Social Impact Consultants

Discovering better ways
to solve social problems

Conrad N. Hilton Foundation
Children Affected By HIV/AIDS Strategy Development
Phase I Landscape Research Findings

Prepared for:

Conrad N. Hilton
FOUNDATION

May 2011

Phase I of the Strategy Development Process for the Children Affected By HIV/AIDS (CABA) Priority Area

<u>Key Activities</u>

•Conducted research on the landscape of **needs, funding flows, and current efforts** of key players attempting to address this population

•Conducted interviews with **30+ experts in funding, service provision, and policy**

•Completed additional **research identifying preliminary opportunities for intervention**

•**Vetted preliminary findings** with Children Affected by HIV/AIDS stakeholders at a convening held at UNICEF headquarters in New York

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The AIDS Pandemic Remains a Massive Global Health Problem Despite Almost Three Decades of Sustained Effort to Address the Disease

33.3 million

people were estimated to be **living with HIV** at the end of 2009 and this number continues to grow

2.6 million

people were estimated to be **newly infected** by HIV in 2009

Almost two-thirds

of those with HIV/AIDS in low and middle income countries are **not receiving the treatment they need**

Source: UNAIDS 2010 Global Report

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Ongoing Efforts Targeting HIV/AIDS and Child and Maternal Health Are Aligned with the Millennium Development Goals

In 2000, the largest gathering of world leaders at the United Nations Headquarters in New York adopted the **United Nations Millennium Declaration**. The Declaration, endorsed by 189 countries, committed nations to a **new global partnership to reduce extreme poverty** and set out a series of targets to be reached by 2015. These have become known as the **Millennium Development Goals (MDGs)**.

MDG 6 aims to have halted HIV/AIDS' growth by 2015 and begin its reverse while achieving universal access to treatment by 2010. While the **growth of HIV has stabilized** in many countries, the **rate of infection continues to surpass** the amount of **treatment resources available**.

Millennium Development Goals

1. Eradicate extreme poverty and hunger
2. Achieve universal primary education
3. Promote gender equality and empower women
4. Reduce child mortality
5. Improve maternal health
6. Combat HIV/AIDS, malaria, and other diseases
7. Ensure environmental sustainability
8. Develop a global partnership for development

MDG's 4 and 5 are also **closely tied** to work in the area of children affected by HIV/AIDS

Children and communities affected by HIV/AIDS require more than just health interventions; poverty relief, education, and support for gender equality are needed for long-term impact

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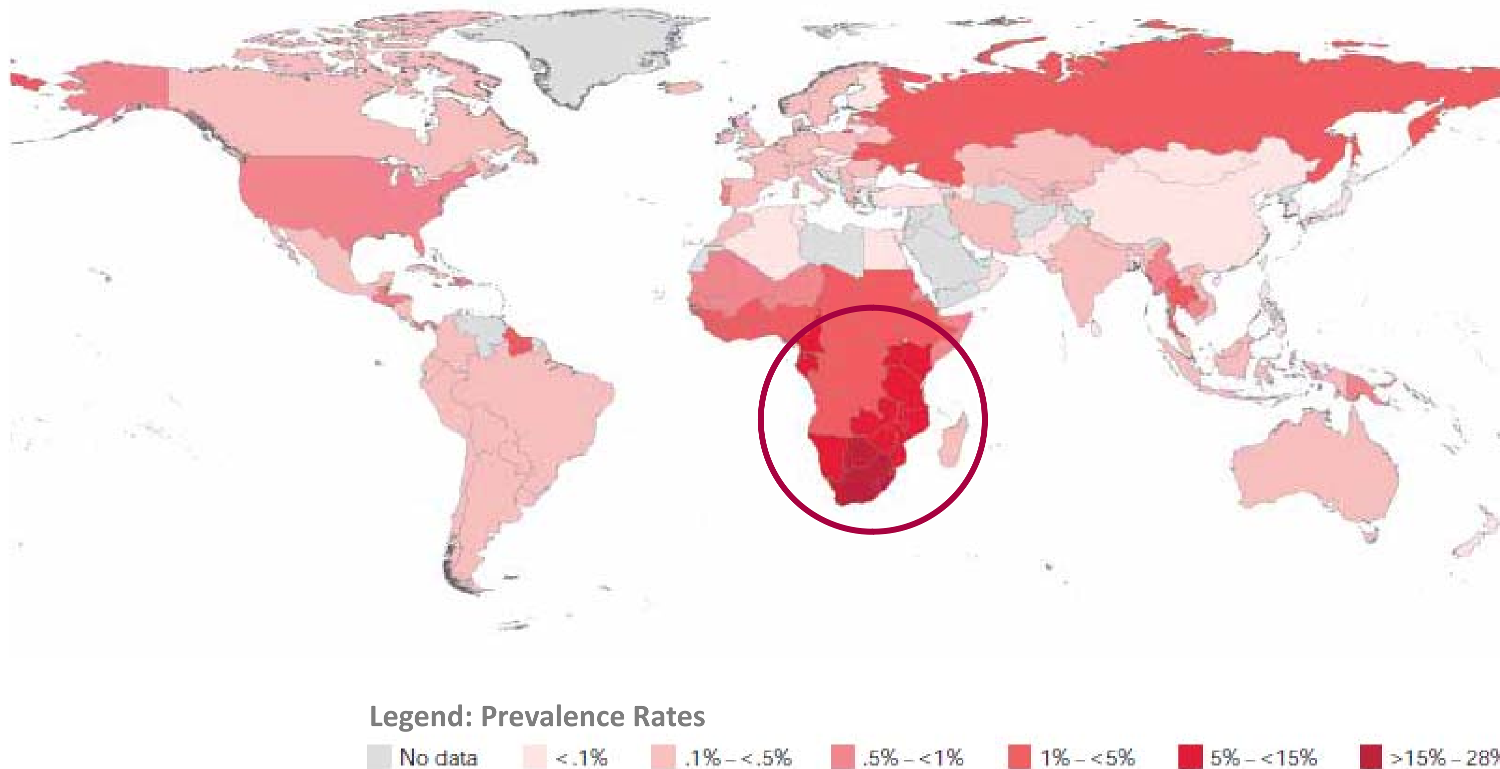
AIDS Continues to Be a Massive Global Health Issue, with Southern and Eastern Africa Bearing a Disproportionate Share of the Burden of the Disease

