the impact of AIDS on other sectors besides health, but necessary for adequate planning. ***Children on the Brink*** contains estimates of the child population for 2000, 2005, and 2010 in each of the 23 study countries. These can be a starting point for discussion with the Ministry of Planning, Finance and key sectoral ministries including health, education, and public welfare.

Aggregate Estimates of Long Term Programme Needs

Long Term Estimates

- Gross sectoral needs
- Long range projections

Purpose

- To describe impact on other sectors for planning purposes
- To mobilise donor assistance

Monitoring and Evaluation

Once a national strategy is developed, the monitoring and evaluation plan can be developed using strategic goals and objectives. There are at least three areas to monitor: **child health and well being**, **care giver status**, and **community status and changes over time**. Most existing project and UNICEF country programme plans have indicators in the first two areas, but little work has been done in the last area. Extensive work was begun at the Nairobi Programme Consultation on indicators in all three areas, and will be circulated with the final report of the meeting.

A monitoring and evaluation plan for orphan programmes will be similar to those for other child protection, health, or education programmes. In fact, basic indicators for child well being may be same as those used in other programmes, but survey instruments should compare their values for orphans and non-orphans, or for children in fostering homes versus children in homes without foster care. It may be useful to evaluate maternal and paternal orphans separately because their problems will be different at different ages.

Deterioration of all children's well being may be seen because of the pressure on families and communities of more dependent children. UNICEF offices in Zambia and several other heavily affected countries are anticipating the possibility of **emergency conditions** in the new few years. For this reason, a monitoring plan should include:

1. The **overall situation of children and their care givers**, established using regular national sample surveys. Poverty alleviation or DHS surveys might be ideal for this purpose;
2. **Monitoring of performance of specific projects** funded by the office, especially pilot projects prior to widespread implementation.

Monitoring and Evaluation Plan

A monitoring and evaluation plan for orphan programmes will be similar to those for other child protection, health, or education programmes

Indicators of child well being may be the same as those used in other programmes but

Survey instruments will compare values for orphans and non-orphans or for fostering families and families without foster children

Deterioration of children's well being may be seen in all children because of the pressure of an increased proportion of orphans

UNICEF offices in Zambia and several other heavily affected countries are anticipating the possibility of emergency conditions within the next few years

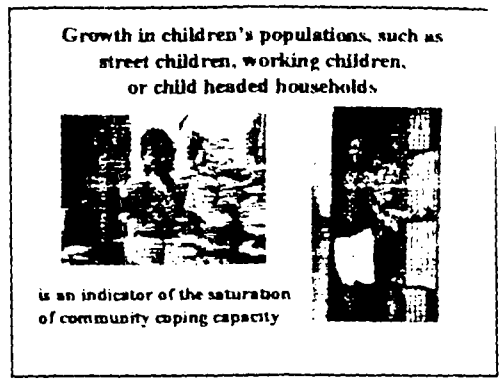
For this reason, two kinds of monitoring are important

Overall status of children and care givers

Performance of specific projects

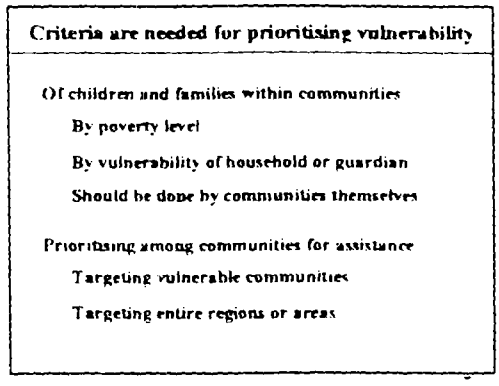
Growth in vulnerable children's populations, such as street children, working children, or child headed households is an indicator of the saturation of community coping capacity. Criteria for prioritising vulnerability of children and families within communities are needed:

1. By poverty level;
2. By vulnerability of household or guardian;



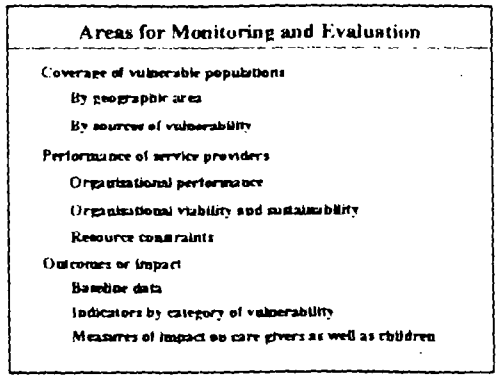
These can be established by the community itself according to its capacity for assistance. In addition, programme planners may wish to prioritise among communities needing assistance for purposes of:

1. Targeting vulnerable communities;
2. Targeting entire regions or areas.



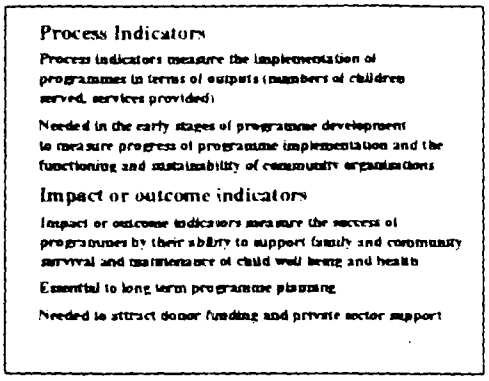
There are several broad areas for monitoring and evaluation:

1. **Coverage of vulnerable populations** by geographic area and by sources of vulnerability;
2. **Performance of service providers**, including the performance of organisations as well as their viability and sustainability over time given a range of resource constraints;
3. **Outcomes or impact of programmes**, for which baseline data will be needed. Indicators can be developed by category of vulnerability of children, and it will be important to measure impact on care givers as well as on children.



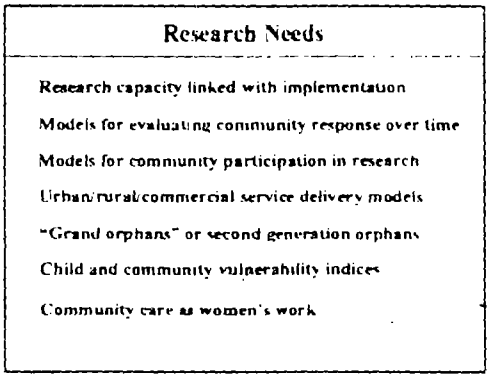
Process indicators measure the implementation of programmes in terms of outputs (numbers of children served, services provided) These are needed in the early stages of programme development to measure the progress of programme implementation, and the functioning and sustainability of community organisations.

Impact or outcome indicators measure the success of programmes by their ability to support family and community survival and maintenance of child well being and health. These are essential to long term programme planning, and are needed to attract donor funding and private sector support.



Research and Training

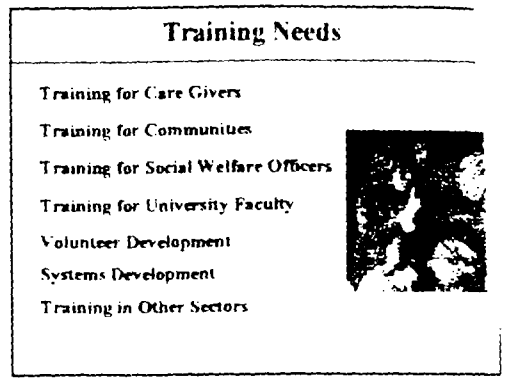
In all six countries assessed, **research needs are many**. First, most countries needed to consciously link in-country research capacity with on going implementation so that simplified operations research, conducted by communities, can be used to inform their process and help policy makers better understand their needs. In all countries, there was sophisticated demographic research capacity, but it needed to be focussed on the issue of orphans and other changes in demographic structure due to AIDS



Models for evaluating community response over time, as the epidemic increases mortality, are needed so that support to communities can be adjusted over time. Again, these can be developed using simplified data collection instruments for the community to monitor and adjust its own response.

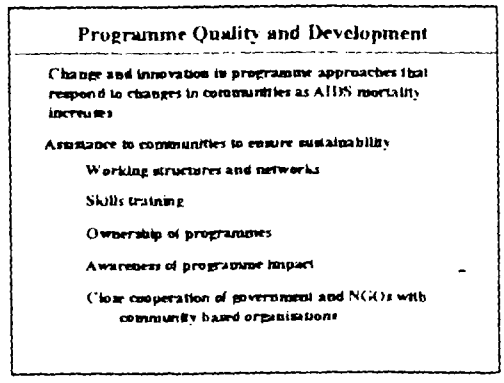
Models are also needed to guide implementation in different settings: urban, rural, and commercial locations. The issue of "grand orphans", or second generation orphans needs to be studied to determine its extent over time. Child headed households are also especially vulnerable. These are simple research problems that can make use of community data. Child and community vulnerability indices are needed so that fragile situations can be identified early and addressed. Finally, all community care issues need research and analysis, including community care as women's work and the impact of care on women, as well as increasing the involvement of men.

