

Orphans & Vulnerable Children *Technical Consultation*



Meeting Report

November 3-5, 2003
Washington, DC



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Cover photo by Giacomo Pirozzi, courtesy of UNICEF (HQ98-0912). In 1998 in Zambia, an older man sits on a mat with his grandson in a suburb of the eastern town of Chipata. Orphaned by AIDS, the boy is now cared for by his grandfather.

April 2004

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ACRONYMNS & ABBREVIATIONS

AED	Academy for Educational Development
AIDS	Acquired Immune Deficiency Syndrome
ART	antiretroviral therapy
ARV	antiretroviral
CBO	community-based organization
DHS	Demographic and Health Survey
FBO	faith-based organization
FHI	Family Health International
HIV	Human Immunodeficiency Virus
IMCI	Integrated Management of Childhood Illness
KHANA	Khmer HIV/AIDS NGO Alliance
NGO	nongovernmental organization
OVC	orphans and vulnerable children
PCP	pneumocystis carinii pneumonia
PMTCT	prevention of mother-to-child transmission of HIV
PWDS	Palmyrah Workers Development Society
SARA	Support for Analysis and Research in Africa
STEPS	Scaling-Up HIV/AIDS Interventions through Expanded Partnerships
UNAIDS	Joint United Nations Program on HIV/AIDS
UNGASS	United Nations General Assembly Special Session on HIV/AIDS
UNICEF	United Nations Children's Fund
USAID	United States Agency for International Development
WCRP	World Conference of Religions for Peace

EXECUTIVE SUMMARY

In May 2003, President Bush signed legislation that will provide unprecedented resources to fight the AIDS epidemic in Africa and around the world. The President's Emergency Plan for AIDS Relief allocates \$15 billion to prevent and treat HIV/AIDS, tuberculosis, and malaria internationally over the next five years. This commitment nearly triples the U.S. investment in international AIDS assistance and will designate funds specifically for children and families deeply affected by HIV and AIDS.

USAID convened this technical consultation to determine a course for an increased response to children orphaned and made vulnerable by HIV and AIDS. The specific objectives were to:

- ⌘ Review the most current research on the impact of HIV/AIDS on children
- ⌘ Share promising models, programs, and approaches to support affected children and their families
- ⌘ Consider lessons from research and experience to formulate recommendations for an expanded response to the epidemic's impact on children and their families

There is global agreement that the foundation of an effective response is to help families and communities continue to care for vulnerable children and adolescents within their communities. The five strategies outlined in the joint UNAIDS/UNICEF/USAID publication *Children on the Brink 2002* (see Annex 3) call for strengthening the capacities of families, communities, and young people through supportive policies, services, and environments. They are supported by 12 human-rights-based principles to guide programmatic responses. Endorsed at the United Nations' General Assembly Special Session on HIV/AIDS (UNGASS) in June 2001 and again at the Special Session on Children in May 2002, those strategies and principles have unified the approaches of international, national, and local groups.

In the month prior to this consultation, organizations participating in the Geneva Partners Forum expanded upon this earlier progress to

develop a *Strategic Framework for the Protection, Care, and Support of Orphans and Vulnerable Children Living in a World with HIV/AIDS*. The Strategic Framework offers operational guidance for senior leaders and decision makers in a position to design policies and programs, allocate resources, and expand the coverage of support for children affected by HIV and AIDS.

Despite discourse and consensus at the highest levels and a proliferation of community- and faith-based programs on the ground, the response to date has been inadequate. Too few vulnerable children and families are receiving the support they need. Of the 40 sub-Saharan countries with generalized epidemics, only six have a national policy on orphans and vulnerable children. Less than half have yet to conduct national situation analyses, the first step in a national response. It is estimated that only five percent of orphans and vulnerable children (OVC) are receiving assistance.

With general consensus on *what* to do, a Strategic Framework which proposes *how* to achieve the UNGASS goals, and the promise of new resources, this Consultation considered the challenges and actions required to accelerate and expand the response for children affected by HIV/AIDS. Over the course of three days, some 400 participants—including representatives of the United States and African governments, United Nations' agencies, nongovernmental organizations (NGOs), faith-based organizations (FBOs), academic institutions, media companies, private corporations, and funding agencies—considered lessons from research and experience to determine how best to provide material and technical support to meet the immediate and future needs of affected children, their families, and communities.

On Day 1, a series of plenary presentations of seminal, cutting-edge information captured the magnitude of the impact of HIV/AIDS on children, and the urgency with which we must respond. A recent UNICEF analysis of household data now published in *Africa's Orphaned Generations* offered evidence of the scale and severity of the epidemic's impact on families. A review of state-of-the-art research prepared as a discussion paper for this consultation exposed specific ways in

which children's survival, health, nutrition, education, and emotional well-being are impacted by HIV/AIDS and highlighted gaps in understanding which research is yet to fill.

Speakers shared models of responses at the global, regional, national, and local levels. Keynote speaker Ambassador Randall Tobias outlined the goals of the President's Emergency Plan for AIDS Relief, not only in the 14 focus countries, but globally. Guided by the Strategic Framework, USAID and UNICEF will focus on accelerating national responses to support the capacities of families and communities. Representatives of community-based organizations (CBOs) in Cambodia, India, Zambia, and Zimbabwe offered lessons to strengthen the capacities of families and communities. UNICEF and the World Conference of Religions for Peace presented preliminary results of a study documenting the pervasive and growing response of FBOs to support orphans and vulnerable children. Finally, Graça Machel reminded us of our responsibilities and potential as individuals: HIV/AIDS must be personal to all of us.

On Days 2 and 3, participants met in technical working groups to consider the practical steps required to meet the specific needs of children orphaned and affected by HIV/AIDS (including their health, nutritional, educational, emotional, economic, and food security needs). The working groups were charged with the task of identifying key challenges, research priorities, and actions needed to move forward. Panel discussions were also held to explore ways to improve monitoring and evaluation, involve children in research and information gathering, and foster positive partnerships with the media.

A wealth of lessons and ideas were shared over the course of three days. Drawing from the proceedings, the following messages gathered strength over the course of the three days. They are posed as key actions to overcome key challenges and accelerate our response to the crisis.

⌘ It cannot be business as usual. AIDS poses an unprecedented challenge for children. There is compelling evidence of the scale, duration, and urgency of this crisis. AIDS is hindering millions of children's chances of survival, health, nutrition, education, and emotional well-being. Even

where HIV prevalence has stabilized or declined, the number of children who lose one or both parents to AIDS will continue to grow or at least remain high for several years. Participants urged flexible funding requirements, speedy allocation of resources, and penetration of resources all the way to the grassroots level—to the millions of children and families who need it most. While meeting emergency needs, donors must also adopt a long-term relief perspective.

⌘ Don't build new structures—strengthen existing ones. Families and communities are at the forefront of the response and should not be replaced by institutions or external programs. CBOs have mobilized responses to support families but find themselves constrained by human resource limitations (lack of experienced staff, high volunteer turnover, and inadequate involvement of young people), financial limitations (mobilizing resources, short donor timeframes, and lack of sustainability), and stigma and discrimination against orphans and people living with HIV/AIDS. Similarly, responses by FBOs have shown impressive reach, influence, organizational capacity and community participation, but, most are managing with little external financial or technical support and generally without training in OVC program delivery, HIV prevention, or organizational development. Rather than create new structures or processes, there is much room for strengthening, scaling-up, and sustaining the effectiveness of CBO and FBO responses.

⌘ Capitalize on the many existing development instruments to benefit children affected by HIV/AIDS. International commitments to the Millennium Development Goals, the UNGASS goals, the Global Fund to Fight HIV/AIDS, Tuberculosis, and Malaria, Education for All, and the Convention on the Rights of the Child all serve the best interests of children. Children will also benefit directly from HIV/AIDS initiatives like prevention of mother-to-child transmission of HIV, voluntary counseling and testing, and efforts to expand access to antiretroviral treatment, as well as child survival initiatives, including Integrated Management of Childhood Illnesses and the Expanded Program on Immunization.

- ⌘ Create synergy with efforts to eradicate poverty and protect the economic viability and food security of affected families.** HIV/AIDS is exacerbating destitution by reducing household incomes and assets while increasing expenditures on health care, funerals, and memorials. CBOs need technical and material assistance to boost income generation, rural livelihoods, microcredit schemes, vocational training, and agricultural development.
- ⌘ Take care of the caregivers.** Research consistently shows that women bear the brunt of caregiving responsibilities for orphans and vulnerable children. This is despite the fact that women have less access to employment and income, education, assets, land, or credit. The epidemic highlights persistent and unacceptable gender discrepancies that only exacerbate the situation for children. Efforts must be made to boost the capacity of caregivers, particularly women and the elderly, by promoting their social and economic development and sexual and reproductive rights. Calls were also made to foster a collective sense of responsibility for children, especially by including men in caregiving.
- ⌘ Invest in young people.** Young participants called for a more meaningful role in program responses; they can be much more than beneficiaries. Young people are already part of the solution, helping their families and caring for ill parents and younger siblings. Most orphans in affected countries are adolescents. They need skills, information, training, and opportunities—particularly in sectors like education, health, and agriculture that are suffering terrible human resource losses from the epidemic.
- ⌘ Create a multisectoral and integrated response to address the multifaceted needs of children and their families.** Healthy child development spans the physical, emotional, and social domains—all of which are equally threatened by HIV and AIDS. Participants consistently called for comprehensive and coordinated efforts involving multiple sectors including health, education, labor, finance, agriculture, planning. This requires stronger and expanded partnerships at all levels.
- ⌘ Acknowledge the different needs and responses required in different contexts and do not apply a one-size-fits-all approach.** An understanding of the local context must be reflected in our program responses, research instruments, and monitoring tools.
- ⌘ Understand better various evolving topics.** We have identified huge gaps in research and must support and stimulate a growing knowledge base. At the same time, much information and experience has been shared at this consultation. We must continue to share those lessons, especially about what is working. Let us continue to build evidence of risk, resilience, and results.