Global Prevalence of HIV, 2009



The majority of new HIV infections and AIDS-related deaths are also concentrated in sub-Saharan Africa*

* 1.8M of 2.6M new infections worldwide and 1.3M of 1.8M AIDS-related deaths occurred in sub-Saharan Africa in 2009. Source: UNAIDS 2010 Global Report

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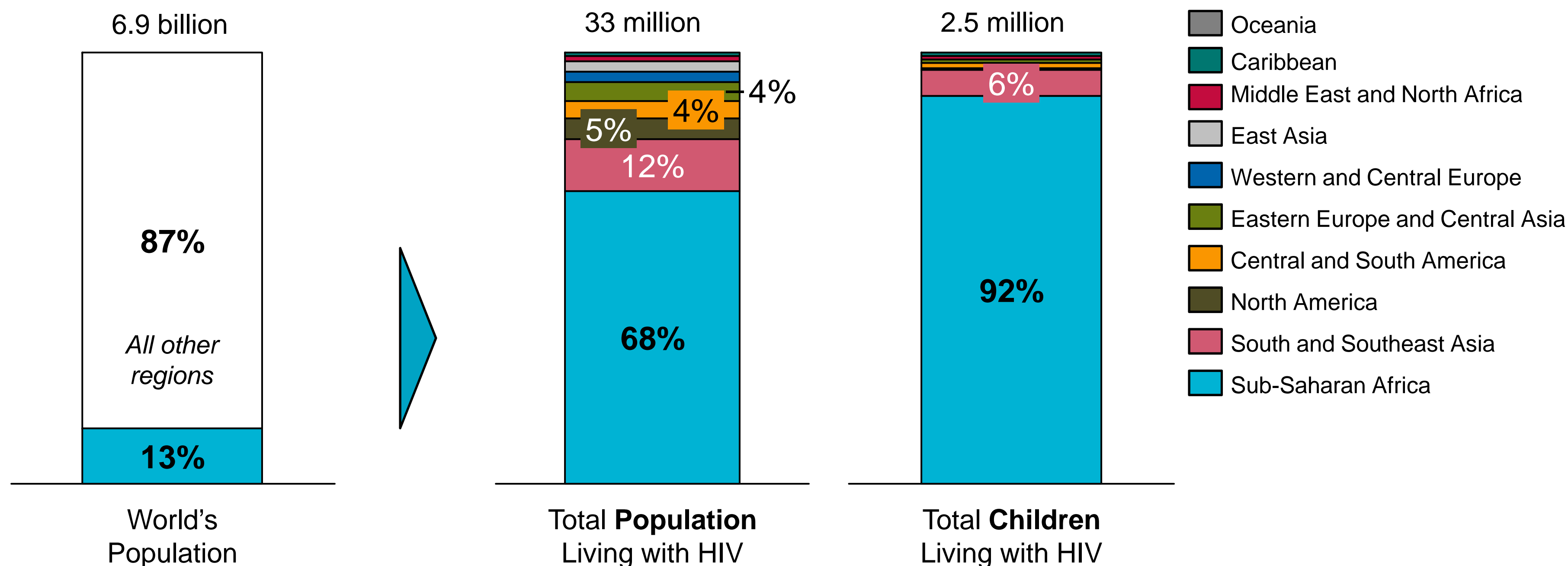
Research suggests that there are approximately 30 million total children affected by HIV/AIDS in Sub-Saharan Africa*



* Based on 2004 World Bank report. Includes children orphaned by AIDS, separated from parents, living with dysfunctional caretakers, or with needs beyond parental care. 2009 UNICEF data on vulnerable children suggests there are over 70 million vulnerable children (due to factors including but not limited to AIDS) within Sub-Saharan Africa.
Sources: UNAIDS 2010 Global Report. Population Reference Bureau, 2010 World Data Sheet; 2004 World Bank report entitled *Orphans and Vulnerable Children (OVC);* number of vulnerable children is a directional figure calculated by multiplying UNICEF' child population statistics (414 million in 2009) by the average of regional percentages of children in African countries that are vulnerable (19.05%) compiled in UNICEF's 2009 Progress Report.