Training needs are also many at all levels, including care givers, communities, social welfare officers, and for university faculty in many disciplines. Training is needed for volunteer and organisational staff so that programmes can be expanded rapidly.



Programme Quality and Development

A monitoring and evaluation plan can look at the quality of programmes in place to serve children, families and communities affected by HIV/AIDS. Are they sufficiently comprehensive? What other models could be encouraged, and how can models be expanded to meet new needs or provide new services?



Is there periodic training for community committees and for family care givers? What allowances are made for development of programming over time in response to changes in the epidemic? What are the material needs and supports? How do programmes encourage innovation, including opportunities for communities to teach and talk with one another? What variation is there in response to differences in programme setting (urban, periurban, rural, commercial and farming settings)? How are children's physical needs, need for socialisation, and psychosocial needs met?

Programme development seeks to encourage change and innovation in programme approaches that respond to changes in communities as AIDS mortality increases. Communities will need assistance to ensure the sustainability of their programmes, including:

1. Working structures and networks;
2. Skills training;
3. Ownership of programmes;
4. Awareness of programme impact;
5. Close cooperation of government and NGOs with community based organisations.

Fund Raising Plan

A fund raising plan can include indigenous sources of support as well as external. In the six countries where programme assessments were conducted, **indigenous sources of support** included the government, communities, religious organisations, commercial or private sector organisations, community fund raising, and small contributors of cash and in-kind goods and services.

External sources of support included programme specific support from UN or multilateral donors, non-governmental organisations, bilateral donors, external funding for religious organisations or hospitals, and World Bank AIDS sector loans.

Collaborative support and synergistic potential was seen during the first six programme assessments through coordination with donors supporting primary education, health programmes, and agricultural programmes, and through the World Food Programme. Orphan programmes also built on programmes developed in other sectors. For example, villagers in Malawi who had participated in a UNDP community development programme were quicker to organise around the orphan issue in subsequent years. It was also found that programmes in other sectors could be targeted at communities with large numbers of orphans. For example, a high protein seed programme organised by the World Food Programme was targeted at heavily affected communities with good results.

National, district and local coordinating committees often stimulated local interest and contributions. In-kind contributions of good and services were often as important as cash contributions and may be easier for groups or individuals to provide.

Expanded funding in other sectors by donors can be used to support mainstreamed services for orphans. For example, programmes for early childhood education and

Indigenous Sources of Support

- Government
- Communities
- Religious organisations
- Commercial or private sector
- Community fund raising
- Small contributors
  - Cash and in-kind
  - Goods and services

External Sources of Financing and Support

- Programme Specific Support
  - UN or multilateral donors
  - Non-governmental organisations
  - Bilateral donors
  - External funding for religious organizations and hospitals
  - World Bank AIDS sector loans
- Collaborative Support/Synergistic Potential
  - Primary Education
  - Health Programmes
  - Agricultural Programmes
  - World Food Programme

Indigenous Sources of Support

National, district and local coordinating bodies can stimulate local interest and contributions

In-kind contributions of good and services will be as important as cash contributions and may be easier for groups to provide

External Sources of Support

Expanded funding in other sectors can be used to support mainstreamed services for orphans

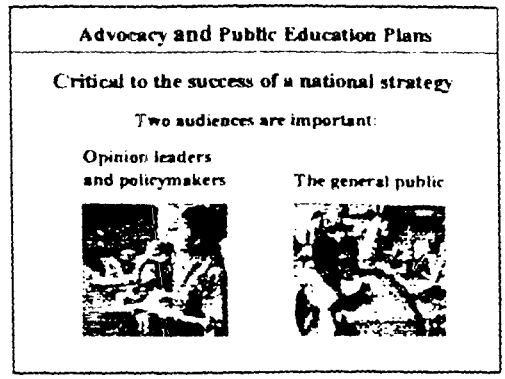
A national development plan and strategy for orphans will be important in increasing resources from external donors and programmes

development were especially important in supporting young orphans. A national development plan and strategy for orphans will be important in increasing funds from external donors and programmes because it can articulate the scale of the problem, strategies being pursued to address it, and the contributions being made by local communities and organisations.

Advocacy and Public Education

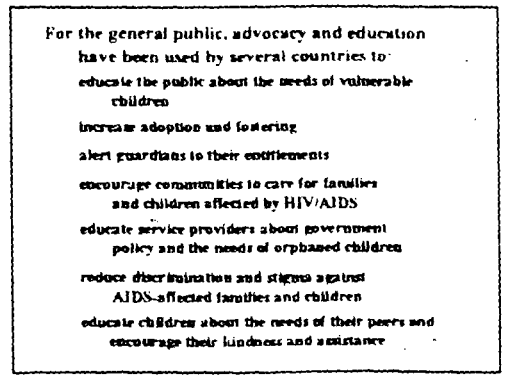
Advocacy and public education plans are critical to the success of a national strategy. Two audiences are important:

1. Opinion leaders and policy makers;
2. The general public.

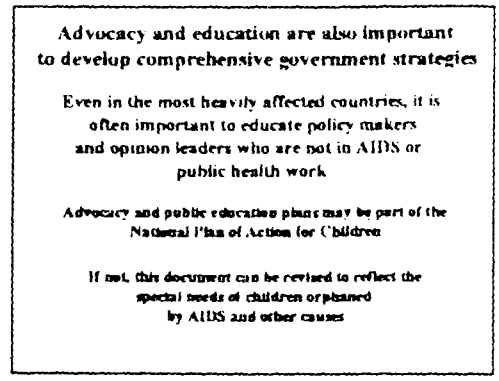


For the general public, advocacy and education have been used by several countries to:

1. **Educate the public** about the needs of vulnerable children and how to care for them;
2. **Increase adoption and fostering** and overcome cultural constraints to both;
3. **Alert guardians to their entitlements**;
4. **Encourage communities** to care for families and children affected by AIDS;
5. **Educate service providers** about government policy and the needs of orphaned children;
6. **Reduce stigma and discrimination** against AIDS-affected families and children;
7. **Educate children about the needs of their peers** and encourage their kindness and assistance.



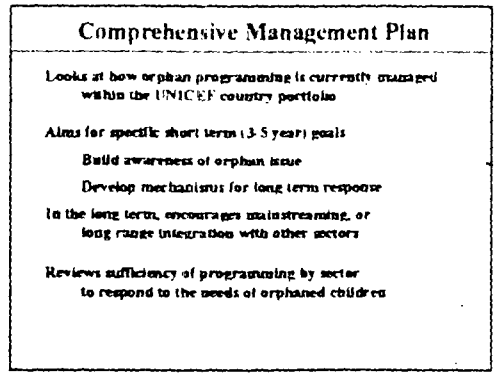
Advocacy and education are also important to develop comprehensive government strategies. Even in the most heavily affected countries, it is often important to educate policy makers and opinion leaders who are not in AIDS or public health work about the impact of the epidemic. It may be possible to work through the National AIDS Control Programme, or, in some countries, with Ministries of Planning and Finance, to better integrate AIDS in development planning. In many sectors, the presence of orphans will demand a change **not only in scale of delivery but in the mechanisms of delivery** of services.



Advocacy and public education plans may be part of the National Plan of Action for Children. If not, this document can be revised to reflect the special needs of children orphaned by AIDS and other causes.

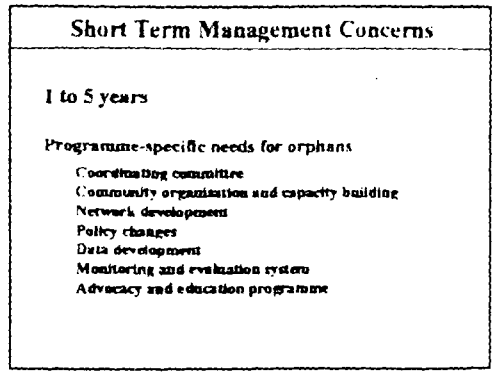
Management Plan

The last thing that needs to be reviewed in a national programme assessment is the way in which the UNICEF country office manages the issue of orphan programming. A management plan should aim for specific short term (3 to 5 year) goals by building an awareness of the orphan issue and developing mechanisms for a long term response. A management plan should encourage coordination within the office so that mainstreaming, or long term programme integration with other sectors, becomes a reality. The sufficiency of programming in each sector to respond to the needs of growing numbers of orphans can be reviewed.