PLENARY SESSIONS

AN OVERVIEW OF THE CRISIS

On Day 1 of the Consultation, a series of speakers presented the most current information available on the impact of HIV and AIDS on children and their families. Sharing state-of-the-art, largely unpublished evidence of the scale, duration, and severity of the crisis, speakers underscored the need for both immediate and sustained action.

The Scale

The profound and pervasive impact of the AIDS epidemic is most evident in sub-Saharan Africa. Over two-thirds of the 42 million people currently living with HIV/AIDS are in sub-Saharan Africa. The proportion is higher among children: at the end of 2002, nearly 90 percent of the 3.1 million children (under 15 years of age) living with HIV/AIDS and 90 percent of new infections in this age-group were in sub-Saharan Africa. The average life expectancy in sub-Saharan Africa is now 47 years and is as low as 37 years in Botswana (a level not seen in that country since before 1950), although life spans are continuing to rise in countries with low prevalence like Mali and Senegal. Highly affected countries have also seen steep increases in under-five mortality since the mid-1980s. Increases are particularly high in Botswana and Zimbabwe, where child mortality was lower than most African countries prior to the AIDS epidemic. Worldwide, 13.4 million children have lost one or both parents to AIDS. Eleven million of those children are in sub-Saharan Africa, a region in which 12 percent of children under 15 have been orphaned by AIDS.¹

The Duration

Almost 40 million people living with HIV/AIDS have no access to treatment. At this rate, the number of orphans will increase and remain high for decades to come. The largest increases will be in countries with the highest HIV rates, such as Botswana, Lesotho, and Swaziland, where the national adult HIV prevalence has exceeded 30 percent.

“As staggering as the numbers already are, the orphan crisis in sub-Saharan Africa is only starting to unfold. By 2010, HIV/AIDS will have robbed an estimated 25 million children under the age of 15 of one or both parents.”

— Neff Walker, Senior Epidemiologist, UNICEF

Even where HIV prevalence has stabilized or declined, the number of orphans will continue to grow or at least remain high for several years, reflecting the long lag between HIV infection and death. In Uganda, for example, HIV prevalence peaked in the late 1980s at around 14 percent. It then declined dramatically to an estimated 5 percent in 2001. The number of orphans, however, continued to increase for 10 years after the country’s epidemic had peaked and is only now beginning to decline, from 14.6 percent in 2001 to a projected 9.6 percent in 2010. Due to heterosexual transmission of HIV, the number of double orphans is increasing, and nearly 8 million double orphans are expected by 2010. By this year, orphans will account for 15 to 25 percent of all children in 12 countries in sub-Saharan Africa.

Evidence of Risk and Resilience

A growing body of empirical, action, and operations research is deepening understanding of precisely how children and their families are affected, and the ways in which they are coping. Some of the most recent sources include:

- A recent analysis of household data from Demographic and Health Surveys (DHS) and Multiple Indicator Cluster Surveys (MICS), recently published by UNICEF as *Africa’s Orphaned Generations*
- A review of the state-of-the-science research prepared as a discussion paper for this OVC Technical Consultation, synthesized findings from approximately 50 recent studies assessing disadvantage among orphans and other children affected by AIDS, titled *Understanding the Needs of Orphans and Other Children Affected by HIV and AIDS in Africa: The State of the Science, Working Draft*

¹ At the time of the presentation

- A series of Presidential Initiative papers, including DHS analyses in the 14 Presidential Initiative focus countries

Through a mix of methods and disciplines, new analyses are contributing evidence related to:

Families

- The impact of AIDS on the size, composition, economic viability, and dissolution of households in different contexts
- The increasing role of women and the elderly in heading affected households and caring for orphaned and vulnerable children

Orphans

- The influence of parental illness and death on children's development from birth through adolescence, including their survival, health, nutrition, emotional well-being, and education
- The differential impact of losing a mother, a father, or both parents
- The nature of vulnerability before, during and after a parents' death, at different stages of childhood

Other Children Made Vulnerable by HIV and AIDS

- The impact on children who experience an adult (not a parent) death in their household
- The experience of children who are fostered though their parents are alive, often due to economic hardship, and children in households that have absorbed orphans and foster children
- Causal pathways of vulnerability, including economic, emotional, and social pathways through which AIDS affect families and children

Many gaps in understanding remain. The review of state-of-the-art research highlights the need for empirical and operational research studies to:

- Identify and enumerate the “other children” made vulnerable by HIV and AIDS and how their needs may differ from orphans and children in general
- Reach the most vulnerable by:
 - sampling from broader populations, including institutionalized, street, and migrant youth, and adolescent-headed households (among whom orphans and affected children are disproportionately represented)
 - following participants who migrate out of original study areas (because affected children are more likely to migrate)
 - tracking members of dissolved or relocated households (because affected households are more likely to dissolve)
- Understand the unique needs of affected adolescents—who have largely been overlooked in research, especially in large household surveys that have limited questions about orphanhood to children under 15 years old (for this reason, future efforts to enumerate orphans will be expanded to include children under 18 years old)
- Understand the psychosocial impact of parental illness and death and means to address children's emotional well-being
- Adopt a more flexible and fluid view of households and families, not only as “those who eat from the same pot” or those who live together
- Measure impact and needs at the community level and develop gauges of community capacity and empowerment
- Understand the interplay between AIDS, poverty, and orphanhood and reconcile conflicting findings in different studies
- Document and learn from efforts to strengthen the economic viability of affected families

(Details are available in the draft state-of-the-science review disseminated to all participants and available online at <http://sara.aed.org/ovc-tc> or by email to sara@aed.org.)

Keynote Address

Ambassador Randall Tobias, United States Government Global AIDS Coordinator

To grasp the magnitude of the AIDS crisis, I ask people to imagine 20 Boeing jets crashing every day—this is how many people die each day from AIDS. The AIDS crisis is at the top of the President's agenda and is a priority of United States foreign policy. President Bush has pledged \$15 billion to fight AIDS abroad over the next five years, including nearly \$10 billion in new money. In May, this commitment was signed into law [H.R. 1298, the United States Leadership Against HIV/AIDS, Tuberculosis, and Malaria Act of 2003; 27 May 2003].

My appointment was confirmed by the Senate on October 6, 2003. I have been charged to coordinate all AIDS activities for the President, not only in the 14 focus countries or Africa, but, globally. Reporting directly to the Secretary of State, my key role is to break down barriers between government agencies, pull all resources together, and develop one unified government response.

My work is guided by three goals of the President's Emergency Plan for AIDS Relief by 2008:

- Treat 2 million HIV-infected people with antiretroviral treatment
- Prevent 7 million new infections (60% of the projected new infections in the target countries)
- Care for 10 million HIV-infected individuals—this includes a range of care, including palliative care and care for orphans and children made vulnerable by AIDS.

Of the \$15 billion pledged, \$5 billion are intended as bilateral, \$1 billion will go toward the Global Fund to fight HIV/AIDS, Tuberculosis and Malaria, and \$9 billion are designated for the 14 focus countries in sub-Saharan Africa and the Caribbean (Botswana, Cote d'Ivoire, Ethiopia, Guyana, Haiti, Kenya, Mozambique, Namibia, Nigeria, Rwanda, South Africa, Tanzania, Uganda and Zambia). There is currently a debate over how best to disperse the funds: whether to contribute \$3 billion every 5 years or escalate from \$2 billion in FY 2004 to \$5 billion in the final year.

I am pleased to have a strong team, including an ambassador and a doctor as my deputies. John Lange is former ambassador to Botswana (1999-2002), and Dr. Joseph O'Neill is our Chief Medical Officer and Director of the Office of National AIDS Policy.

The plan will address problems to build capacity and infrastructure (for example, delivery systems) and scale up responses. Goals for each country will be developed by determining the needs and responses in the field. It will be a plan that "shakes hands" with policies of the home countries, reflecting local realities. It will identify programs that can be carried out and scaled up by nongovernmental organizations. Overall, it is a global response, with a focus on specific countries and will work in partnership with the Global Fund, the World Health Organization, the World Bank, and UNAIDS.

That children have been affected by the pandemic is recognized by the president and Congress. The most important providers of care are the community themselves. We must get everyone moving in the right direction, harnessing creativity and looking to orphan and vulnerable children experts to offer their expertise.