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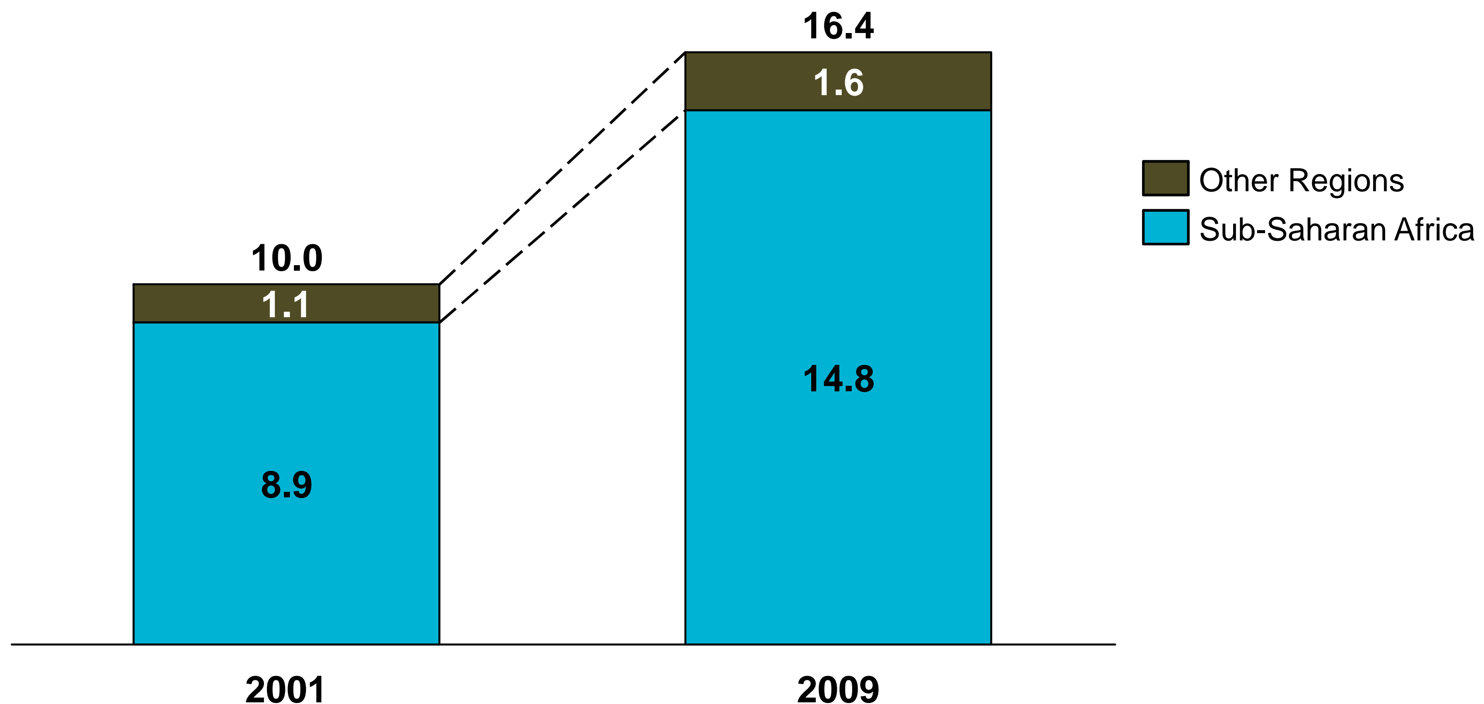
The Number of Orphans Due to AIDS Also Continues to Grow, with Sub-Saharan Africa Again Shouldering the Majority of the Burden



Source: UNAIDS 2010 Global Report

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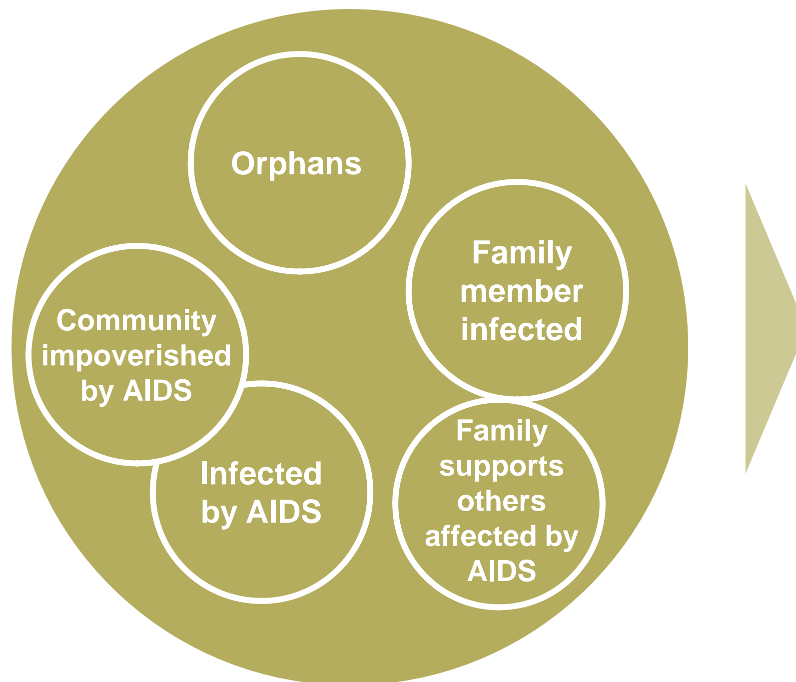
Children Are Affected by HIV/AIDS in a Variety of Ways – Those Who Are the Most Vulnerable Are Often Those Who Are Not Orphans

Children Affected by HIV/AIDS in sub-Saharan Africa *(~30M Total)*



In order to truly address the most vulnerable and destitute children, it is critical to serve *all* children affected by HIV/AIDS

Targeting orphans may discriminate against other vulnerable children, lead to stigmatization of orphans, and may result in children being called orphans to access services

Sources: JLICA Final Report; Richter, (2010) "An introduction to family-centred services for children affected by HIV and AIDS," Journal of the International AIDS Society. Richter, Manegold and Pather. (2006), *Family and Community Interventions for Children Affected By AIDS,* funded by the WK Kellogg Foundation.