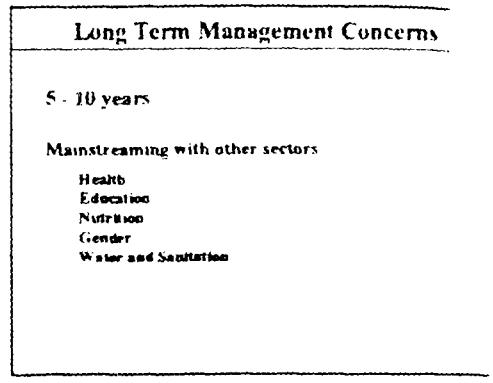


Short term management concerns may run from one to five years, and include programme-specific needs for orphans and families affected by HIV/AIDS:

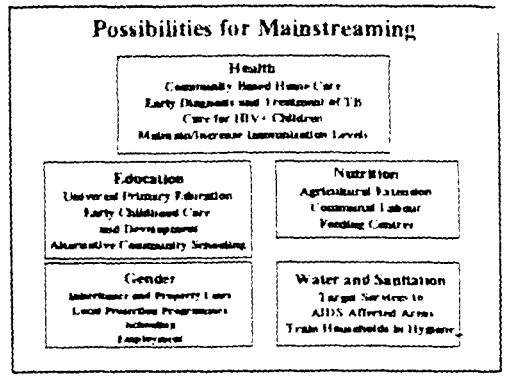
1. The coordinating committee;
2. Community organisation and capacity building;
3. Network development;
4. Policy review and changes;
5. Data development;
6. The monitoring and evaluation system;
7. An advocacy and education programme.



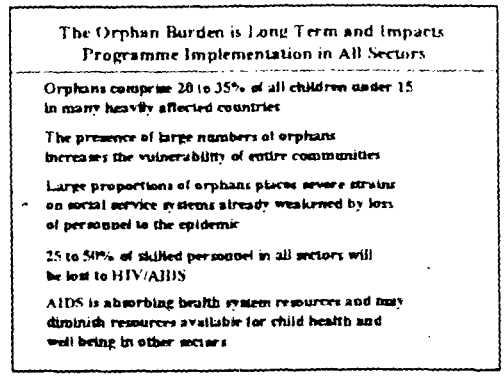
Long term management concerns revolve around effective mainstreaming with other sectors, including health, education, nutrition, gender, water and sanitation Possibilities for programme mainstreaming are many.



The first step in mainstreaming is to review how effectively programming in all sectors responds to the needs of orphaned children or other children left vulnerable by the epidemic In countries where orphans are a significant minority of children this will be especially critical.

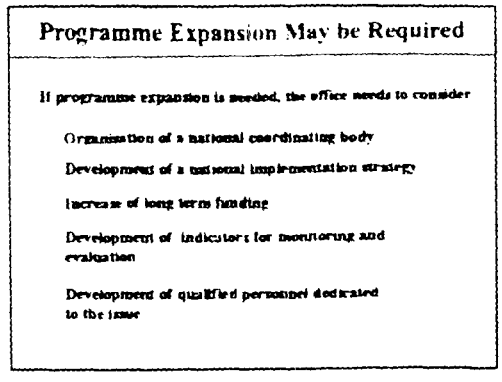


The orphan burden is long term and will impact programme implementation in all sectors. Orphans already comprise 20 to 35% of all children under 15 in many heavily infected countries. The presence of large numbers of orphans increases the vulnerability of entire communities because it places severe strains on social systems already weakened by loss of personnel to the epidemic. One quarter to one half of all skilled personnel in key sectors will be lost to HIV/AIDS within 10 years. AIDS is also absorbing health resources and may diminish those available for other child health programmes.



Programme initiation or expansion may be required. If it is needed, the office needs to consider:

1. Organisation of a national coordinating body;
2. Development of a national implementation strategy;
3. Increase of long term funding;
4. Development of indicators for monitoring and evaluation;
5. Development of qualified personnel dedicated to the issue.



World AIDS Campaign

LISTEN, LEARN, LIVE!

World AIDS Campaign with Children and Young People

Secretariat

UNAIDS

Steering Committee

• UNAIDS
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• *Others:*
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International Federation of Red Cross and Red Crescent Societies

International Save the Children Alliance

MTV International

World Association of Girl Guides and Girl Scouts

World Organization of the Scout Movement

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Children and HIV/AIDS

UNAIDS Briefing Paper

Updated from the briefing paper for the 1997 World AIDS Campaign issued in June 1997.

Joint United Nations Programme on HIV/AIDS (UNAIDS), February 1999

Pages

Children and HIV/AIDS

From the sick and neglected infants dying of AIDS in the orphanages of Ceaucescu's Romania to the young people watching over their dying parents in East Africa, images of the children of the AIDS epidemic have been among the most compelling reminders of the reach of this global crisis.

Today's children – defined by the United Nations Convention on the Rights of the Child as people below the age of 18 years – are growing up in a world with AIDS. They are having to cope not only with issues and problems that have long existed and are now being revealed by the HIV/AIDS epidemic, but also with those that result directly from the epidemic and which, until recently, people only had to face as adults.

More children are contracting HIV than ever before, and there is no sign that the infection rate is slowing.

Children below the age of 18 are vulnerable to infection through mother-to-child transmission, unsafe blood and injection practices, sex – including sexual abuse, coercion and commercial exploitation – and injecting drug use. Much of this vulnerability stems from failure to respect their rights, including those guaranteed under the United Nations Convention on the Rights of the Child.

Unfortunately, the magnitude of the problem remains to be documented with any precision. There is a glaring gap in data on the incidence of infection among children as they grow into adolescence.

One of the shortcomings of HIV epidemiological surveillance to date has been to use the cut-off point of 14 years for younger children in the collection and aggregation of data – the older 15-49 year age group being considered as adults. A first step therefore in governments in fulfilling their obligations to children in the context of HIV/AIDS is to collect comprehensive data on HIV transmission among older children and adolescents, so that they can design effective prevention and care programmes in the light of these data.

The number of children infected around birth is easier to estimate. Around 90% of children who become infected under the age of 15 years acquire the virus from their HIV-infected mothers, whether before or during birth or through breastfeeding. And as women of childbearing age themselves become infected in ever greater numbers – a trend reflecting their own social vulnerability to HIV – the number of babies infected through mother-to-child transmission rises correspondingly.

Since the beginning of the HIV/AIDS epidemic in the late 1970s and early 1980s, UNAIDS and WHO estimate that more than 4 million children under the age of 15 years have been infected with HIV. In 1998 alone, around 1400 children died of AIDS daily and an even larger number became newly infected with each passing day. At the end of that year, it was estimated that 1.2 million children under 15 were living with the virus. Well over 90% of these children live in developing countries.

In sub-Saharan Africa, the region most severely affected by AIDS so far, the US Bureau of the Census has predicted that AIDS will offset improvements in infant and child mortality achieved in the past decade. **By the year 2010, if the spread of HIV is not contained, AIDS may increase infant mortality by as much as 75% and under-five child mortality by more than 100% in those regions most affected by the disease.**

Children are not only infected by HIV, they are also affected. While the number of those infected by HIV continues to grow, the epidemic is also having a direct and devastating effect on millions of other children whose lives have been permanently altered by the intrusion of HIV/AIDS into their households or communities.

Children living in hard-hit communities feel the impact as they lose parents, teachers and caregivers to AIDS, as health systems are stretched beyond their limits, and as their families take in other children who have been orphaned by the epidemic.

Individual households struck by AIDS often suffer disproportionately from stigma, isolation and impoverishment, and the emotional toll on the children is heavier still. As the number of children orphaned or otherwise affected by AIDS rises, social security systems, already underfunded and overburdened where they exist, reach breaking point. The impact is most acute on girls and boys already facing hardship or neglect – children in institutional care, children in poor neighbourhoods or slum areas, refugee children – and even more so for young girls who have unequal opportunities for schooling and employment.

In countries such as Uganda, where the epidemic already took hold over a decade ago, the impact of AIDS on the socioeconomic fabric of communities is becoming increasingly visible. As one UNICEF/WHO report puts it, "the effects of the epidemic are starkly obvious from the banana plantations going fallow, the houses closed or abandoned, the funeral processions on the roads and the recent graves near homes where grandparents care for children whose parents have died." AIDS sets back development and changes patterns of life. To a child, this translates **into a world turned upside down.**

But the shadow of the epidemic extends far beyond even these millions of infected and affected children. **In the final analysis, all children of the world henceforth face a lifetime of risk from HIV. They are exposed to the risk of HIV infection at different life stages as they grow into adulthood, because of circumstances such as sexual exploitation and abuse, or simply due to violation of their rights to information, to education and services.** There is a need for greater recognition of the specific requirements of girls and of especially vulnerable children, both boys and girls, such as refugees, street kids, and children exposed to drug use.

In short, children and young people in all countries, and those who care for and are responsible for them, are having to adjust and adapt to this new world. The global epidemic is continuing to accelerate. There is, as yet, no vaccine against the virus. Neither is there a cure. For all the welcome recent advances in scientific treatments, there also remains great uncertainty as to whether and how such treatments could ever be made accessible to the vast majority of people living with HIV who are in the developing world.