Perhaps most importantly, there must be better links between research and action. So that the knowledge base can better guide the design and direction of programs, the allocation of resources, and increase the quality and effectiveness of support for affected children, we must encourage:

- More research of high quality with practical relevance
- Meaningful community involvement and ownership of information gathering (e.g., closer collaboration between researchers and CBOs to ensure relevance and application of findings)
- Wider distribution of information, distilling findings in ways that are useful to communities and practitioners
- Promotion of ethics and children's best interests as young people are increasingly involved in research
- More widespread and systematic monitoring and evaluation of efforts at the global, national, and program levels

GLOBAL, NATIONAL, REGIONAL, AND COMMUNITY RESPONSES

The Consultation showcased models of responses from those of the President's Emergency Plan for AIDS Relief, USAID, international agencies, NGOs, and FBOs working directly with affected families and communities.

Global and National Strategies and Regional Responses

Recent years have seen growing consensus and commitment at the international level to the needs of orphans and vulnerable children. In the United Nations General Assembly Special Session devoted to HIV/AIDS (UNGASS) in June 2001, heads of state and government representatives endorsed three goals directly related to children orphaned and made vulnerable by HIV/AIDS. They are articulated in the *Declaration of Commitment on HIV/AIDS*:

- By 2003 develop and by 2005 implement national policies and strategies to:
 - build and strengthen governmental, family, and community capacities to provide a supportive environment for orphans and children infected and affected

by HIV/AIDS by providing appropriate counseling and psychosocial support

- ensure enrolment of orphans and vulnerable children in school and ensure access to shelter, good nutrition, and health and social services on an equal basis with other children
- protect orphans and vulnerable children from all forms of abuse, violence, exploitation, discrimination, trafficking, and loss of inheritance
- Ensure nondiscrimination and full and equal enjoyment of all human rights by promoting an active and visible policy of destigmatization of children orphaned and made vulnerable by HIV/AIDS
- Urge the international community, particularly donor countries, civil society, and the private sector to complement effectively national programs to support programs for children orphaned or made vulnerable by HIV/AIDS in affected regions and in countries at high risk and to direct special assistance to sub-Saharan Africa

To help meet these UNGASS goals, the joint UNICEF/UNAIDS/USAID publication of *Children on the Brink 2002* outlined strategies and programming principles specifically for children affected by HIV and AIDS (see Annex 3). More recently, a range of organizations participating in the Geneva Partners Forum expanded upon this earlier progress to develop a *Strategic Framework for the Protection, Care, and Support of Orphans and Vulnerable Children Living in a World with HIV/AIDS*. The Framework is intended as guidance for senior leaders and decisions makers who are in a position to design policies and programs, allocate resources, and expand the coverage of support for children affected by HIV and AIDS. The Strategic Framework offers operational guidance in the form of the following five strategies:

1. **Strengthen the capacity of families to protect and care for orphans and vulnerable children by:**
 - Improving household economic capacities
 - Providing psychosocial support and counseling for affected children and caregivers
 - Strengthening child care capacities, including early childhood development
 - Prolonging the lives of parents
 - Strengthening young people's life skills

2. *Mobilize and strengthen community-based responses by:*
 - Engaging local leaders
 - Enabling open discussions on HIV/AIDS
 - Organizing cooperative activities
 - Promoting and supporting community care for children without family support

3. *Ensure access for orphans and vulnerable children to essential services by:*
 - Increasing school enrolment and attendance
 - Ensuring birth registration
 - Providing basic health and nutrition services
 - Improving access to safe water and sanitation
 - Administering justice
 - Strengthening district and local planning
 - Ensuring placement services for children without family care

4. *Ensure that governments protect the most vulnerable children by:*
 - Adopting national policies, strategies, and action plans
 - Enhancing government capacity
 - Developing and enforcing a legislative framework
 - Allocating adequate resources and ensuring their use at the community level
 - Establishing mechanisms to ensure information exchange and collaboration of efforts

5. *Raise awareness to create a supportive environment for orphans and vulnerable children by:*
 - Conducting a collaborative situation analysis
 - Mobilizing influential leaders to reduce stigma, silence, and discrimination
 - Strengthening and supporting social mobilization activities at the community level

Despite discourse and consensus at the highest levels, the response to date has been inadequate and too few vulnerable children and families are receiving support. The Strategic Framework of the Global Partners' Forum suggests these key steps to carve the way forward:

- Accelerate and support national government efforts
- Encourage governments to assess budgets and resource allocations to the response and increase financial investments by all stakeholders
- Encourage and support innovative government strategies to channel resources to ensure services reach affected communities
- Advocate to keep orphans and vulnerable children high on the global agenda and reduce the widespread stigma and silence surrounding HIV/AIDS that continues to hamper the response at all levels
- Promote agendas for research and action: learn more and do more and measure our progress over time

The USAID Response

For the past decade, USAID has been a global leader in implementing activities that support orphans and other vulnerable children and adolescents. In the 1990s, USAID focused on supporting families and communities through the Displaced Children and Orphans Fund. In 2000, an ongoing financial commitment of the Food for Peace funds was made to support vulnerable children and their households. With a focus on the overall well-being of children greatly at risk, USAID has expanded its efforts from a handful of projects in 1999 to funding 99 projects in 21 countries in 2003.

Today, USAID is operating in a global framework, guided by the UNGASS goals, the Millennium

“The impact of AIDS on children and youth and on their families is so vast that only a unified effort can truly begin to mitigate its impact.”

— Linda Sussman, Bureau for Global Health, HIV/AIDS, USAID

Development goals, the President's Emergency Plan for AIDS Relief, and the new Strategic Framework. USAID contributed to the Framework's development at the Global Partners' Forum in Geneva. To support children and adolescents orphaned and affected by AIDS, USAID's goal is to enable local institutions to provide community support to at least 25 percent of HIV/AIDS-affected children in countries with a high prevalence of HIV/AIDS by 2007. To help communities develop and sustain strategies to meet the needs of vulnerable children, USAID's work is guided by these strategies:

1. ***Provide direct support to programming and monitoring and evaluation by:***
 - Strengthening the abilities of families to provide care and support (including business training and low-interest credit)
 - Mobilizing and supporting community-based responses
 - Helping children and adolescents meet their own needs (e.g., by staying in school and receiving training in vocational skills and adequate nutrition and health services)
 - Creating a supportive social and policy environment
 - Building the capacity of governments and CBOs to protect children and provide essential services (through basic legal protection, transforming public perceptions of HIV/AIDS, and strengthening HIV prevention and mitigation efforts in the education sector)
 - Supporting research and information sharing to identify successful approaches
2. ***Expand the knowledge base through:***
 - Guides to assist monitoring and evaluation, costing of programs, situation analyses, and documentation of technical issues
 - Research to develop models of intervention, with a focus on succession planning, interventions to address children under 5 years old (e.g., Speak for the Child), methodology and evaluation of program effectiveness (e.g., REACH), and positive models of youth involvement (e.g., YouthNet)

3. *Information dissemination and exchange initiatives, including:*

- This OVC Technical Consultation
- An electronic toolkit (see Annex 4)
- Regional workshops to support national action in Africa
- The interagency OVC, HIV/AIDS, and education task teams
- The Children Affected by AIDS (CABA) listserv for e-mail discussion of technical issues, information about new documents, tools, workshops, jobs, and queries for resources and opinions

USAID is working in close partnership with national governments, United Nations organizations, donors, the private sector, FBOs, and CBOs.

Lessons from Community-Based Responses

Shifting attention from global and national strategies, the afternoon of Day 1 focused on actual responses at the community level. Representatives of the Masiye Camp in Zimbabwe, the Khmer HIV/AIDS NGO Alliance (KHANA) in Cambodia, the Palmyrah Workers Development Society (PWDS) in India, and STEPS (Scaling-Up HIV/AIDS Interventions through Expanded Partnerships) in Zambia shared models of community-based responses to support affected children and families. Each demonstrated that families and communities are at the forefront of caring for affected children. They are the key source of child welfare in most affected communities. In many settings, for example, the vast majority of financial assistance to affected families for food is provided by relatives, followed by friends. CBOs have a wealth of experience in strengthening those capacities and interests of families and communities.

Each community is unique, and specific needs, responses, processes, and time frames thus vary. Despite these differences, each organization represented found ways to motivate, equip, accompany, link, and sustain their communities (e.g., “MEALS” approach) and offer lessons that have relevance across affected communities.

A Comprehensive Response to HIV/AIDS

Rather than narrowly focusing on specific aspects of the epidemic, effective programs are linking care and support for people living with HIV and AIDS with support for orphans in addition to HIV prevention and advocacy to reduce stigma and discrimination. KHANA in Cambodia, for example, has found that home-based care programs are a good entry point to identify and support orphans and vulnerable children. STEPS is focusing on both preventing HIV and mitigating AIDS’ impact on children and their families.

Integration of HIV/AIDS into Community Development

Not only are CBOs focusing only on HIV/AIDS, but they are building HIV/AIDS programs into broader community development objectives. Because HIV/AIDS is contributing to poverty and destitution, CBOs are responding with microcredit schemes, income generation, vocational training, infrastructure, and human resource development. For example, KHANA is providing no-interest loans to widows to start up small businesses. To ensure food security, STEPS expanded its work to include communal gardens, food relief, off-season farming, and animal rearing. PWDS works across sectors of agriculture, community health, child care, and education to provide services in home-based care, fostering and adoption, and housing support.