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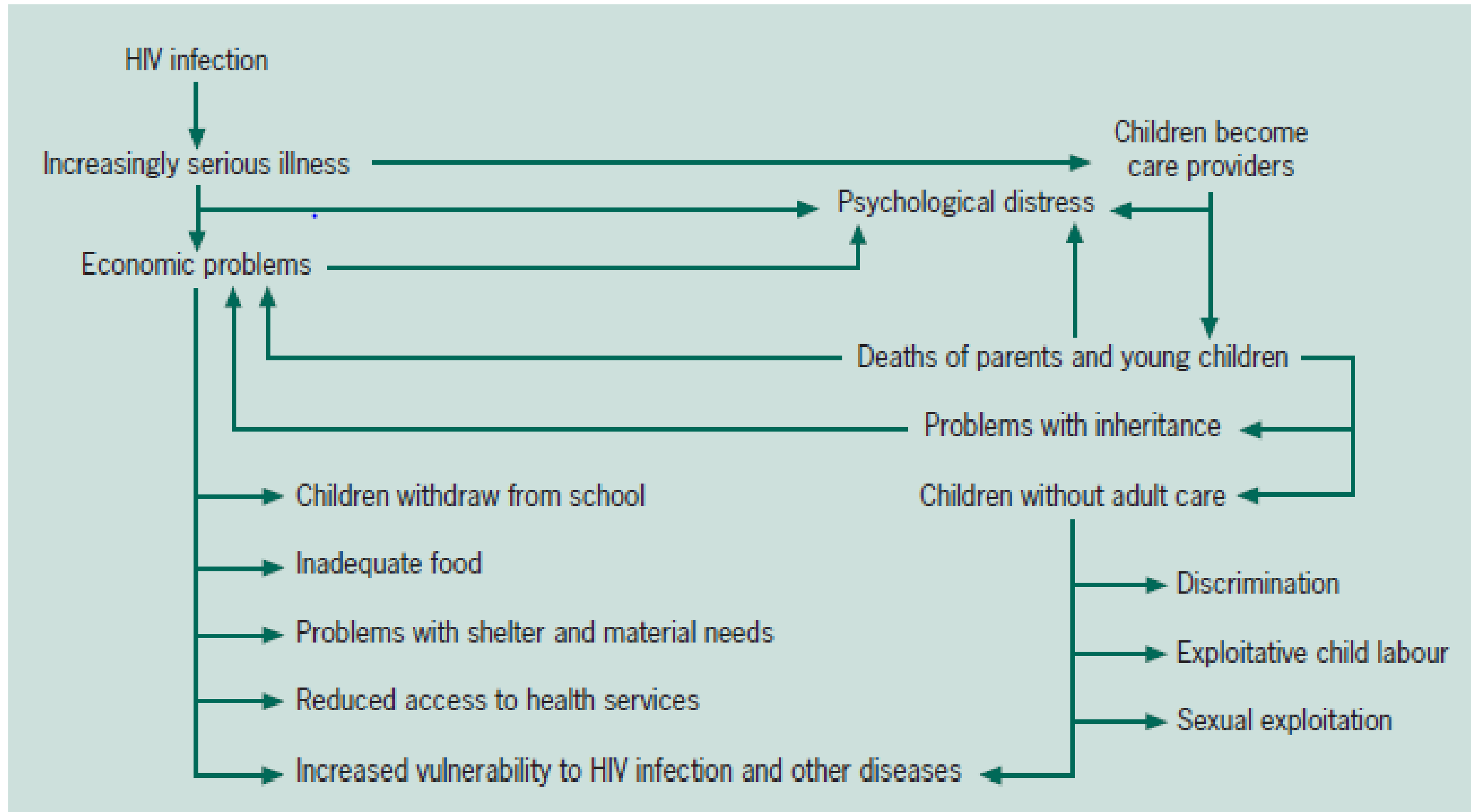
When a Family Member Is Infected with HIV, It Triggers a Range of Interrelated Problems for CABA

Problems Among Children and Families Affected by HIV/AIDS



Sources: Lippincott Williams & Wilkins, 2000, as referenced in Richter, Manegold and Pather. (2006), *Family and Community Interventions for Children Affected By AIDS,* funded by the WK Kellogg Foundation.

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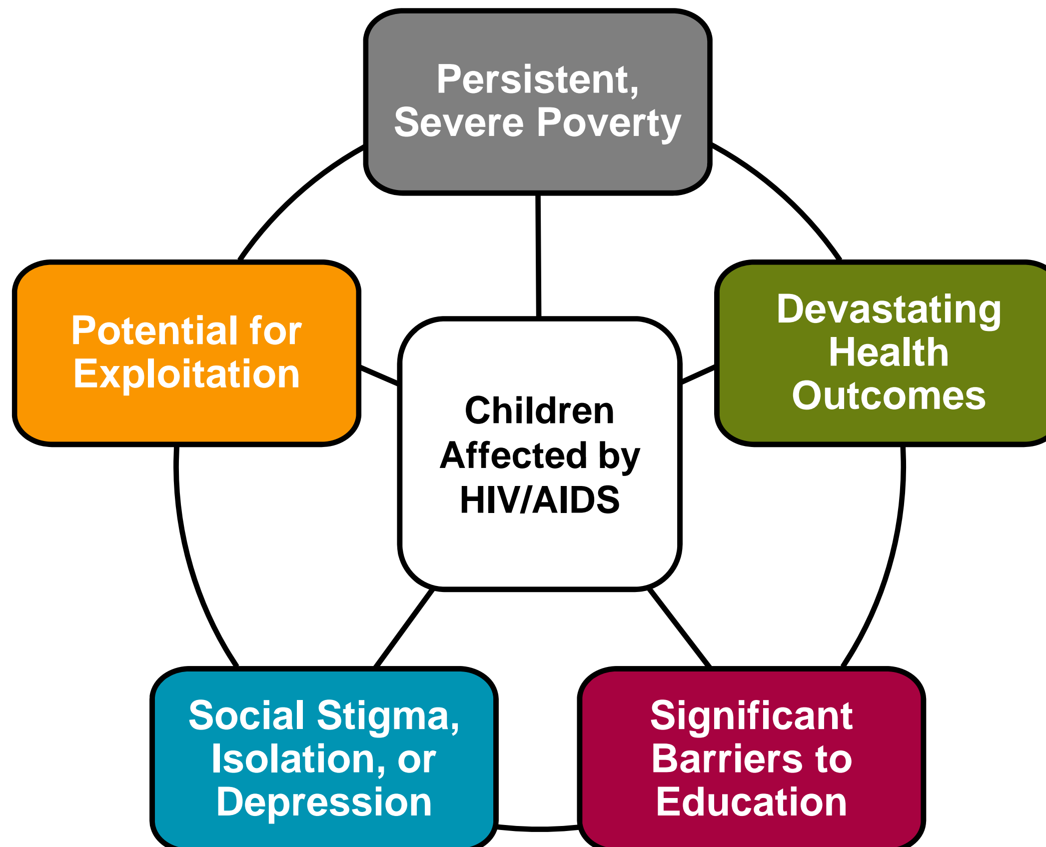
The Problems Impacting Children Affected By HIV/AIDS Are Wide-Reaching and Mutually-Reinforcing



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Each of These Areas Adds to the Challenges that CABA Face

Persistent, Severe Poverty

- Reduced family income **affects the ability to provide** for children's basic needs
- Surviving family members can be **forced to sell their assets**
- For orphans, **deeper slides into poverty** due to weakened family structure
- **Lower future income potential** stemming from barriers to education