AIDS has changed the world for children. The United Nations Convention on the Rights of the Child provides a framework for promoting and protecting the rights of children which can minimize the impact of the HIV/AIDS epidemic on them. Yet, despite almost universal ratification, the response to infected, affected and vulnerable children has remained inconsistent. Internationally, AIDS programmes for children have been ad hoc and fragmented and have lagged behind those for adults. In many developing countries, this situation is worsened by poverty and other factors, such as wars and the resulting social breakdown of many communities.

The industrialized world has unmet needs as well. In a survey conducted in 1992 in the United States, government lobbyists on children's issues admitted that while they were generally successful in promoting other causes such as education and anti-poverty programmes, they were much less so with childhood AIDS issues such as prevention, orphan care and education around sexual health.

> **In a world with AIDS, children must become everybody's responsibility.**

On World AIDS Day 1994, heads of government from 42 countries attending the Paris AIDS Summit called for a global partnership to reduce the impact of the HIV/AIDS epidemic on children and young people.

This briefing summarizes how the epidemic is having an impact on children who are infected by HIV, on those who are directly affected by HIV/AIDS in their families or communities, and on children who are at risk of HIV infection. It outlines the global and national action needed to support children and their families as they face life in a world with AIDS.

The Rights of the Child in the context of HIV/AIDS

All children under the age of 18 living in today's world — whether they are themselves infected with HIV, affected by AIDS in their households or communities, or living in the shadow of HIV risk — are recognized by the United Nations Convention on the Rights of the Child.

In the context of HIV/AIDS, the United Nations Convention on the Rights of the Child has spelled out principles for reducing children's vulnerability to infection and to protect children from discrimination because of their real or perceived HIV/AIDS status. This human rights framework can be used by governments to ensure that the best interests of children with regard to HIV/AIDS are promoted and addressed:

- **Children's right to life, survival and development should be guaranteed.**
- **The civil rights and freedoms of children should be respected, with emphasis on removing policies which may result in children being separated from their parents or families.**
- **Children should have access to HIV/AIDS prevention education, information, and to the means of prevention. Measures should be taken to remove social, cultural, political or religious barriers that block children's access to these.**
- **Children's right to confidentiality and privacy in regard to their HIV status should be recognized. This includes the recognition that HIV testing should be voluntary and done with the informed consent of the person involved, which should be obtained in the context of pre-test counselling. If children's legal guardians are involved, they should pay due regard to the child's view, if the child is of an age or maturity to have such views.**
- **All children should receive adequate treatment and care for HIV/AIDS, including those children for whom this may require additional costs because of their circumstances, such as orphans.**
- **States should include HIV/AIDS as a disability, if disability laws exist, to strengthen the protection of people living with HIV/AIDS against discrimination.**
- **Children should have access to health care services and programmes, and barriers to access encountered by especially vulnerable groups should be removed.**
- **Children should have access to social benefits, including social security and social insurance.**
- **Children should enjoy adequate standards of living.**
- **Children should have access to HIV/AIDS prevention education and information both in school and out of school, irrespective of their HIV/AIDS status.**
- **No discrimination should be suffered by children in leisure, recreational, sport, and cultural activities because of their HIV/AIDS status.**
- **Special measures should be taken by governments to prevent and minimize the impact of HIV/AIDS caused by trafficking, forced prostitution, sexual exploitation, inability to negotiate safe sex, sexual abuse, use of injecting drugs, and harmful traditional practices.**

Source: *The Role of the Committee on the Rights of the Child and its Impact on HIV/AIDS: Problems and Prospects*, presentation by the World Health Organization Global Programme on AIDS at "AIDS and Child Rights: The Impact on the Asia-Pacific Region", Bangkok, Thailand, 21-26 November 1995.

Children with HIV: A future compromised

HIV/AIDS is a disease of the young. Last year altogether 590 000 children under the age of 15 years became infected with HIV worldwide, bringing the total number of children living with the virus at the end of 1998 to 1.2 million. Hundreds of thousands of HIV-infected babies are born every year to HIV-positive mothers.

In 1998 alone, of the 2.5 million people who died of AIDS, 510 000 were children under 15. Health services, already under strain in many developing countries and in poorer areas of the industrialized world, are likely to have to care for increasing numbers of children with severe HIV-associated illnesses.

Children with HIV/AIDS in developing countries

HIV infection in children typically runs a faster course to AIDS and then death than in adults. And paediatric AIDS kills especially fast in developing countries. Sick children in developing countries are generally at greater risk of death than children in industrialized countries and this is no less true of children with HIV. In Europe, 80% of HIV-infected children survive at least until their third birthday, and more than 20% reach the age of 10. In Zambia, however, nearly half of HIV-infected children in one study had died by the age of two. In another study in Uganda, 66% were dead by the age of three.

In Africa, in general, the situation for sick HIV-positive children is very grave. **Many of the common, inexpensive antibiotics and other medications used to treat sick children without HIV also work for children with HIV — but often, even these drugs are unavailable.** Poor families are less able to afford health care and basic drugs to tackle opportunistic infections, a problem which is even more acute in countries with low health budgets and where health services are difficult to access. In addition, drugs for the rarer HIV-associated illnesses have not been part of essential drug programmes that supply the world's poorest hospitals and clinics, and clinical practice guidelines for paediatric AIDS are often less clear than those for adults. Increasing the availability of basic antibiotics for acute respiratory infections, of antifungal drugs for thrush and cryptococcal meningitis (a severe infection of the nervous system), and of drugs that can cure tuberculosis is an urgent priority for developing countries with children and adults affected by AIDS. UNAIDS has made greater access to these drugs one of its primary concerns.

However, the more rapid course of paediatric AIDS in Africa is explained not only by less developed health care systems, but also by poor nutrition and widespread infectious diseases to which children are particularly vulnerable.

Poverty is a key reason why children die more quickly of AIDS in developing countries. If children are sleeping three or four to a room, for example, which is more common in poorer households, they are far more likely to transmit and contract tuberculosis or other respiratory diseases if one of them has any of these infections. If children are poorly nourished, their immune systems will weaken. If families do not have access to clean water, they are more vulnerable to waterborne diseases including diarrhoea.

Children with HIV commonly experience wasting and delayed development and are often killed by typical childhood diseases like diarrhoea, measles, tuberculosis and other respiratory infections. Because these diseases are often the same as those that kill other children, it is sometimes difficult for health workers in poor countries, without access to expensive HIV testing equipment, to distinguish HIV-positive children from others. This may have at least two important consequences. First, children with HIV may not receive the special care they need. Secondly, a general apathy about child health may arise, with consequences for all children. In communities around the world, increases in infant and child deaths due to AIDS may lead to a mistaken belief that immunization and nutrition programmes for children do not work. Disenchantment with these programmes could increase mortality in uninfected children.

Women and children — a dual vulnerability

During 1998, 5.2 million adults became infected with HIV, nearly half of them women.

Women of childbearing age make up an ever-increasing proportion of people with HIV worldwide — a trend that reflects their own biological and social vulnerability to to infection. Long-standing legal, economic and societal manifestations of gender discrimination and inattention to their sexual health influence women's vulnerability to HIV considerably.

In Kenya, for example, an AIDSCAP report found that the vulnerability of women is exacerbated by historical trends which have removed men from their families for lengthy periods of time, increased the acceptability of male sexual activity outside of marital relations, and sanctioned the behaviour of older men to use their wealth and prestige to seek sex with girls and young women.

In the longer term, therefore, reducing the vulnerability of infants to infection with HIV demands the same kind of action as reducing the magnitude of sexual transmission to women. The human rights of women must be fully promoted and protected. This approach was reinforced by both the International Conference on Population and Development held in Cairo in 1994 and the United Nations Fourth World Conference on Women, held in Beijing in 1995, which called for gender-sensitive initiatives to address HIV/AIDS and to end the social subordination of women and girls. Such an approach encompasses the ability of all women, whether or not infected with HIV, to make and carry out decisions about their reproductive and sexual health, including the avoidance of unplanned and/or unwanted pregnancies.

In the immediate, it is also vital to increase women's access to information about the prevention of HIV transmission in general and, within this, about existing ways of diminishing the risk of mother-to-child transmission. But for prevention strategies to be equitable and effective, AIDS programmes must avoid falling into the ancient trap of seeing women only as mothers. It would be tragic if, once again, as for contraception, women alone were left with the responsibility for HIV prevention within sexual relationships, and men were absolved of this responsibility. HIV prevention must also move beyond measures that focus narrowly on reducing the transmission of HIV between sexual partners. As stressed by UNFPA and other leading agencies, the respective status and roles of men and women in society must be considered in order to understand and act on the constraints imposed by the gender gap on behaviours relevant to HIV.

The dominant mode of transmission of HIV to newborn babies is so-called mother-to-child transmission (also known as vertical or perinatal transmission). While in poorer countries some babies are still being infected through contaminated blood or medical equipment, **virtually all HIV-infected infants have acquired the virus from their HIV-positive mothers during pregnancy, labour or delivery, or acquired it after birth through breastfeeding.** Of the more than 4 million infants and children under 15 years infected with HIV since the beginning of the pandemic, over 90% acquired the virus through this route.