A Holistic, Comprehensive View of Young People’s Needs

CBOs are providing more than basic material needs. For example, in addition to food, clothing, and shelter for young people the Salvation Army Masiye Camp in Zimbabwe is providing:

- Emotional support through psychosocial counseling and mentoring
- Recreation and fun through arts, crafts, and recreation
- Practical skills development, including practice in coping and HIV prevention skills
- A mobile law clinic to provide legal assistance families and children
- Income-generation opportunities (e.g., the Splash Girls bicycle messenger service)

KHANA is also creating vocational training, employment opportunities, and microcredit schemes for young people.

An Effective, Integrated Response Requires Partnerships

“We are talking about the life of a child—with needs ranging from wanting to be held to the need for shelter and education. No single organization or group is capable of providing this in a holistic manner.”

— Brenda Yamba, STEPS Malawi

Where possible, the CBOs are not working alone, but, in partnership with local government, the private sector, and other CBOs.

Young People Should Have a More Meaningful Role in Programmatic Responses

“Youth are a resource, not a problem. We can’t be seen as deviant, nor as helpless victims. Nor should we be seen simply as beneficiaries.”

— Brighton Gwezera, Masiye Camp, Zimbabwe

Young people are already a critical part of the solution, helping their families, ill parents and younger siblings. They must be included in designing, managing, and evaluating programs. They can be involved in participatory assessments and ongoing consultations. They need skills, information, and training in youth leadership and a platform more often at these kinds of consultations.

Build on Existing Strengths and Structures without Undermining or Replacing Them

“If I want to send my child to school, I don’t build a new school. If I need medical care, I don’t build a new hospital.”

— Reji Chandra, Palmyrah Workers Development Society

The speakers urged against re-creating or starting new processes, but, to focus on existing positive community responses. The challenge is to scale up promising approaches to reach more vulnerable

children. Religious organizations have existing structures that can coordinate a scaleable response. Speakers suggested that efforts to scale up should be careful to keep communities at the center of the response, to preserve their sense of ownership.

Community-based Organizations Face a Range of Challenges That are Limiting Their Impact

“Putting communities at the center of the response enables an easy expansion of coverage.”

— Pok Panhavichetr, Khmer HIV/AIDS NGO Alliance

By sharing the most significant challenges they face, the speakers highlighted opportunities to improve the effectiveness of community- and faith-based responses. One common area of concern relates to human resource capacity. The speakers recognized the lack of experienced staff, high volunteer turn-over, and inadequate involvement of young people. CBOs also experience financial limitations and identified challenges in:

- Resource mobilization (especially for the “software” aspects of development, which are important but not easily visible)
- Short donor timeframes (e.g., timeframes of 1-2 years do not reflect the pace of community mobilization and are insufficient to demonstrate impact quantitatively)
- Sustainability
- Donors’ “adherence to results” packages that do not recognize process and contributions

Many CBOs face an uphill battle working in conditions of severe poverty, illiteracy, and recurrent food insecurities. Also impeding the effectiveness of CBOs are pervasive attitudes that promote stigma and discrimination targeted at orphans and people living with HIV/AIDS, a preference for orphanages as the best solution, and fatalistic attitudes about HIV/AIDS. Finally, CBOs must make difficult decisions about providing alternative services versus mainstreaming and whether to prioritize HIV-affected children and families in contexts with many marginalized, poor children.

Faith-Based Responses

“Responses are faith based, not faith focused. Support is provided on the basis of need, not creed.”

— James Cairns, Director, Program on Children, World Conference of Religions for Peace

Preliminary results of the *Study of the Response of Faith-Based Organizations to Orphans and Vulnerable Children* reveal the powerful role and potential of FBOs in supporting AIDS-affected children and families. Commissioned by World Conference of Religions for Peace (WCRP) and UNICEF in 2001, research teams have thus far conducted interviews with 686 faith-based initiatives in Kenya, Malawi, Mozambique, Namibia, Swaziland, and Uganda. These include:

- Congregations or local groupings of believers such as churches, mosques or temples
- Religious coordinating bodies, or organizations that supervise and support congregations (e.g., the National Council of Churches and the Inter-Religious Council)
- Faith-based NGOs and CBOs

Nearly 90 percent of the FBOs interviewed claimed to have an OVC initiative. Many religious coordinating bodies were unaware of OVC responses by their congregations indicating that local religious groups have largely initiated their own responses to the HIV/AIDS epidemic. Most of those initiatives are recent, with half established

since 1999. The vast majority of OVC initiatives provide material support to children, such as food and clothing, as well as school fees and other school-related expenses. Many FBOs initiated institutional responses (up to 20 percent in Kenya and Malawi), despite national policies discouraging the establishment of new institutions.

The strengths of FBO efforts include their extensive reach, strong influence, community participation, and duration. Of the 505 interviews processed at the time of this presentation, 322 FBOs supported 139,409 orphans and vulnerable children, for an average of 428 vulnerable children per organization. Most FBOs scored highly in assessments of organizational capacity, suggesting that religious organizations have existing structures that can coordinate a scaleable response. However, most are managing with little external financial or technical support, and generally without training in OVC program delivery, HIV prevention, or organizational development. They could also have a greater impact through improved communications between congregations and interfaith collaboration.

In a workshop in May 2003, representatives of the study teams, WCRP, and UNICEF developed recommendations for congregations, religious coordinating bodies and donors (details are available in the Preliminary Summary Report disseminated to all participants). These recommendations are presented in the table below. A final summary of the study is now available at: <http://www.synergyaids.com/caba/documents/FBO-OVC%20Study%20Summary-final.pdf>.

Congregations	Religious Coordinating Bodies	Donors
<ul style="list-style-type: none"> ◆ Promote community-based (rather than institutional) OVC responses ◆ Encourage the participation of children and youth in program design and implementation ◆ Encourage the establishment of committees on AIDS/OVC 	<ul style="list-style-type: none"> ■ Encourage and prioritize interreligious collaboration and networking with other RCBs ■ Increase coordination and communication with congregations ■ Build capacity at congregation level through training, resource mobilization and documentation ■ Increase public advocacy by religious leaders 	<ul style="list-style-type: none"> ■ Identify the comparative advantages of FBOs and utilize their strengths ■ Recognize and utilize existing religious structures and work with appropriate tiers of RCBs ■ Support small grants funds operated by RCBs to resource activities initiated by congregations ■ Ensure that funding policies and processes are guided by the experience and capacity of local religious partners

Keynote Address

Graça Machel, Founder, Foundation for Community Development, Mozambique

I come from southern Africa, the region most affected by HIV and AIDS. This is where you find the most disturbing images, consequences, and impact of AIDS. We should be able to say we have a clear understanding of the impact, but we don't. At meetings and conferences, we try to come to terms with the problem but are unable to comprehend the magnitude. Most people have never had experiences like the communities that are so deeply affected. We have to go deeper to understand this reality.

I want to talk about the three generations of orphans. First, there are those who are now orphans. They are in the millions. These are the groups that have suffered the worst. The second generation is yet to come: their parents are still alive but infected; and we have to work to keep the parents alive, particularly the mothers. There is a huge difference between becoming an orphan at 3 versus 12 or 15. Those engaged in caring for orphans must also advocate to keep the parents alive. Give mothers the opportunity to keep children alive, so they can prepare their children for life.

When I travel and talk to communities, children ask about their parents. They wonder how their parents were, what they looked like. I always remember one orphan who visited a photo stand at the market, staring at photos of other people, wondering what her mother looked like. These are the emotional needs we do not address, because we don't always stop to think.

The problem of orphans will be here for decades. We are part of the chain of solidarity. We want to contribute so they will grow. Bring it as close as taking the place of the parents. If there is a huge difference between 'us' and 'them', forget it.

Who is taking care of the children? The majority of the millions of orphaned are being cared for. By whom? Grandmothers. We take for granted that grandparents know how to do the job. In Zambia with Stephen Lewis, we visited a family where the grandfather was 83 and had 30 grandchildren to care for. Eight of his own nine children had died from AIDS, and the ninth was ill. Are our programs working to empower these old people? They are much closer to the children than we are.

Also, more and more families are headed by women and children. They are heads of the households and the caregivers, keeping families together. They need recognition and empowerment.

Community members are offering help to children and often stepping into the role of parents. In Zambia, I asked a 13-14 year old if she had begun to menstruate. She said yes. I asked her who told her what it meant. She said, "Auntie so-and-so." Neighbors are the ones giving support when parents can't.

Teachers are also offering counseling. Children have the right to go to school. Teachers can do more than teach reading and writing; they can also build emotional support.

In every effort we do, we identify our needs in terms of knowledge and skills. Local institutions should be able to do these things. I suggest three things: empowerment, empowerment, and empowerment of local caregivers and local institutions.

Orphans need more than food. They need citizenship, education, health, recreation. Yes to their property rights; that plot of land is something they have to cling on to. We need to change existing legislation. Current laws only allow land to be inherited at age 18; so younger children (adolescents) get nothing. These laws must be changed.