Devastating Health Outcomes

- Higher **risk of Mother-to-Child Transmission**
- **Poor nutrition**, due to reduced family income or increased family expenditures
- **Less likely to be immunized**, and to get adequate care for childhood illness
- **Less likely to receive HIV treatment**, lack of access to Antiretroviral Therapy
- **Loss of access to services** after loss of chief advocate

Significant Barriers to Education

- **Inadequate coverage/quality** of early childhood development programs
- **Low levels of school readiness** due to lack of formative learning opportunities
- Children are **withdrawn from school** to become caregivers or laborers
- Cost of care for family makes school (uniforms, transport) **unaffordable**
- **Stigma** prevents children from going to school

Social Stigma, Isolation or Depression

- Subject to **stigma/discrimination** due to association with infected individual
- Feelings of **depression or isolation**, particularly after losing family members
- **Psychological distress** due to their role as a caregiver or head of household or due to economic strains

Potential for Exploitation

- Children affected by HIV/AIDS often face **sexual exploitation or violence, or exploitative labor**, particularly in domestic settings
- Discrimination may stem from community members or caregivers (e.g., **less food, lack of support for school, increased domestic chores**)

See appendix for key sources

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One Can Evaluate a Child's Overall Level of Vulnerability Based on Several Different Criteria

Age

Research and interviews suggest that early childhood years (0-5) and adolescence (12+) are the ages when CABA are most vulnerable.

Family Structure

Children are less likely to be vulnerable to the extent that they have at least one adult in their lives who provides consistent care, attention, and support and who ensures they are safe from abuse, neglect, or exploitation.

Economic Circumstances

Socioeconomic status has a significant bearing on outcomes for children affected by HIV/AIDS. Poverty is an issue that pervades all efforts in this space.

Health Status

Children who are infected with HIV/AIDS or at risk of being infected by a parent are made physically vulnerable by the (threat of the) disease.

Sources: FSG interviews, literature review and analysis; Child Status Index, accessed at www.ovcsupport.net.

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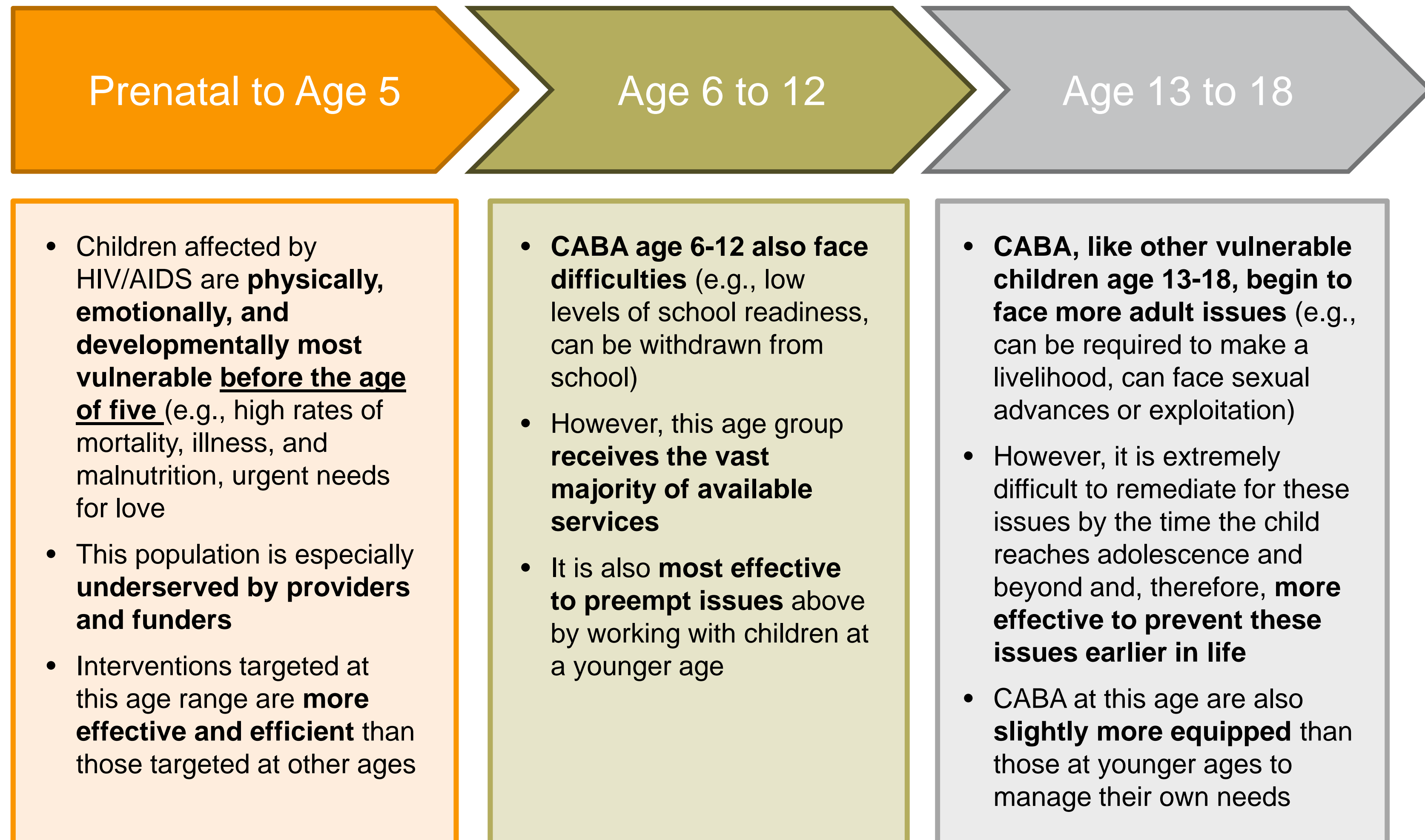
The Prenatal-to-Five Age Range Is Widely Regarded as the Time During Which CABA Are Most Vulnerable



See appendix for further age-specific detail. Sources: FSG interviews and analysis. Sherr, (2005), *Young Children and HIV/AIDS: Mapping the Field,* Bernard van Leer Foundation. WHO *Role of the Health Sector in Strengthening Systems*, 2006. *Coordinator's Notebook: An International Resource on Early Childhood Development,* (2002), The Consultative Group on Early Childhood Care and Development.