At least 95% of all infants infected through mother-to-child transmission live in a developing country. Most live in sub-Saharan Africa. However, the number of cases in India and South-East Asia appears to be rising rapidly.

While not all children born to HIV-positive mothers become infected, **this risk is, again, significantly greater in poorer countries.** Most studies suggest that in the absence of preventive measures, the probability that an HIV-positive woman's baby will be infected ranges from 25% to 35% in developing countries, where breastfeeding is the norm, and from 15% to 25% in industrialized countries.

There are a number of factors that increase a woman's risk of having an infected baby. They include a depressed immune status, poor nutrition, complications during pregnancy, and protracted labour after the waters break.

A major risk factor for the baby is breastfeeding — a practice that by and large is the norm in developing countries. It is estimated that in populations where breastfeeding is the norm it may account for more than one-third of all infections transmitted from mother to child. **But while breastfeeding can kill by transmitting HIV, bottle-feeding can also be dangerous and increases risks to child health.** In recent years, breastfeeding has been heavily

promoted and encouraged for good reason. It affords vital protection against deadly childhood diseases, particularly diarrhoea and respiratory infections. And breastfeeding is a natural, cost-free method, whereas the cost of infant formula and even the clean water and fuel needed to prepare it are often beyond the means of poor families in developing countries.

Mothers of a newborn who know they have HIV thus face a difficult dilemma in choosing between breastfeeding and bottle-feeding. The context will differ depending on the country and the woman's own socioeconomic status. For example, in Thailand where there is relatively wide access to safe water, HIV-positive mothers are being given free infant formula by the government and provided with information on the risk factors, and are encouraged to opt for this replacement feeding. In countries in sub-Saharan Africa, however, providing infant formula would not be appropriate in many settings because clean water for making up the formula is not available. In many places, realistic and sustainable options may eventually include wet-nursing by relatives who have been tested and are HIV-negative, and the use of home-prepared formula made from animal milks, typically from cows, goats, buffaloes or sheep. The composition of animal milks is different from that of human milk, and they may lack micronutrients, especially irons, so they would need to be modified for infants according to nutritionally approved recipes.

Given the importance of breastfeeding to infant health, but recognizing the part breast milk plays in mother-to-child transmission, UNAIDS, UNICEF and WHO recommend that appropriate alternatives to breastfeeding be made available and affordable for women whom testing has shown to be HIV-positive, while efforts to protect, promote and support breastfeeding by women who are HIV-negative or of unknown HIV status be strengthened.

Anti-HIV drugs to keep babies from getting infected

The policy of UNAIDS and its cosponsors is to encourage HIV-positive mothers to be given as much information as possible on the relative risks of breastfeeding and alternative feeding methods so that they can decide whether to breastfeed or not or whether to shorten the breastfeeding period. Women must decide for themselves how to handle the delicate balance between the risks and advantages of the various approaches – there can be no universally valid recommendation. But only women in possession of all the information are in a position to make fully informed choices; this information includes knowing whether one is infected or not, which requires that voluntary HIV testing and counselling facilities be available.

In 1994, French and American researchers found that a two-month course of the antiviral **drug AZT (zidovudine) administered to HIV-positive women in pregnancy, during labour and delivery, and after birth to their newborns reduced the rate of mother-to-child transmission by two-thirds in the absence of breastfeeding.** This was clearly an important breakthrough, and in many industrialized countries including the United Kingdom and the United States, and in countries such as Brazil, the initial AZT regimen is now routinely offered to HIV-positive pregnant women and their newborns.

However, it soon became clear that this preventive regimen would be difficult if not impossible to apply in many developing country settings. To begin with, AZT is a very expensive drug. **A full course of preventive treatment for a pregnant woman and her newborn costs about US$1000 per pregnancy in the United States.** An equally important problem is that the AZT regimen as initially developed calls for the drug to be given for several months before delivery, and to be administered as an intravenous infusion during delivery. **In many developing countries, where the annual per capita health expenditure may be as little as US$10,** and where women often attend clinics for prenatal care late in pregnancy if at all, AZT is only available to the very wealthy. UNAIDS therefore promoted and supported research to find alternative drug regimens that would better suit the circumstances of women in the developing world.

A trial concluded in Thailand in February 1998 showed that a short regimen of zidovudine pills given during the last weeks of pregnancy cuts the rate of mother-to-child transmission by half, at less than a tenth of the cost of the longer course. Because the women were also given safe alternatives to breastfeeding, overall transmission to the infants in the study population was reduced to 9%, compared with the norm in developing countries

of 25% to 35%. Other research is in progress to develop still shorter regimens, including a regimen which could be used even for women who do not come for care before they enter labour. In addition, researchers are still looking into the question of whether some regimens might be helpful for reducing transmission to infants that are breastfed.

UNAIDS together with WHO and UNICEF, has launched an initiative in 11 pilot countries to reduce HIV transmission from mother to child in low-income countries and increase HIV-positive mothers' chances of having healthy children. The initiative seeks to support approximately 30 000 HIV-positive women. It has six components: early access to adequate antenatal care, voluntary and confidential counseling and HIV testing for women and their partners, antiretrovirals before and after pregnancy and delivery for HIV-positive women and their newborns, improved care during labour and delivery, counselling for HIV-positive women explaining a range of choices for infant feeding, and support for HIV-positive women who choose not to breastfeed.

At the same time, every effort must be made to ensure that women are counselled and supported in refusing unsafe sex during pregnancy — for their own sake, to maximize their chances of staying uninfected, and for the sake of protecting their infants. It is equally important to recognize and promote male responsibility in this respect.

To increase women's control over the situation, it is important for countries to make voluntary HIV testing and counselling more widely available. As preventive interventions become more widespread, HIV-infected women would have to know their HIV status in order to benefit from them. Whether such services are made available in general or within prenatal programmes, they should include confidentiality, referral to psychological support, and care services for HIV-positive women who may face abandonment by their family and community ostracism. Even in the absence of therapeutic interventions, voluntary counselling and testing offers benefits for HIV-positive women, men and their sex partners. It permits them to make informed decisions regarding sexual activity, contraception, termination of pregnancy (where legally available) and methods of infant feeding, and gives them the opportunity of seeking early access to care.

It is not just mother-to-child

- **About 10% of HIV-positive children under age 15 become infected through routes other than mother-to-child transmission.**
- **Some children acquire HIV from blood products containing HIV or from contact with unsterile skin-piercing instruments.**

In Western Europe and the United States, a large number of children with haemophilia, a blood-clotting disorder that affects mainly males, were infected through blood products in the early 1980s. Although medical practices and blood supplies have since been improved in these and many other countries, elsewhere the dangers of transmission through unsafe blood and contaminated injection equipment in hospitals and other medical settings persist. The risk of contracting HIV infection through a blood transfusion is particularly great for children living in countries where the blood supply is not properly screened for HIV.

Adolescents are particularly vulnerable to HIV infection through injecting drug use and, above all, through sex. Issues regarding these children at risk are described in a later section of this report.

Children orphaned by AIDS

No one knows exactly how many children have been orphaned by AIDS worldwide but UNAIDS estimates that, between the beginning of the epidemic and the end of 1997, 8.2 million children had lost their mother to AIDS before they turned 15; more than 90% of them lived in a sub-Saharan African country. At the end of 1997, there were around 6.2 million such orphans under age 15 struggling to survive without their mother, and often without their father too.

While the cumulative figure of 8.2 million orphans is appalling, it reflects only a tiny part of a far larger tragedy. Children whose mother, or both of whose parents, have HIV begin to experience loss and suffering long before their parents' death. In any given country, the number of children with an infected parent is far greater than the number of children who have already lost a parent to AIDS. Children orphaned by AIDS are just the more visible part, the tip of the iceberg, of the larger looming concerns over children who have a parent living with HIV/AIDS.

Most children orphaned by AIDS are concentrated in those countries most severely affected by the epidemic. UNAIDS estimates that by the end of 1997, 1.1 million Ugandan children under the age of 15 had lost at least one parent to AIDS.

According to UNICEF, children orphaned by AIDS in Zimbabwe are the largest and fastest growing category of children in difficult circumstances. UNAIDS estimates that by 1997, approximately 8% of children under 15 had lost their mothers to AIDS.

A uniquely painful experience

Children who lose a parent to AIDS suffer grief and confusion, like any other children who experience the death of a parent. But there are special differences.

For one thing, the psychological impact can be even more intense than for children whose parents die from more sudden causes, such as in armed conflict or as a result of an accident. HIV ultimately makes people ill but it runs an unpredictable course. There are typically months or years of stress, suffering or depression before a parent dies. And in developing countries, where the epidemic is concentrated, effective pain or symptom relief is often unavailable to alleviate a parent's suffering.