We must build partnerships to bring microcredit schemes into programs. Children need skills development in addition to basic education. In Uganda, where there is universal access to primary school, there are two types of educated children: those that get to go to secondary school and those who don't. We must make sure orphans and vulnerable children can get to technical school. I asked President Museveni of Uganda, what about the orphans and vulnerable children and their need to go to secondary school? He has committed to improving access beyond primary school.

Strengthening the value systems—morality strengthening. In Rakai District, Uganda, 60 percent of early pregnancies are by orphans. These are the third generation: orphans that will produce other orphans. Villages should empower self-supporting groups that build morality and value systems of children. This is the software we need in programs. Spiritual and moral values build personality. We should help communities address the anxieties, fears, and vulnerabilities that orphans face. Who meets the needs of these adolescents?

There are positive movements and models. Let us connect these models to become a movement, like a web, not worrying first about scaling-up. This is the movement that will turn the tide. This is the only way to face the AIDS pandemic and the orphan crisis. Models are making an impact, but, only on a very small scale. Please build the movement.

PANEL DISCUSSIONS

Monitoring and Evaluation

Though programs to support orphans and vulnerable children have proliferated in recent years, little is known of their effectiveness. A paucity of evaluation data exist from which lessons can be drawn. Efforts are underway, however, to promote monitoring and evaluation of efforts at all levels—global, national, and community—with hopes to:

- Monitor progress in meeting the UNGASS goals
- Assess the impact of interventions and programs for replication and/or scaling up
- Advocate for evidence-based policies and programs
- Encourage a flow of information from the community outwards and mobilize community-level action

Monitoring National Responses

The core set of indicators UNAIDS developed to monitor the UNGASS Declaration of Commitment includes only one indicator related to orphans: orphan school attendance.² Deeming this inadequate, UNICEF and UNAIDS held a consultation in Botswana in April 2003 to develop a more comprehensive set of core indicators and a monitoring and evaluation framework that focuses on children orphaned and made vulnerable by HIV/AIDS. Those discussions have resulted in a draft guide to monitoring and evaluation of national responses for children orphaned and made vulnerable by HIV/AIDS. Presented in the table below, the guide outlines 10 core indicators, organized within the five strategies of the Strategic Framework (Global Partners' Forum, Geneva, October 2003).

Strategic Approach	Core Indicators	Additional Indicators
<p>1. Strengthen the capacity of families to protect and care for orphans and other children made vulnerable by HIV/AIDS</p>	<ul style="list-style-type: none"> ■ <i>Indicator 1:</i> Basic material needs ■ <i>Indicator 2:</i> Malnutrition-under weight prevalence ■ <i>Indicator 3:</i> Sex before the age of 15 	<ul style="list-style-type: none"> ■ Food security ■ Psychosocial well-being ■ Connectedness to an adult caregiver ■ Succession planning ■ Orphans living with siblings
<p>2. Mobilize and strengthen community-based responses</p>	<ul style="list-style-type: none"> ■ <i>Indicator 4:</i> Children outside of family care ■ <i>Indicator 5:</i> External support for households with OVCs 	
<p>3. Ensure access to essential services for orphans and vulnerable children</p>	<ul style="list-style-type: none"> ■ <i>Indicator 6:</i> Orphan school attendance ratio (10-14) ■ <i>Indicator 7:</i> Proportion of OVCs that receive appropriate psychosocial support ■ <i>Indicator 8:</i> Birth registration 	
<p>4. Ensure that governments protect the most vulnerable children</p>	<ul style="list-style-type: none"> ■ <i>Indicator 9:</i> OVC Program Effort Index 	<ul style="list-style-type: none"> ■ Property transfer ■ Quality of institutional care ■ Stigma and discrimination
<p>5. Raise awareness to create a supportive environment for children affected by HIV/AIDS</p>	<ul style="list-style-type: none"> ■ <i>Indicator 10:</i> Percent of children who are orphans 	

² *Monitoring the Commitment on HIV/AIDS: Guidelines on Construction of Core Indicators.* UNAIDS, 2002.

Program-Level Responses

To learn from programmatic experience, USAID, Family Health International (FHI), and UNICEF have initiated a collaborative effort to develop a guide for program-level monitoring and evaluation. Efforts are also underway to develop a costing tool, titled *Guidelines for Calculating Costs of OVC Programs*. The guidelines are intended to help nongovernment, government, and donor institutions calculate the costs of OVC interventions and use costing information to make decisions about scaling-up, replicating, and monitoring and evaluating OVC activities. Futures/REACH and FHI/IMPACT will field test the costing tool in Zambia and Rwanda in February 2004.

Who is Evaluation for?

“The ideal is to have a system of information collection that is useful and realistic for people at each level. We do not want to be solely driven by donors’ demands, but to make sure the information and lessons learned from monitoring and evaluation flow back to the community.”

— Kate Harrison, International HIV/AIDS Alliance

Efforts are being made to ensure that program-level indicators are closely linked with those to be measured at the national level. However, the motivations and utility of monitoring and evaluation at the community level often differ from those at national and international levels. For example, local implementers often have different criteria for success than external funders. Tension also exists between standardized indicators that allow comparability across countries and locally defined indicators that better inform local responses. While there are many needs for more and better data through monitoring and evaluation, a balance must be struck to ensure those needs are complementary and not competing. Monitoring and evaluation must ultimately benefit those made vulnerable by HIV/AIDS.

Children’s Participation in Research

Calls for the meaningful involvement of young people are increasing in all aspects of the response to HIV/AIDS. This includes their participation in research, monitoring, and evaluation. Why involve children in information gathering efforts?

- Because they have a right to participate
- They have better knowledge of their own views and priorities
- Their input will yield more effective and relevant responses

To give a voice to children affected by HIV/AIDS, information gathering efforts are increasingly obtaining information directly from young people, for example, as participants in focus groups, interviews, participant observation, and participatory research exercises such as mapping exercises.

To ensure such experiences do not result in harm to children, USAID, UNICEF, FHI, and Horizons are jointly developing practical ethical guidelines to ensure the protection of children and adolescents in difficult circumstances. The guidelines will outline specific ways to follow these 16 principles for ethical work with children:

Jeopardy	Confidentiality
Unforeseen consequences	Informing participants
Reporting results	Implications of findings
Scientific misconduct	Personal misconduct
Nonharmful procedures	Informed consent
Parental consent	Additional consent
Incentives	Deception
Anonymity	Mutual responsibilities

It is not always appropriate to involve children in research efforts, for this may not be in the children's best interests. To help decide whether to gather information with and from children, Save the Children UK suggests these guiding questions:

- When is children's participation appropriate?
- Is their participation necessary?
- Why use a participatory approach?
- What are the benefits to children?
- What is the capacity for participation of a representative group?
- What capacity exists for follow-up support? (e.g., if you learn a child has been abused)
- Can their confidentiality be assured?

It is also essential that programs and organizations working closely with children adopt a child protection policy.

Positive Images: The Role of Media

The media can be a powerful tool through which to advocate for children's issues, raise public awareness, reduce stigma, promote dialogue, and highlight good models of care. Organizations dedicated to children and HIV/AIDS are learning to work in partnership with media companies and journalists to ensure that the increasing coverage of orphans and other children affected by HIV/AIDS is productive and positive. The Staying Alive campaign, for example, is a collaboration of media and broadcasting companies, foundations, NGOs, and United Nations agencies dedicated to promoting positive messages about young people and HIV/AIDS through youth forums at international conferences, public service announcements, a documentary film of real life stories of young people, and a Staying Alive concert and website. The partnership has faced a number of challenges and offers lessons for fostering positive relationships with the media, as shown in the table below.

Challenges	Ways to Overcome Challenges through Partnerships with the Media
<p><i>Ensuring the technical accuracy of media programming</i></p> <p><i>Potential to increase stigma and/or hopelessness</i></p> <p><i>Convincing media that positive stories are as compelling as sad ones</i></p> <p><i>Ensuring the protection of young people featured</i></p>	<ul style="list-style-type: none"> ■ Offer media our services as reviewers ■ Help train them on technical aspects ■ Let them see the resiliency of young people with their own eyes; bring the field to them ■ Let them see people and programs that will inspire them ■ Provide them with angles ■ Lead by example: Don't focus on negatives in our own results reporting ■ Develop and distribute a step-by-step guide to protect young people in the media ■ Develop a generic consent form for young people and guardians

“We need to work together with the media to find ways to make the resiliency stories as compelling AND as profitable as the sad, stigma-producing stories.”

— Halley Mahler, YouthNet

CBOs have also found that some media representatives do not always have the best interests of children in mind. Brenda Yamba of Save the Children recalls reporters asking such questions as: “Could all the orphans raise their hands?”; “Has the child got AIDS?”; and “Can we have the grandmother alone with the orphans?” To ensure a newsworthy story that will sell papers, some reporters may distort facts through alarming

headlines or inflated figures, ignore protocols, or take and publish photographs without child or guardian consent. The risks to alarmist reporting are many and include:

- Perpetuating stigma
- A long-term, negative impact on individual children
- Creating rifts between community members (Why them and not us?)
- Raising expectations
- Undermining mobilization process

For effective media involvement, Save the Children suggests that we see the media as partners, not just reporters. For this, they should be competent in children’s issues. Programs can help by developing guidelines for media.