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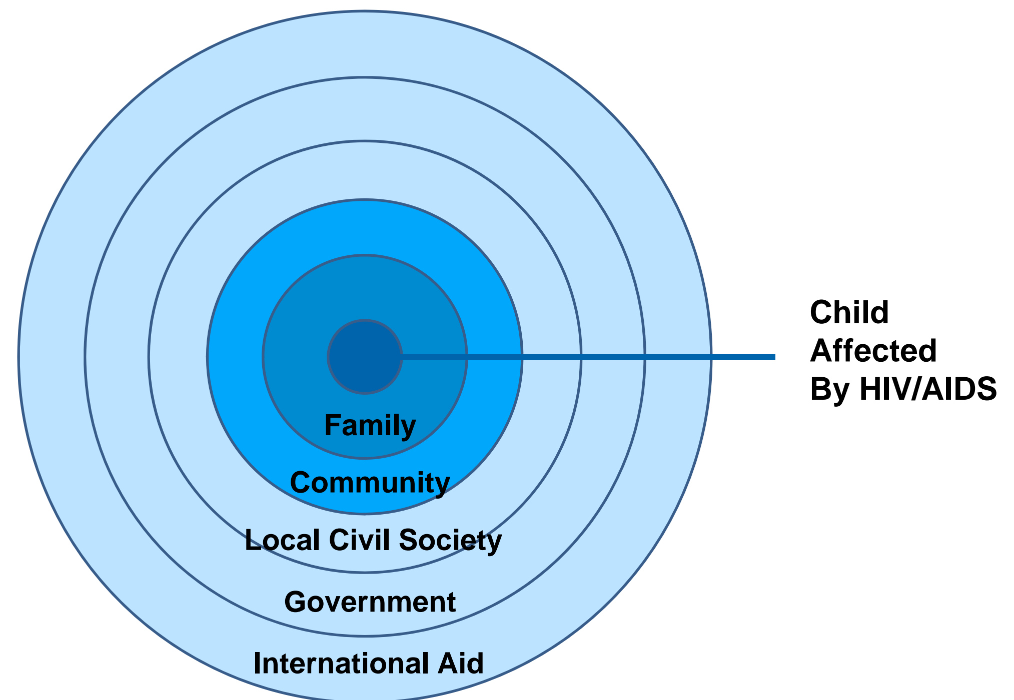
While Improving Outcomes for CABA Requires the Efforts of All Players in the Surrounding Ecosystem, Families and Communities Are the First, Crucial Line of Response

- ~**95% of all CABA,** including those who have lost parents, **continue to live with their extended family**
- **Community-based initiatives for CABA have unparalleled reach in sub-Saharan Africa, and enjoy high levels of approval and trust** among the people they serve
- **Community and family networks are under increasing strain** in many settings, as the pressures of HIV/AIDS, poverty, and food insecurity intensify. However, they remain vital for CABA
- **External efforts reach only a fraction of the most vulnerable children**, suggesting that interventions will only have significant, sustainable impact to the extent they strengthen the capacities of families and communities to protect and care for vulnerable children



Building family and community capacities is not sufficient, but it must be the foundation for addressing the impacts of HIV/AIDS on children

Sources: JLICA, Final Report. Richter, Manegold and Pather. (2006), *Family and Community Interventions for Children Affected By AIDS,* funded by the WK Kellogg Foundation.

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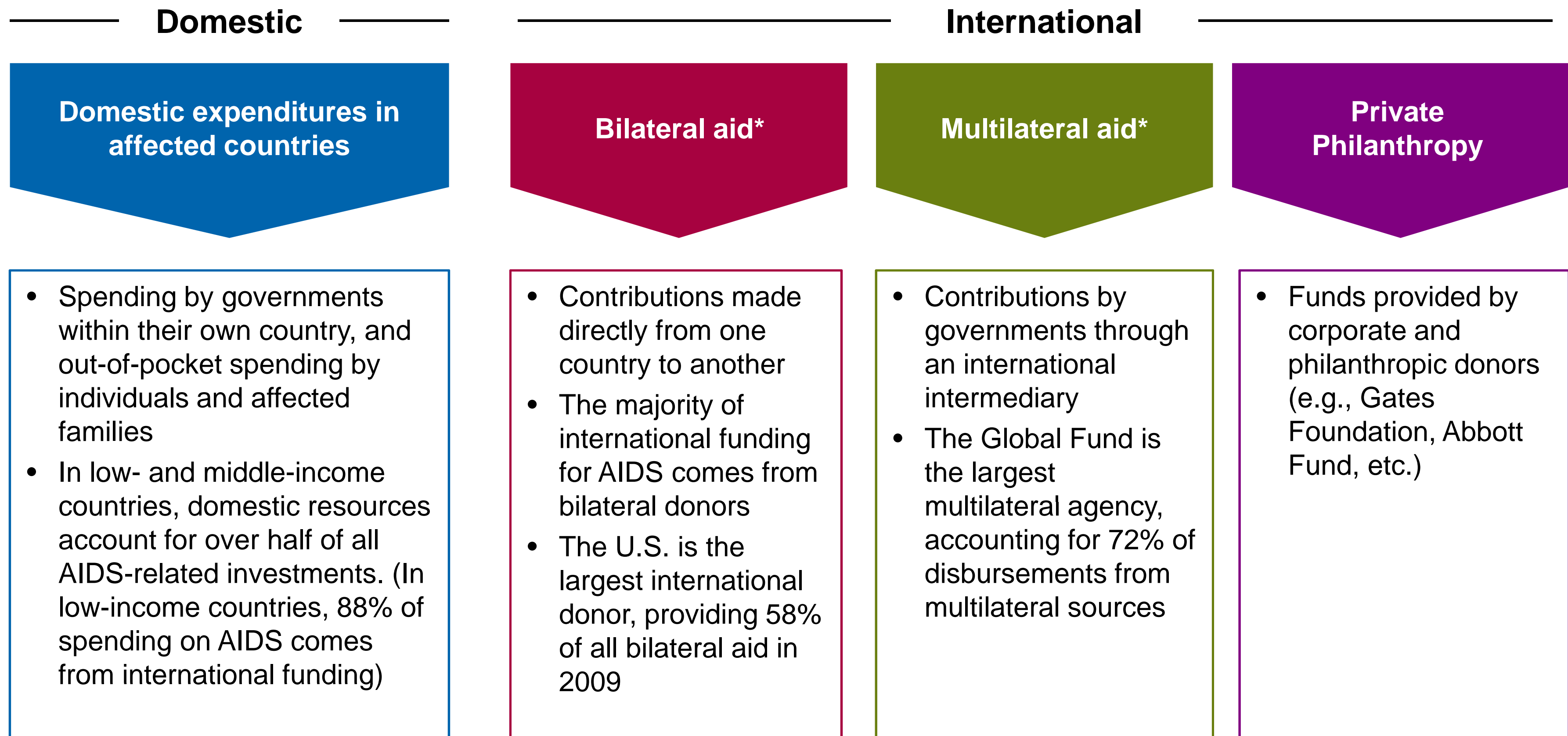
There Are Four Main Sources for HIV/AIDS Funding Globally