The children's distress is often compounded by the prejudice and social exclusion directed at individuals with HIV and their families. This stigma may translate into denial of access to schooling and health care and into a violation of the inheritance rights of orphaned children. In this respect, girls may be at a further disadvantage.

A final cruel difference from other parental diseases is that HIV may well have spread sexually between the father and mother. Thus the child's chances of losing a second parent relatively quickly are far higher than, say, those of a child who has lost a parent to accidental death or to a non-infectious disease.

The uniquely painful features of parental HIV/AIDS are of course of deep concern to adults themselves. For HIV-positive mothers and father, making provision for their families is a main priority when they learn that they are infected. "My biggest fear was what was going to happen to the children", says Major Ruranga Rubamira, a major in the Ugandan army and the founder of the Ugandan National Association of People Living with HIV/AIDS. "I didn't know how long I was going to live and I still felt that within the time left I must try to do something. I tried to start some kind of business for my wife and I tried also to put up a house."

Extended families soak up the pressure — but for how long?

The extended family is the traditional social security system in many countries. In many developing countries, deep-rooted kinship systems have accordingly provided support to children and families affected by AIDS. It is common, for example, for orphaned children to be taken in by aunts and uncles or even grandparents, who may have little income and who may even have been counting on being supported

by the very son or daughter who died of AIDS.

The remarkable generosity of many people in countries most affected by AIDS is also shown by the high incidence of fostering of orphans by unrelated families, often by neighbours. A study in Kagera, Tanzania, indicated that families who had themselves experienced an AIDS death were more likely to take in AIDS orphans from other households. Those households with the most dependents were also the most willing to take on additional orphans.

Financial pressures on those least able to afford them have inevitably increased. "I have 11 orphans living with me", says Leone Navalaka from Uganda. "My elder sister died and left me with her six children. And the other five belong to my daughter who also passed away. Taking care of these children is a real burden, " she says.

Even before the AIDS epidemic, many of these communities were already being pushed to breaking point as a result of labour migration, demographic change and other factors. With the advent of AIDS, the constraints have become even greater. One of the symptoms of this is the increasing number of households now headed by children and young people - households which may previously have been headed by grandparents at the death of the parents. "The death of a grandparent may leave a situation where there is nobody else in the extended family willing to care for the children, giving rise to orphan households headed by older siblings", says Geoff Foster of the Family AIDS Caring Trust in Zimbabwe.

It is not only in developing countries that the extended family system is under strain. "Many European countries, particularly in Central and Eastern Europe, are experiencing problems as family systems come under pressure because of changing social structures and demography", argues Naomi Honigsbaum of the European Forum on HIV/AIDS, Children and Families. The same is increasingly true, for example, in metropolitan areas of the United States, such as New Haven and New York.

A vicious circle of poverty and discrimination

The relation between HIV/AIDS, impoverishment and denial of human rights is apparent in the impact of the epidemic on children who have been orphaned by AIDS.

When an HIV diagnosis in the family becomes known, friends may come to visit less often, and children may be taunted or harassed by schoolmates. In Zimbabwe, focus group discussions with members of AIDS-affected communities indicated that the **social isolation of children orphaned by AIDS was common.** And in the north of Thailand, a 1994 study of 116 households affected by HIV found that stigmatization, due largely to incorrect beliefs about HIV transmission, was widespread in everyday life. It was acknowledged by 20% of such households that other children in the area were forbidden to play with children from HIV-affected families.

Family poverty can follow in the footsteps of stigmatization. The Thai study found that as a result of AIDS many parents had lost jobs and family enterprises had lost customers.

Many extended families that have accepted orphans cannot afford to send all their children to school, and **orphans are often the first to be denied education.** "My foster mother wants to stop me from going to school. She wants me to work as a maid so I can earn money to buy food", says Beatrice, a 16-year-old from Kenya. A study in Zambia indicated that in urban areas, 32% of orphans were not enrolled in school, compared with 25% of non-orphans. In rural areas, 68% of orphans were not enrolled compared with 48% of non-orphans.

For many families, sending their children to school simply becomes an impossible option. "When my father died I was 14 years old", says Maurice Kibuuka, from Uganda. "There were eight of us and my mother was left in care of us. I became the head of the family and I was responsible for looking for money, food, clothing, and even shelter... I had no choice but to drop out of school."

Discrimination in accessing health care is a major form of social exclusion faced by people infected or affected, including orphans. About two-thirds of children born to HIV-positive mothers do not contract the infection and grow up to be as healthy as any other child in the community. However, this fact is often unknown or ignored. Evidence suggests that AIDS orphans may be at greater risk of dying of preventable diseases and infections because of the mistaken belief that when they become ill it must be due to AIDS and therefore

there is no point in seeking medical help.

Children orphaned by AIDS are also at risk of losing their property rights, and rights to inheritance. Moreover, as shown before, the realization of children's rights is inextricably linked with their mothers' human rights — hence laws which disenfranchise widows have a devastating effect on the lives of their children.

The resulting poverty and isolation can create a vicious circle, placing AIDS orphans, and particularly orphaned girls, at greater risk of contracting HIV themselves.

"This lady likes mistreating me because my mother is dead", says one Ugandan girl interviewed by Panos. "She wants me to sleep with men because I stay at her house. She brings these men into her house and introduces me to them. She often tells me to be good to them and says this the only way I can continue to live in her house."

What is being done to help?

The problems faced by HIV-affected families have become a major priority for many national aid programmes, as well as for international organizations such as UNICEF and the Save the Children Fund. There are thousands of small community-based schemes around the world that aim to provide care and support to children orphaned by AIDS. In Uganda, for example, an organization called Uweso provides emergency material support and vocational training for these orphans. In Côte d'Ivoire, the International Catholic Child Bureau is helping to place orphans in foster homes and provides training and assistance. In Kenya and Tanzania, the African Development Foundation has funded farm projects, secondary education and housing for AIDS-affected families.

But **such projects are not being carried out on the scale that is required.** Most orphan programmes can only help fewer than a hundred children at one time. In countries like Thailand, Uganda and Zambia where tens or hundreds of thousands of children are affected, the response desperately needs to be geared up to provide even basic support to those who most need it.

Finance is an important consideration. Many such programmes rely on funding from non-governmental organizations based in economically affluent countries and UN agencies, and are seldom self-sustaining. Investment in AIDS-affected children is necessary for a stable future, both for the children themselves and for their communities. **But in the world's poorest countries, children orphaned by AIDS may be seen as only one of many competing urgent priorities.**

Despite a widespread belief that orphans are well-served by AIDS care organizations, there is a growing realization that such care is inadequate and that **children orphaned by AIDS are a neglected group.**

Reaching children before their parents die

Problems for children affected by HIV are most acute from the time that infection is diagnosed in a parent. If organizations wait until children become orphans, it is almost too late. Before the massacres in Rwanda in 1994, Caritas Rwanda, an NGO, tried to help parents plan for the future of their children. They worked with parents to identify solutions and arrange for children to move in with relatives or foster parents. Caritas also advised parents on legal and property matters.

In 1994, representatives from NGOs throughout southern and East Africa drew up the "Lusaka Declaration on Support to Children and Families affected by AIDS". It urged that wherever possible, efforts should be made to keep children of AIDS-affected families in their communities. These efforts, it argued, should begin before the death of the parent. Home-based care schemes, in which visiting health or community support teams attend AIDS patients at home, should also be involved in helping parents plan ahead for their children.

The declaration also recognized that families affected by HIV/AIDS are vulnerable to exploitation and recommended that NGOs inform people affected by HIV/AIDS of their legal rights, and that governments revise existing laws to further protect these individuals.

Orphanages should only be considered as a last resort in providing care to those orphaned by AIDS, according to experts. Orphanages are far more expensive than community-based approaches and they can be culturally inappropriate if they cut children off from their social origins. The link between generations is very important.

Children in the shadow of HIV risk

In a world with AIDS, there are children who are infected with HIV and those who are affected by the epidemic's intrusion into their families or communities. But the epidemic casts its biggest shadow by far on the hundreds of millions of children who live in risk of HIV infection — either because their fundamental rights, including the right to health care and to HIV information and education, are ignored, or because their personal or societal circumstances make them especially vulnerable.

HIV and child sexual abuse

Sexual abuse during childhood and adolescence, while not a new phenomenon, has recently emerged as a pervasive problem affecting all societies.

Sexual abuse of children takes two main forms — commercial sexual exploitation, which is now known to be a multi-billion dollar world industry; and sexual abuse in the home or community, whether by relatives, "friends" or associates of the child's family, or others with easy access to the child, such as schoolteachers or employers. Whatever its form, such abuse usually leaves serious psychological damage in its wake.