TECHNICAL WORKING GROUPS

SYNTHESIS

On Days 2 and 3 of this OVC Technical Consultation, participants met in technical working groups to consider the practical steps required to meet the specific needs of children orphaned and affected by HIV/AIDS. Grounded in reality and recent research, the working groups focused on the specific ways in which children are affected by HIV/AIDS, including:

- Health and nutrition
- Education
- Emotional well-being
- Children without family care
- HIV-positive children
- Models of community approaches
- Economic and food security

The aims of the technical working groups were to:

- Discuss current and planned research/evidence
- Share programmatic experience
- Propose the top 3-5 research priorities, top 3-5 research and programmatic challenges, and top 3-5 actions needed to move forward

Some participants took part in one of two video film screenings related to children affected by HIV/AIDS. These sessions generated dynamic, powerful discussion and emphasized the need for a coordinated, expanded response.

The outputs from each working group are listed in the next section. Full reports from the groups are available on the consultation website: <http://sara.aed.org/ovc-tc/>. A number of messages emerged across the groups and have been synthesized below.

Actions to Move Forward

While focusing on a specific theme, each group acknowledged the links between issues and called for a holistic approach to the care and protection of children infected and affected by HIV and

AIDS. Healthy child development spans the physical, emotional, and social domains—all of which are interconnected and equally threatened by HIV and AIDS. While ensuring shelter, sustenance, and medicines, for example, we cannot overlook children's needs for love, affection, and mentoring. With this in mind, groups consistently called for integrated and comprehensive efforts involving multiple sectors, rather than narrow and vertical programs.

Most groups noted that such efforts will not necessarily require new systems and structures. Rather, existing programmes that benefit all children will also benefit orphans and vulnerable children and should be strengthened, linked, and scaled up. Specific initiatives mentioned include HIV/AIDS programs including Prevention of Mother to Child Transmission *Plus* (PMTCT+), Voluntary Counselling and Testing (VCT), and expanded access to antiretroviral (ARV) treatment, as well as child survival initiatives including Integrated Management of Childhood Illnesses (IMCI) and the Expanded Programme of Immunization (EPI). Broad efforts to promote child welfare were also emphasized, including Education for All, school health initiatives, water and sanitation programs, and successful community-based models. Participants warned against abandoning other health and welfare needs in favor of HIV/AIDS and suggested tackling them together.

Also featuring prominently across groups was an emphasis on caring for the caregivers. Speakers and participants shared research and experience revealing the many ways in which children's well-being is inextricably linked to the health and survival of their primary caregivers. A mother's infection with HIV, for example, poses threats for her child during pregnancy, delivery, and breastfeeding. Young children are also highly vulnerable during their mothers' terminal illness and immediately following her death. Among surviving and orphaned children, risks can persist throughout their biological, emotional, and educational development. Programs cannot limit their attention to children but must also address

the health, nutritional, emotional, and economic well-being of parents and guardians. The groups acknowledged the important role of government in supporting families and communities. There were strong calls for governments to:

- Assess current laws regarding child protection
- Develop and enforce clear policies for acceptable standards of care for affected children, especially within institutions
- Increase advocacy to highlight the needs of orphans and vulnerable children and elevate actions on HIV-positive children

In addressing investments, groups called, above all, for an investment in people. Strengthening human resources is a prerequisite for scaling-up.³ Specific human resource needs were mentioned, including training of:

- Caregivers through skills training and income-generating activities
- Community members, teachers, social workers, and health professionals in simple tools to monitor child well-being (including psychosocial assessment)
- Volunteers, upon whom many community-based programs depend
- New and substitute teachers to fill teacher gaps created by absenteeism and death due to AIDS
- Primary care practitioners in symptomatic diagnosis to suspect HIV infection in children
- Community members in agricultural methods, production, and use of medicinal herbs
- HIV training for chiefs and midwives, positive living, and home-based care

Groups emphasized the importance of involving children and young men and women in trainings and skills development, thereby creating opportunities for them to earn income and contribute to the widening gaps in human resources, knowledge, and skills created by AIDS. Young people should also be included in designing interventions and assessing and developing indicators, because what they say they need and what adults say children need often differ. These were but a few of the ways suggested to harness

the power and potential of young people. Investments should also be made in the networks that connect people. For example, relationships must be actively fostered between sectors (e.g., health, labor, finance, and planning), public and private parties, and between residential institutions, community-based organizations (“community to community transfer”), and faith-based organizations.

Challenges

Impeding efforts in all areas are a number of persistent challenges, identified across the working groups:

- Poverty exacerbating the adverse effects of HIV/AIDS
- Balancing emergency needs with long-term responses
- Deteriorating or inadequate infrastructure and human resource constraints
- Balancing community needs and donor requirements
- Fostering a collective sense of responsibility for children
- Ensuring sustainability of programs

Research Priorities

With regard to enhancing the knowledge base, the technical working groups called for:

1. Further scientific research in some areas, for example:
 - Ways to halt the downward spiral of poverty in HIV/AIDS-affected households and communities
 - Understanding the role and effectiveness of treatments to prolong the lives of children and parents, including:
 - the potential toxicity of maternal ARV therapy for breastfed infants
 - the effects of ARV regimens on children in resource-poor settings, including long-term effects
 - associated health care and access costs, even where ARVs are free of charge (e.g., transportation, lab tests)

³ Expressed by Dr. Don de Savigny, International Development Research Centre, Canada, in a presentation entitled: “Minds the gaps: Can we deliver on Millennium Goals with 20th century health system approaches?” London, 20 November 2003.

- interactions between micronutrient supplements and ARVs
 - the impact of *pneumocystis carinii pneumonia* (PCP) prophylaxis on malaria resistance to sulfadoxine-pyrimethamine (i.e., Fansidar®)
 - The health and nutritional needs of orphans and vulnerable children over 5 years of age
2. A deeper understanding of local needs, experiences, norms, and coping mechanisms to design appropriate interventions in different contexts (because “one size does not fit all”). Suggestions were made to:
- Improve the body of qualitative research related to orphans and children made vulnerable by AIDS
 - Provide guidance for the local adaptation of research instruments, such as the General Health Questionnaire and the Child Behavior Checklist
 - Understand ways in which different children will be affected (for example, boys versus girls, differences by age, and developmental stages of children) and the contextual determinants of their well-being (e.g., what is expected of children in different cultural contexts, how distress may be manifested and recognized in different settings, and gender roles and equity)
 - Identify local barriers to ensuring the rights of affected children, including education costs, relevance of educational opportunities, stigma associated with HIV/AIDS, taboos surrounding illness, and death and sexual abuse
 - Estimate costing needs in different settings
 - Enumerate children without family care and map institutions
- While encouraging local understanding, several groups also highlighted the need to bridge local and global efforts with flexible, locally relevant indicators that are also comparable across settings. Similarly, global standards of care must be balanced with regional and local specificity.
3. Operations and evaluation research to build evidence for program models, for example:
- The abolishment of school fees and/or provision of scholarships and food directly to orphans and children affected by AIDS
 - The role of schools in supporting families affected by AIDS (e.g., school gardens and extracurricular clubs)
 - The benefits and limits of family care units
 - Models of reintegration of children from institutions to community and family-based care
 - Engaging boys and men in the role of caregiving
 - The appropriate role of food aid and safety nets in the context of AIDS
 - Implementation of microenterprise/microfinance programs
- Finally, groups urged transferring knowledge to benefit people. One specific suggestion was to translate research into simple tools for local use (for example: to assist psychosocial assessment, action and monitoring by community service providers).

OUTPUTS

The outputs resulting from each technical working group—summarized on pp. 21-24—were presented in the closing plenary session. (See the Consultation website, <http://sara.aed.org/ovc-tc/>, for full reports from the technical working groups.)

Health and Nutrition

Challenges	Research Gaps	Key Actions
<ul style="list-style-type: none"> ■ Targeting the most vulnerable with food distribution and health interventions ■ Balancing concerns about sustainability and dependency versus urgency ■ Working with inadequate and deteriorating health infrastructure and human resources ■ Making breastfeeding safer in resource-poor environments ■ Tailoring IMCI and other efforts to meet the needs of HIV-infected and affected children 	<ul style="list-style-type: none"> ■ The appropriate role of food and safety nets ■ Questions of the toxicity of maternal ARV drugs for breastfed infants ■ Enhancing the quality of guardianship and care, including incentives for men ■ Health and nutritional needs of orphans and vulnerable children over 5 years of age ■ Prevention of abuse and HIV infection of older orphans and vulnerable children 	<ul style="list-style-type: none"> ■ Set more flexible parameters for resource allocations ■ Use resources earmarked for HIV/AIDS to improve general health infrastructure ■ Invest in capacity of governments and institutions to formulate and implement policies and programs ■ Scale up PMTCT+ and highly active ARV therapy for HIV-positive parents through existing primary health care efforts ■ Support informed choice of infant feeding methods