Overall, the U.S. provides the largest proportion of global funding (through bilateral and multilateral channels, as well as philanthropically)

* Taken together, bilateral and multilateral aid are often referred to as Official Development Assistance (ODA). Source: *Financing the Response to AIDS in Low- and Middle-Income Countries: International Assistance from the G8, European Commission,and Other Donor Governments in 2009* http://www.kff.org/hivaids/upload/7347-06.pdf, UNAIDS Global Report 2010

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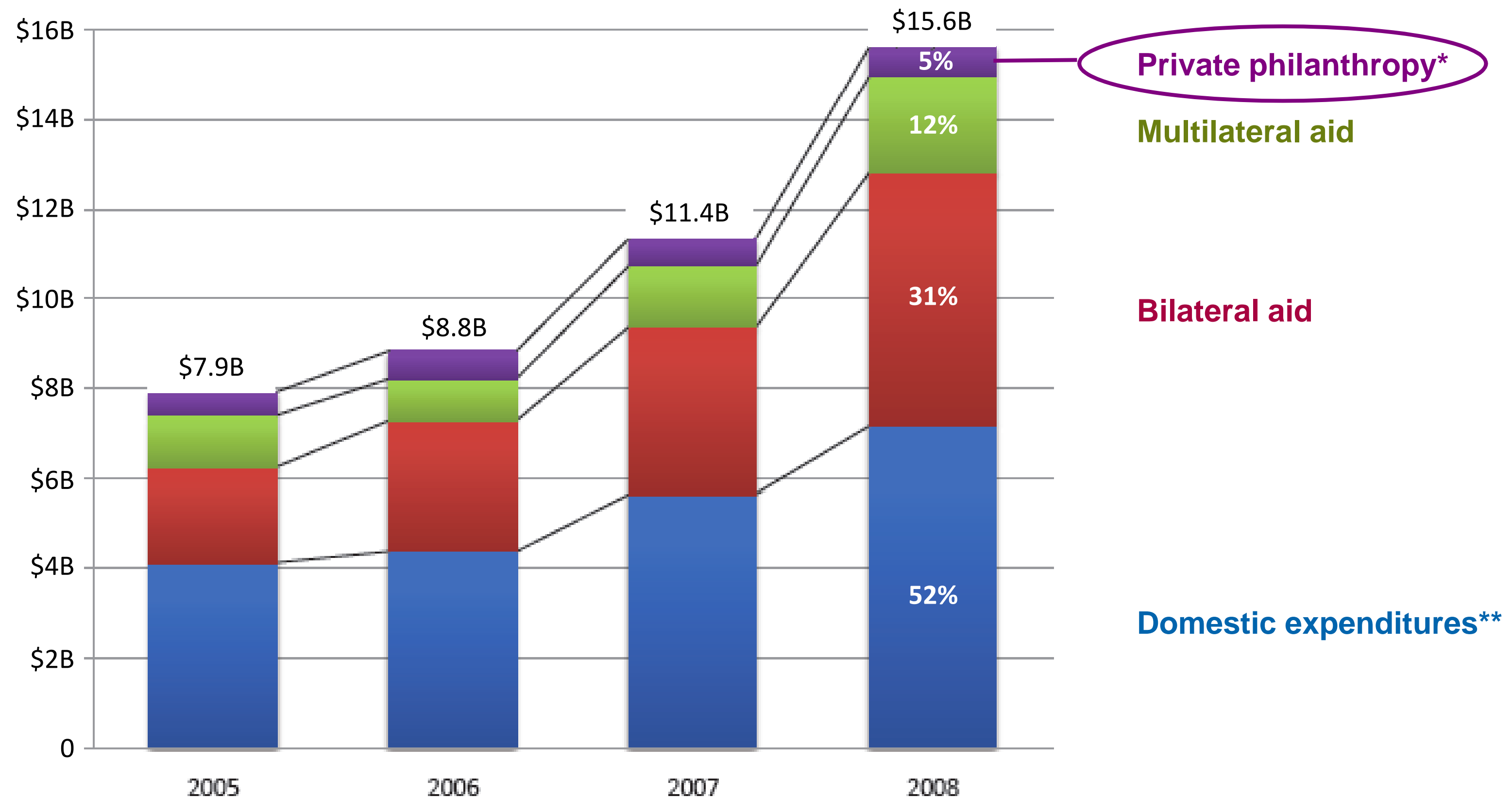
Public Funding for HIV/AIDS Efforts Dwarfs the Funding Made Available by Private Philanthropy

Total Funds Made Available for HIV/AIDS in Developing Countries, 2005-2008



Private funders must leverage their investments in order to make an impact, given the relatively small proportion of dollars they contribute

*The Gates Foundation provides a significant portion of all private philanthropic funding (e.g., its 2008 disbursements totaled ~$380M out of ~$780M in total private funding).
**This data represents average sources of funds in low- and middle-income countries. Low-income countries receive only 12% of funding from domestic sources.
Source: *Costs and Choices: Financing the Long-Term Fight Against AIDS,* Results for Development Institute, 2010. Accessed at: http://www.resultsfordevelopment.org/sites/resultsfordevelopment.org/files/resources/aids2031%20Cost%20&%20Choices.pdf.