Children in the sex trade

No one knows how many child sex workers there are in the world. Because of the clandestine nature of the trade, precise figures are not known, and there is a chronic lack of accurate research in this area. Figures reported to the first World Congress Against Commercial Sexual Exploitation of Children, which took place in Stockholm in August 1996, suggested that:

- worldwide, more than a million children enter the sex trade every year;
- children are working as prostitutes in Europe;
- there are between 400 000 and 500 000 child prostitutes in India, according to a survey by *India Today* magazine;
- around 25 400 minors are engaged in prostitution in the Dominican Republic, according to a survey there.

What research has been done suggests that such exploitation is growing, and the age of the children involved is falling. Most children in the sex industry are girls aged between 13 and 18, although there are instances of much younger children being sold. Many such children spend most of their lives on the street, often because they are escaping violence or sexual abuse at home. Other children live in brothels, having been drawn into prostitution by procurers. For example, female children are often purchased from their parents or lured to the city with promises of jobs, education or money, only to be sold to a pimp.

Girls are at greater risk than boys because of systematic gender discrimination resulting in lack of access to educational and employment opportunities. Those who have been abused or forced into prostitution are often stigmatized and marginalized, which further undermines their status, and reduces their opportunities for accessing education, formal employment and, in many societies, marriage.

The HIV/AIDS epidemic has made child sexual abuse and child prostitution more dangerous than ever before. **Studies everywhere indicate that rates of HIV infection among child sex workers and street children are often very high.** Surveys of Kenyan girls living on the street indicated that as many as 30% were HIV-positive.

The belief that children are less likely to be infected has raised the demand for younger sex workers in recent years. The vulnerability of children to sexual exploitation, either through sex work or abuse, may well result in their becoming infected with other sexually transmitted diseases such as gonorrhea, syphilis and chancroid. By damaging the surfaces of the reproductive tract, physical trauma and sexually transmitted disease each increase the child's susceptibility to HIV as well as the HIV/STD risk to their clients. The problem is compounded by the lack of health care services meeting the sexual and reproductive health needs of children.

Only recently has a strong activist movement, driven primarily by non-governmental child action groups, brought the commercial sexual exploitation of children to international attention. The 1996 Stockholm World Congress Against Commercial Sexual Exploitation of Children marked the first concerted international attempt to tackle the problem.

Steps are being taken at national levels to target commercial sexual exploitation not only at home but also abroad. New extra-territorial laws in some countries, including Australia, Germany, Japan, the Netherlands, Sweden, the United States and the United Kingdom, now permit countries to prosecute nationals guilty of sex offences against children overseas. The World Trade Organization recently established a new Task Force to target tour operators and hotels that knowingly cater to sex tourists. Enforcing these new sanctions and laws will require international cooperation from a variety of actors including government entities such as the police and judicial systems, as well as NGOs.

However, several experts at the Stockholm conference also stressed that, while sex tourism is a major problem and was well documented, "commercial sexual exploitation of children is predominantly a local issue, with both clients and agents coming from the local community."

Whether the exploiters are local or foreign, punishment is necessary – but not sufficient. There is an urgent need to campaign for a change in the sexual attitudes and behaviour of adults.

Abuse closer to home

Awareness of the scale of child abuse which takes place in or near the home is growing all over the world. **An unknown number of children in developing and industrialized countries alike – above all, girls – are at risk of sexual abuse by relatives, other members of the child's community, or strangers.** Sexual abuse in the home is also a significant factor in pushing children to leave home, thereby perpetuating a cycle of vulnerability.

A study in Zimbabwe found that most cases of child sexual abuse probably go unreported. Some are detected when the child develops a sexually transmitted disease – proof that abuse took the form of actual sexual intercourse. For example, during a one-year period 907 children under 12 were treated for a sexually transmitted disease at the Genito-Urinary Centre in Harare. Most of the offenders responsible for passing these infections to the child were either neighbours or close relatives.

While in some cases sex takes the form of actual rape, in many instances it ranges from enticement to coercion. The growing phenomenon of "sugar daddies" illustrates the grey area surrounding the exchange of sex for goods and cash. These are older men who seek out young girls (often because they believe they are at less HIV risk from children) and entice them into sex with offers of meals, clothes, luxuries and cash, including money for school fees. The age disparity between the girls and their sugar daddies, who are older and sexually experienced men, creates a particularly great HIV risk for the children.

Girls employed as domestics are vulnerable to another type of sexual abuser – the male head of household, or his sons. Occupational exposure to sexual coercion is, of course, not restricted to household employees, but live-in domestics run a particularly great risk because they are accessible around the clock.

Sanctions and laws are only a first step in stopping child sexual abuse. In the shorter term they may raise awareness of this terrible affliction. Increased attention will in turn help change the culture of silence surrounding abuse and make societies more sensitive to abused and exploited children. But **while laws forbidding sexual exploitation of children exist in nearly every nation on earth, they are notoriously hard to enforce.** Even when cases are brought to court, abused children often make reluctant witnesses.

HIV and consensual sex with peers

Children are at risk of HIV infection not only when they are sexually exploited or abused, but also when they engage in consenting sex. In many countries, many children have their first sexual relationships when they are under the age of 18. Adolescents also engage in unprotected sex with sex workers.

A major source of vulnerability as far as children is concerned is their lack of knowledge about pregnancy and about STD/HIV transmission, and their lack of skills in recognizing situations that may turn risky, such as alcohol consumption, standing up to pressure for sex (and drugs), and negotiating condom use and other forms of safer sex.

Love and trust also make children vulnerable. The rate of partner turnover is often greater during adolescence and the early twenties than in later years. This applies not only to casual partners but to regular relationships which occur one after the other. Although these relationships may not last long, in the minds of young people they are often considered to be "safe" in terms of HIV transmission because they are regular and monogamous. Thus unprotected sex (intercourse without a condom) occurs with a series of partners, but the risk is masked by the apparent monogamy and trust involved in each such relationship. Yet the unwanted pregnancies and high rates of STD infection among young people show that the unintended consequences can be severe and – in a world with AIDS – lethal.

HIV and drug use

In a world with AIDS, the injection of illicit drugs, always a risky behaviour, carries an additional danger – HIV infection. When people of whatever age share needles and syringes to inject drugs, microtransfusions of blood occur – and these are relatively efficient for transmitting HIV and other microbes. Drug injecting is thus a phenomenon that policy-makers, educators and HIV prevention workers concerned with child protection cannot afford to neglect.

Drugs do not have to be injected to carry an HIV risk. Alcohol, smoking drugs or glue-sniffing are apt to make people forgetful or careless about safe sex, and reduce the likelihood of condom use. While some adolescents inject drugs, many more engage in non-injecting use of substances that can increase their vulnerability to HIV infection.

Many factors, both individual and social, influence drug use. However, the association between drug use and HIV infection appears to be particularly dangerous for young people of low socioeconomic status, including girls involved in commercial sex and girls and boys living on the street. The environmental factors involved include poverty, discrimination and lack of access to education and health services. "When surveyed, young people in developed or developing countries often indicate that boredom, curiosity and wanting to feel good are perceived as the main reasons for use. Other functions served by substance abuse are to relieve hunger, to adopt a rebellious stance, to acquire courage to beg or be involved in commercial sex, to keep awake or get to sleep, and to dream", says a WHO report.

Children in difficult circumstances are more apt to maintain and escalate substance abuse. For girls living or working on the street, the risks are particularly great, since they often have to cope with violence, HIV and other STDs, unplanned pregnancies and unsafe abortions. If they carry their pregnancies to term, they are often left to their own devices to support themselves and provide for their children.

Refugee and displaced children

As civil conflict, political persecution, and natural disasters continue to plague many countries, millions of people are forced to live outside their countries of origin. The majority of the world's refugees are children and women. In conditions ranging from large rural encampments with very limited infrastructure to intensely crowded urban shanty towns, young refugees are particularly vulnerable to nonconsensual sex. Even if there is consent the availability of condoms is often quite limited.

The same is also true for many displaced children who remain within the borders of their country, but not in their homes. They survive in very unstable, often threatening environments where risks are high and rights are rarely protected. To make matters worse, refugee and displaced children are known to be targeted for rape and sexual abuse by adult tormentors from within their own communities, and from external exploiters taking advantage of these environments in which children's rights are often violated.

Children in detention and HIV

Similar to the saga of their adult counterparts in prisons, children who are in detention or remand centres are often exposed to violence, abuse, and unwanted sex. Drug abuse is also a compounding factor for HIV transmission, along with the prohibition of condoms; so are body piercing and unsanitary/unsafe tattooing. Young people in reformatories and other such facilities often have few, if any, options for preventing HIV and other sexually transmitted diseases. Without radical reform in juvenile justice and social welfare institutions, these children will remain with their rights violated – and their risks increased.

The window of hope

Strengthening development to strengthen coping

The socioeconomic costs of AIDS are affecting the ability of developing economies to sustain their development gains – and this has enormous repercussions on children.