Education

Challenges	Research Gaps	Key Actions
<ul style="list-style-type: none"> ■ Increasing access to learning opportunities ■ Making learning (more) relevant for OVCs ■ Expanding and strengthening support systems that make it possible for OVCs to go to school ■ Declining teaching and education management personnel ■ Working multisectorally 	<ul style="list-style-type: none"> ■ Operations research on the impacts of various models of complementary learning and incentives ■ Determine local relevance at the local level, in local settings ■ Understand full scope of support systems and how to strengthen them ■ Research on determinants of well-being for children ■ How to harness youth leadership to fill the gap ■ Create new language and methodology for research in this ever-changing environment 	<ul style="list-style-type: none"> ■ Make schools more gender and OVC sensitive and free of discrimination and harassment; abolish school fees ■ Establish systems for community dialogue to help determine local relevance ■ Inventory successful models of school-driven/based OVC support and expand these models ■ Support countries to establish substitute and teacher aide programs with youth ■ Step out of our sectoral roles and fund what needs to be done to improve the lives of orphans and vulnerable children

Emotional Well-Being

Challenges	Research Gaps	Key Actions
<ul style="list-style-type: none"> ■ Contextually appropriate psychosocial-support initiatives are not easily replicable across cultures and take time to develop ■ Lack of gender equity—girls are at especially at high risk of sexual abuse ■ Taboos against discussions with children of death, abuse, or sexual exploitation ■ Lack of functioning child protection systems ■ Children’s guardians are under great stress themselves, also suffering from loss 	<ul style="list-style-type: none"> ■ Capturing local experience to understand traditional coping mechanisms ■ Local adaptation and validation of research instruments ■ Indicators that consider local norms and culture ■ Psychosocial components of a minimum service package for orphans and vulnerable children 	<ul style="list-style-type: none"> ■ Designate/earmark funds for psychosocial support to orphans and vulnerable children and their caregivers/families ■ Develop program and national psychosocial indicators ■ Develop simple tools for research, psychosocial support assessment and monitoring and train service providers in their use ■ Provide psychosocial support to those who support orphans and vulnerable children (e.g., grandparents and families) ■ Increase assessments of current laws regarding child protection and increase advocacy on child protection

Economic Strengthening and Food Security

Challenges	Research Gaps	Key Actions
<ul style="list-style-type: none"> ■ Minimizing the loss of assets that can rarely be recovered ■ Building child’s assets (e.g., educational attainment, health status) ■ Making food aid available before it is too late and depoliticizing it ■ Ensuring food security responses are more than just food aid and distribution 	<ul style="list-style-type: none"> ■ Common language ■ Funding requirements ■ Complexity of multisectoral nature of the issue ■ Linkage of community and household responses to OVC ■ Appropriate use of food aid 	<ul style="list-style-type: none"> ■ Promote community definitions ■ Support locally designed interventions ■ Empower communities with knowledge of rights, collective action to hold government accountable ■ Link with governments and private sector to build social protection and resources

Models of Community Care

Challenges	Research Gaps	Key Actions
<ul style="list-style-type: none"> ■ Increasing poverty in HIV/AIDS -affected communities and households ■ Addressing the crisis situation while developing long-term responses ■ Building government capacity and multisectoral collaboration ■ Long term support for volunteers ■ Sustainability in the face of termination of donor funding 	<ul style="list-style-type: none"> ■ How to halt the downward spiral of poverty in HIV/AIDS-affected communities and households ■ How to effectively implement economic strengthening in AIDS affected communities ■ The use of income generating activities to improve psychosocial situation and coping ■ Costing of effective community mobilization programs 	<ul style="list-style-type: none"> ■ Promote community definitions ■ Support locally designed interventions ■ Empower communities with knowledge of rights, collective action to hold government accountable ■ Link with governments and private sector to build social protection and resources

HIV-Positive Children

Challenges	Research Gaps	Key Actions
<ul style="list-style-type: none"> ■ HIV/AIDS care and support is primarily adult focused ■ How and when to disclose HIV infection to a child ■ Clinical and social criteria for access to ART for children with HIV/AIDS ■ HIV+ children as development not just medical issue (translate into national policies and comprehensive care) ■ Palliative care for children (pain relief and helping infected children live well) 	<ul style="list-style-type: none"> ■ The impact of HIV on the psychosocial and mental health of a child ■ Natural history of HIV infection in children ■ Guidelines for what programs that provide food and nutrition support for infants and children should do differently in the context of HIV/AIDS ■ Short-term and long-term efficacy of ARV treatment regimens among infants and children in limited resource settings ■ Impact of PCP prophylaxis on malaria resistance to Fansidar®. 	<ul style="list-style-type: none"> ■ Ensure HIV+ children are considered at all levels of care and programming (ART, nutrition, research) ■ Identify and elevate priority actions on HIV+ children ■ Improve quality and access of services through training and addressing barriers to testing and diagnosis ■ Link child survival interventions to HIV/AIDS programs ■ Strengthen interventions to improve and maintain health of parents

Children without Family Care

Challenges	Research Gaps	Key Actions
<ul style="list-style-type: none"> ■ Lack of consistent and clear standards of care ■ Balancing global standards with regional and local specificity ■ Addressing gender dimensions in the context of domestic workers, caregivers, and transitional shelters ■ How to address the absorptive capacity of families ■ Involving children in determining quality care and developing indicators for care 	<ul style="list-style-type: none"> ■ Not enough information on where, how many, and why children are out of family care ■ Costs involved in community-based programming ■ Definition of quality care and minimum standards ■ Ways to accurately map the number and types of institutions 	<ul style="list-style-type: none"> ■ Support preventative programming—identify vulnerable families before children become abandoned ■ Invest in infrastructure so that communities can sustain programs beyond the life of projects ■ Support adoption of consistent and clear government policies on standards of care ■ Expand the participation of children in assessing and developing indicators for care ■ Encourage men to participate in caregiving

MOVING AHEAD

CONCLUDING SESSION

Though difficult to truly comprehend, we are capturing the magnitude of the impact of HIV and AIDS on children. On Day 1, we had a chance to hear seminal cutting-edge information, not yet published, verifying the scale and duration of the impact and urgency with which we must respond. Through a growing body of research and the experience of programs and communities, we are understanding the numerous needs of millions of orphans and vulnerable children, at different stages of their development. We must respond quickly and effectively to meet those needs, while, at the same time, preventing future generations of orphans by preventing HIV and keeping parents alive.

How can our response to the epidemic better match its severity? The working groups offered us useful guidance:

- AIDS poses an unprecedented challenge, it cannot be business as usual.
 - We must get the funding flowing, ensuring it reaches all the way to the grassroots level—to those who need it most. This requires flexibility of funding, and funding driven by the needs of communities—not donors.
 - Keep sustainability in mind. The numbers of affected children will increase and remain incredibly high for decades to come. Thus, long-term sustained action is needed.
- We do not need new structures.
 - We must strengthen the existing structures (like faith-based organizations) and the capacity of communities and families currently caring for most orphans.
 - We must also build on our own strengths. At the international level, we have reached agreement on methods of enumerating orphans, we are developing models of what works, and we are building a knowledge base. Though the work ahead is daunting, we can not be paralyzed. We must be energized. As Tony Blair has said, “We are best when we’re bold.”
- Our response must be multisectoral and integrated, to address the multifaceted needs of children and their families. For this:
 - We need to foster stronger and expanded partnerships on the ground. We need to break down the walls blocking us from collaboration, to connect, share, and support each other. True collaboration is not easy, and it makes us vulnerable. But, we can do it by keeping our eye on the goal.
 - We need to enhance and support those who are truly working together, from the global to local levels.
- We must acknowledge the different needs and responses required in different contexts, and not apply a one-size-fits-all approach.
- We must include adolescents and children in our efforts. USAID commits to involving young people as we develop orphan and child programs and policies.
- We need better understanding of various, evolving topics. We have identified huge gaps in research and must support and stimulate a growing knowledge base. At the same time, much information and experience has been shared at this consultation. We must continue to share those lessons, especially about what is working. We do not have time to waste reinventing the wheel.
- There is resilience. We need to build on that. People with so little are managing to give to those with less. That is the strength we are working with.
- The consultation started with a challenge from Graça Machel: HIV/AIDS must be personal to all of us. To get our leaders committed, they must see the faces behind the numbers, and they must be personally touched. We are the genesis of a movement for children affected by AIDS. The recommendations are not for others to act on; they are our collective responsibility. We must ask what contributions each of us can make. We can do more and much better, together.

USAID COMMITMENTS

We will take this meeting “on the road” to countries, governments, and those working with communities. Our global level efforts here must be linked with action at the grassroots. For example:

- We will share our work at the upcoming meeting in Lesotho, where 10 southern African governments will be in attendance.
- We will share the report and presentations of this meeting with:
 - USAID missions
 - UNICEF/UNAIDS offices
 - NGO networks
 - Collaborating partners
 - North American OVC task force members (meeting the week of November 19th, 2003)
 - World Bank
- We will have similar state-of-the-art meetings with:
 - Africa USAID missions and partners
 - European colleagues
- We will continue to build on and share our knowledge base. For example, we will:
 - Complete the state-of-the-science review and share it with colleagues so that it can help inform programming

- Develop the Presidential Initiative Data Papers
- Facilitate an African OVC Research Network by linking African research institutions
- Stimulate new research to fill the gaps we have identified (e.g., USAID has issued a request for applications for studies related to orphans and vulnerable children in 10 priority countries.)
- We will find out where we are in countries and feed the needs to the Presidential Initiative. How many children are receiving services? We need a series of rapid assessments to:
 - Establish coverage baselines
 - Enumerate the number of organizations providing services
 - Validate programs on five key actions
 - Identify trigger points
 - Demonstrate collaboration and working together
 - Mobilize action at the country level

We will also debrief Ambassador Tobias and Dr. Anne Peterson with specific recommendations to ensure that the Presidential Initiative responds to the needs of children, their caregivers, and their communities.

ANNEXES

ANNEX ONE

AGENDA

Orphans and Vulnerable Children: Technical Consultation Renaissance Washington Hotel Washington, DC November 3-5, 2003

Day 1: November 3, 2003

- | | |
|-------------|---|
| 8:15-8:45 | Coffee and Registration |
| 8:45-10:00 | <p>Opening Session
 <u>Chair:</u> Keith Brown, <i>Deputy Assistant Administrator, Bureau for Africa, USAID</i></p> <ul style="list-style-type: none"> ■ Welcome & Introduction: Keith Brown, <i>USAID</i> ■ Workshop Modalities & Objectives: Linda Sussman <i>Bureau for Global Health HIV/AIDS, USAID</i>, and Peter McDermott, <i>Bureau for Africa, USAID</i> ■ Overview: Anne Peterson, <i>Assistant Administrator, Bureau for Global Health, USAID</i> ■ Size and Magnitude of the Crisis: Neff Walker, <i>Senior Epidemiologist, UNICEF</i> |
| 10:00-10:30 | <p>Keynote Address</p> <ul style="list-style-type: none"> ■ Ambassador Randall L. Tobias, <i>U.S.G. Global AIDS Coordinator</i> |
| 10:30-10:45 | Coffee Break |
| 10:45-11:05 | <p>Global Overview of the Situation of Children Affected by HIV/AIDS
 <u>Chair:</u> Connie Carrino, <i>Director Office of HIV/AIDS, USAID</i></p> <ul style="list-style-type: none"> ■ Roeland Monasch, <i>Team Leader, Monitoring & Evaluation, HIV/AIDS, UNICEF</i> |
| 11:05-11:25 | <p>Impact of HIV/AIDS on Children</p> <ul style="list-style-type: none"> ■ Moses Dombo, <i>Senior Technical Officer, Family Health International</i> |
| 11:25-11:45 | Question and Answer Session |
| 11:45-12:25 | <p>Global/National Strategies and Action
 <u>Chair:</u> Roxanna Rogers, <i>Deputy Director Office of HIV/AIDS, USAID</i></p> <ul style="list-style-type: none"> ■ Mark Connolly, <i>Child Protection Adviser, UNICEF</i>
 Peter McDermott, <i>USAID</i> |
| 12:25-12:45 | <p>Overview of the Knowledge Base
 Isolde Birdthistle, <i>Consultant</i></p> |
| 12:45-1:00 | Question and Answer Session |
| 1:00-2:00 | <p>Lunch Program - USAID Responses</p> <ul style="list-style-type: none"> ■ Linda Sussman, <i>USAID</i> |

- 2:00-4:00 **Programs, Models and Approaches**
Chair: Linda Sussman, *USAID*
- **Psychosocial and Youth Involvement**
Brighthon Gwezera, *Masiye Camp & YOCIC*
 - **NGO Umbrella Network** (Cambodia)
Pok Panhavichetr, *Khmer HIV/AIDS NGO Alliance*
 - **Linking with Community-based Care and Support** (India)
D. T. Reji Chandra, *Palmyrah Workers Development Society*
 - **Strengthening Local Community Responses** (Africa)
Brenda Yamba, *Save the Children, U.S.*
- 4:00-4:30 **Keynote Speaker**
Chair: Anne Peterson
- **Mrs. Graça Machel**, *Founder, Foundation for Community Development, Mozambique*
- 4:30-5:30 **Overview of Faith-Based Response Study**
Chair: Michael Magan, *Director Faith Based Initiative, USAID*
- James Cairns, *Director, Program on Children, World Conference of Religions for Peace*

Day 2: November 4, 2003

- 8:15-8:30 **Coffee**
- 8:30-9:00 **Introduction to Working Groups**
- 9:00-10:30 **Plenary: Monitoring and Evaluation**
Chair: Daniel Kabira, *Senior Advisor HIV/AIDS and M&E, USAID*
- Roeland Monasch, *UNICEF*
 - Kate Harrison, *Program Officer: Children, International HIV/AIDS Alliance*
 - Inoussa Kabore, *Associate Director for Monitoring & Evaluation & Research, Family Health International*
 - Leanne Dougherty, *Senior Research Associate, The Futures Group*
- 10:30-10:45 **Coffee**
- 10:45-1:00 **Small Group Session I** (some sessions are repeated)
- Education
 - HIV+ Children
 - Models of Community Approaches
 - Health and Nutrition
- Concurrent Session: Video Screening**
- 1:00-2:30 **Lunch**
- Optional session: Introduction to Building Blocks Community Resource (1:30-2:00)

- 2:30-4:45 **Small Group Session II**
- Education
 - HIV+ Children
 - Children without Family Care
 - Emotional Well-Being

Day 3: November 5, 2003

- 8:15-8:30 **Coffee**
- 8:30-9:00 **Plenary: Introduction to Available Resources**
- 9:00-11:15 **Small Group Session III**
- Models of Community Approaches
 - Children without Family Care
 - Economic Strengthening and Food Security
 - Emotional Well-Being
- Concurrent Session: Video Screening**
- 11:15-11:30 **Coffee**
- 11:30-12:30 **Plenary: Research Issues**
Chair: Douglas Webb, *HIV/AIDS Adviser, Save the Children, UK*
- Jan Williamson, *Consultant*
 - Diane Swales, *Save the Children U.K.*
- 12:30-1:45 **Lunch** (Marketplace of Tools and Documents)
- 1:45-2:45 **Positive Images: The Role of Media**
Chair: Renuka Bery, *Dissemination and Advocacy Manager, SARA Project, AED*
- Hally Mahler, *YouthNet*
 - Brenda Yamba, *Save the Children U.S.*
 - Annmarie Christensen, *Director of Publications, Global Health Council*
- 2:45-3:45 **Presentations from Small Groups**
- 3:45-4:30 **Next Steps and Closing**
Chair: Hope Sukin, *Health Team Leader, Bureau for Africa, USAID*

ANNEX TWO

PARTICIPANT LIST

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Renaissance Washington Hotel
Washington, DC
November 3-5, 2003**

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ANNEX THREE

STRATEGIES AND PRINCIPLES FROM *Children on the Brink 2002*

Strategies to Assist Children

1. Strengthen and support the capacity of families to protect and care for their children.
2. Mobilize and strengthen community-based responses.
3. Strengthen the capacity of children and young people to meet their own needs.
4. Ensure that governments develop appropriate policies, including legal and programmatic frameworks, as well as essential services for the most vulnerable children.
5. Raise awareness within societies to create an environment that enables support for children affected by HIV/AIDS.

Principles for Programming

1. Strengthen the protection and care of orphans and other vulnerable children within their extended families and communities.
2. Strengthen the economic coping capacities of families and communities.
3. Enhance the capacity of families and communities to respond to the psychosocial needs of orphans, vulnerable children, and their caregivers.
4. Link HIV/AIDS prevention activities, care and support for people living with HIV/AIDS, and efforts to support orphans and other vulnerable children.
5. Focus on the most vulnerable children and communities, not only those orphaned by AIDS.
6. Give particular attention to the roles of boys and girls and men and women and address gender discrimination.
7. Ensure the full involvement of young people as part of the solution.
8. Strengthen schools and ensure access to education.
9. Reduce stigma and discrimination.
10. Accelerate learning and information exchange.
11. Strengthen partners and partnerships at all levels and build coalitions among key stakeholders.
12. Ensure that external support strengthens and does not undermine community initiative and motivation.

ANNEX FOUR

ADDITIONAL RESOURCES

- ⦿ The International HIV/AIDS Alliance and Family Health International's Institute for HIV/AIDS are working together to create an electronic toolkit for programs working with orphans and other vulnerable children, so programs can more easily share and learn from each other. The toolkit brings together a library of electronic resources collected from NGOs, CBOs, FBOs, and civic and government programs around the world who are working with OVC. The toolkit will include guidance on topics such as: how to set up and run a CBO and technical advice on child health and nutrition, psychosocial support, household economic security, and treatment and care of children living with HIV/AIDS. Also included are examples of situation analyses, key studies, grant reporting forms, and enumeration forms.

Send useful resources to:

Kate Harrison: kharrison@aidsalliance.org or
Gretchen Bachman: GBachman@fhi.org

The toolkit will be available via the Internet (early Spring 2004), on the international HIV/AIDS alliance website, www.aidsalliance.org and on CD-ROM. By Summer 2004, a hard copy summary will also be available.

- ⦿ The Displaced Children and Orphans Fund has compiled a CD-ROM with over 270 documents relating to children affected by HIV/AIDS. Contact Sandy Jenkins at sandy@dcofwwf.org for more information. Additional information/documents on orphans and vulnerable children are available from www.usaid.gov and www.synergyaids.com.



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