Other diseases have profound effects on the survival and well-being of children. But a distinctive feature of AIDS is that it affects a tremendous number of young people who are also parents – adults in their most sexually active and most productive years. In the worst-hit areas, resources become increasingly stretched as AIDS mortality increases the burden of income-generation and child care and places it on the shoulders of fewer and less able-bodied adults. AIDS stigma can affect the willingness of communities and extended families to care for and support those who are most affected. Society's coping capacity is further adversely affected by the fact that the effects of HIV manifest themselves over periods of years and that AIDS deaths tend to be clustered within families, with very often more than one parent and more than one child in a particular household becoming infected.

However, it is still difficult to make reliable estimates of the impact of AIDS on economies, because AIDS impacts differently on different socioeconomic systems and even on different sectors within the same economy. For example, the loss of a single income earner in a family may have a different impact in rural and urban areas according to the type of family structures. In urban areas, the loss of a single wage earner can affect a large group of extended family members. Labour-intensive farming systems are also more vulnerable to the loss of able-bodied adults than others.

Improving understanding of these issues is not just of theoretical interest. It is a practical necessity. Unless knowledge of the socio-economic effects of AIDS improves and is reflected in planning and policy development, strained economies around the world will tend to consider HIV/AIDS as just one more competing need to respond to, and may find it increasingly difficult to allocate resources for prevention programmes.

Just as importantly, a deeper understanding of these issues strengthens the argument for building up development as a way of helping families and communities withstand the impact of AIDS.

A shift of emphasis is needed away from relief towards longer-term intersectoral approaches to meeting the needs of AIDS-affected children. A relief approach of providing directly for children's needs is generally not sustainable where the number of affected children is large. Wherever possible, resources should be directed to enabling families and communities to establish and maintain a sufficient economic base to provide for children's needs. Children themselves need to have their educational and employment opportunities bolstered if they are to break out of the pernicious cycle of poverty and AIDS.

While children are an increasing part of the AIDS problem, they are also a critical part of the solution. "We have a window of hope between the ages of 5 and 18 years", says Dr Sam Okware, Uganda's Commissioner for Health. "If that group can be educated, if their behaviour change can be modulated to ensure they do not have risk behaviour, I think we have a future."

Education and empowerment combined with the promotion of children's rights are believed by leading agencies such as UNICEF and UNESCO to be key to HIV/AIDS prevention. However, much of this needs to be directed not only to the youngsters themselves but to their families – the most important social support for children. Reducing children's vulnerability to HIV means improving the economic situation of their families. Development agencies such as UNDP have repeatedly emphasized the need to create micro-funds, micro-credit schemes, rural employment schemes and other instruments that can raise living standards and ensure sustainable livelihoods for children and their families. Reducing children's vulnerability also means keeping the various communities' HIV risks constantly in mind when, for example, targeting development assistance. In northern Thailand, for example, the Daughters of Education project

provides funding for girls who might otherwise be sold into the sex trade to remain in school and develop better employment prospects.

In other words, development not only strengthens society's ability to cope with the impact of HIV/AIDS. Development strengthens society's ability to withstand HIV transmission.

School education on HIV/AIDS

Provision of AIDS education and education concerning sexual health is an issue fraught with controversy the world over. The objection to providing education on sexual health is most commonly stated as a fear that such education will encourage early sex. UNAIDS recently commissioned an update of an earlier WHO review of studies – mostly in the USA and Europe – on the effect of sexual health education. The aim was to assess the impact of sexual health education on the behaviour of students in terms of rates of teenage pregnancy, abortion, birth, sexually transmitted diseases, and self-reported sexual activity.

The review showed that responsible and safe behaviour can be learned. Education on sexuality and/or HIV does not encourage increased sexual activity. Quality programmes in fact help delay first intercourse, and protect sexually active young people from sexually transmitted disease, including HIV, and from pregnancy. Among other things, quality programmes feature a clear explanation of the risks of unprotected sex and methods – including abstinence – for avoiding them, and help young people practise communication and negotiation skills. Experience with successful programmes shows that peer-led education has greater credibility and acceptance. The involvement of children themselves in developing messages and approaches is a critical element.

There are questions as to how early the provision of AIDS and sexual health education should begin. Issues such as the increasing evidence of sexual abuse in particular have persuaded some teachers and AIDS workers that some form of "life-skills" education is necessary in primary school. The UNAIDS-commissioned review also found that sexual health education is best started before the onset of sexual activity. Such early education is believed to be particularly important by AIDS workers in developing countries, where secondary school enrollment is much lower than primary, especially for girls. In many countries, the majority of children have left school by the age of 15. Many of these children are poor, are unable to read and write and are among the most vulnerable to HIV infection. Reaching them quickly enough is arguably the highest AIDS prevention priority.

According to one AIDS worker in Zimbabwe, "we start in schools from about 8 years or 9 years old. It sounds too early but in our country there is a lot of child sex abuse, even rape, which makes it very important for us to introduce the subject during that period or even earlier. We want to have this child know that this is my body, nobody has a right to my body, if anybody fidgets around with my body I should report it to my mum and dad so that I am protected. We start talking about the information that helps this child to know who they are and how they can best protect themselves."

In recognizing the important role children can play in protecting themselves and their communities from HIV, it is equally important to recognize the power that many people and institutional structures may exercise in preventing children from accessing education, information and life-skills training. These "gate-keepers" may be parents, teachers, educators, community and religious leaders, media professionals, policy makers, and government officials. Experience shows, however, that when parents are given the facts, they generally agree on the need for AIDS education. There is an urgent need to bring these gate-keepers on board and gain their cooperation in promoting early life-skills education and prevention for children. This implies the need to provide AIDS and sexual health education also to adults.

Reaching children outside the school setting

Although some of the most intense arguments around AIDS education have centred on sexual health education in the school setting, organizations such as UNICEF and WHO argue that education also needs to be targeted as a high priority for those children who are not in school.

In some countries, up to 80% of children do not continue beyond primary level. It is these groups who are often at higher risk of HIV infection than those who stay in school. Among these children are those living in rural

areas, in urban slums, those employed in factories, refugees, migrants and those who are sexually exploited.

Street children are among those at greatest risk. Many millions of children and adolescents in the world are working or living on the street, often in violent and dangerous situations. In Brazil alone, there are an estimated 7 million children and adolescents from very poor families living and working on the streets. These groups are some of the most vulnerable to HIV infection and to other dangers. For many, sex may be a means of securing money, food, shelter, protection, comfort or affection.

Injecting drug use and HIV prevention

As with the prevention of sexual transmission, HIV prevention related to drug use must encompass far more than the simple provision of information. There must be an emphasis on the acquisition of skills for negotiation, building self-confidence, making the right decisions, resisting peer pressure, and gaining access to prevention tools and drug treatment. The disempowering context within which these children live must be recognized and remedied – for example, the interface between drug use – where stigma is particularly strong vis-à-vis females – and the commercial sexual exploitation of girls.

A key need is to integrate sexual health education and drug prevention education, not conduct them separately, because they are both inextricably intertwined in HIV transmission.

Measures must be designed and carried out in a way that helps build a supportive environment for these children.

Information per se is not enough. HIV prevention means tackling vulnerability at its roots. It means helping the children acquire the skills they need to negotiate safer sex, resist peer pressure for sex and drug use, and establish personal support networks. It also means providing literacy education, training in employment skills, and welfare assistance as necessary. Counselling is important because it helps children mature and make sound decisions. In short, preventing the HIV risk associated with drug use calls for programmes targeted at the drug users themselves, their sex partners and family members, health care workers and the general community. It also requires advocacy to raise the consciousness of adults not to lure children into drug use.

Involving children

If children really do offer a "window of hope" for influencing the future course of the AIDS epidemic, understanding their needs and perceptions will be critical.

At an international conference on AIDS in Marrakech in 1995, a "delegation" of young Africans from 11 countries, some as young as 14, issued a declaration of their needs and priorities. "We strongly believe that our energy, idealism and commitment can be used to stop the further spread of the AIDS epidemic that is devastating the social and economic fabric of our countries", they declared.

At the same time, it must be recognized that children are not alone in this world. Parents, school teachers, religious and community leaders must also be involved in developing programmes for children if these programmes are to be accepted by the community and help build a safe and supportive environment. Securing adults' involvement requires ensuring that they hear the concerns and aspirations of children. Creative ways can be found of "amplifying" the voice of children. In Thailand, for example, a Children's Forum has been created in parliament, while a "media page" in newspapers and magazines captures children's voice and channels their experience to the adult world.

Children and children's organizations must be recognized for their potential to contribute to families, communities and society. To expand the response to AIDS in countries calls for expanding partnerships with groups representing children – and with children themselves.

AIDS is the most publicized disease in the world, but its impact on children has received an inadequate response. Adults can and must do their part to ease the suffering of children infected with HIV, help children in AIDS-affected homes and communities, and enable all children living in the shadow of HIV risk to grow up uninfected. But it may be that the epidemic's future course will be shaped by the actions of those it is increasingly affecting: the children who live in a world with AIDS.