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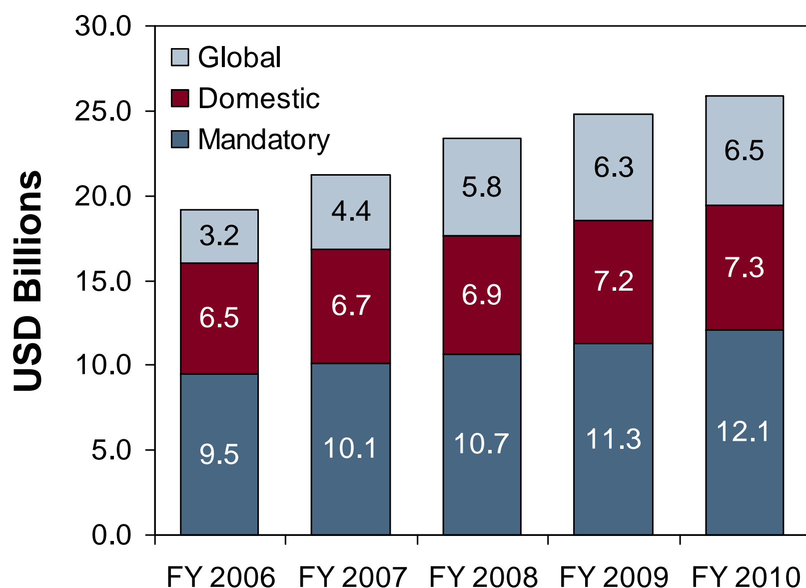
The U.S. Government Spent $23.4B in 2008 on HIV/AIDS with the Majority of Funding Allocated to Domestic Care and Treatment

The 2010 U.S. Federal Budget for HIV/AIDS Totaled $25.9 Billion



Federal Funding for HIV/AIDS Focuses Primarily on Care and Treatment

(in billions)

Category	2006	2007	2008	2009	2010
Care/ Treatment	$10.3	$11.0	$11.7	$12.5	$13.2
Cash/Housing Assistance	$2.1	$2.2	$2.3	$2.4	$2.5
Prevention	$0.9	$0.9	$0.9	$0.9	$1.0
Research	$2.6	$2.7	$2.7	$2.8	$2.8
Global	$3.2	$4.4	$5.8	$6.3	$6.5
Total	**$19.2**	**$21.2**	**$23.4**	**$24.8**	**$25.9**

- Mandatory budget includes domestic entitlements, such as Medicare, Medicaid, SSI
- Global and Domestic are annual discretionary funding
- PEPFAR is included in Global budget line
- Research includes CDC and NIH

Source: KFF HIV/AIDS Policy Fact Sheet, “U.S. Federal Funding for HIV/AIDS: The President’s FY 2010 Budget Request” May 2009

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PEPFAR, the Global Fund, and the World Bank's Multi-Country HIV/AIDS Programs Are the Three Most Significant Channels for Bilateral and Multilateral HIV/AIDS Funding

PEPFAR (President's Emergency Plan for AIDS Relief)	• Contributed $39.1 billion to HIV/AIDS efforts from 2003 to 2011 • Distributes bilateral HIV/AIDS-related funding and contributes to Global Fund • 10% of funds are authorized for OVC-focused programs • Targets 15 focus countries (Kenya, South Africa, and Nigeria received the most in 2009)
Global Fund to Fight AIDS, Tuberculosis and Malaria	• Provides funding to fight all three diseases • In the most recent round of funding, 61% of funds went toward HIV/AIDS • In total, from 2002-2010, the Fund distributed $11 billion focused on HIV/AIDS • Has funded provision of support for 4.9 million orphans, distribution of 2.3 billion condoms, and ART treatment of 2.8 million people with HIV
World Bank's Multi-Country AIDS Programs	• Provided $1.98 billion in loans from 2001-2011 • Supports HIV/AIDS prevention, care, support and treatment, and emphasizes need for evidence-based programs, building capacity, and scaling interventions • Requires existence of an HIV/AIDS coordinating body and government agreement to implement quickly and use multiple implementation groups

Source: AVERT website(*http://www.avert.org/aids-funding.htm*), World Bank Multi-Country AIDS Program website

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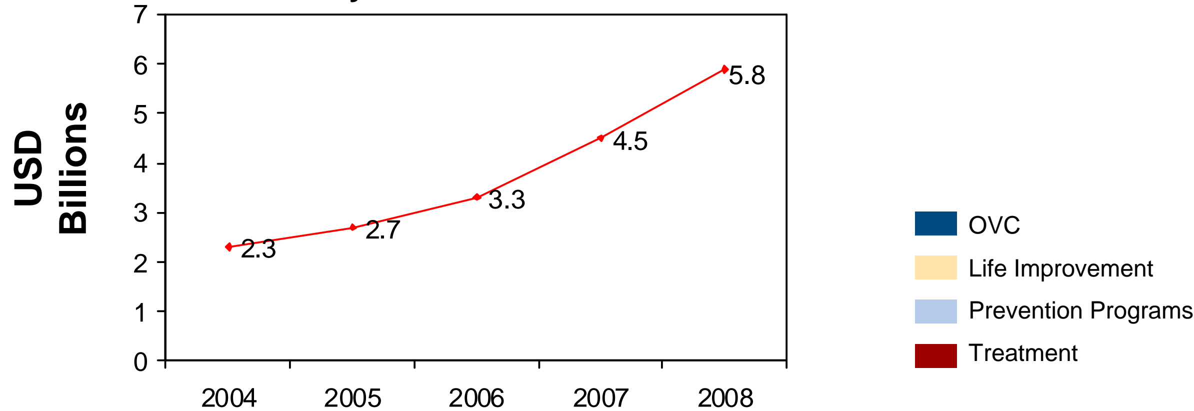
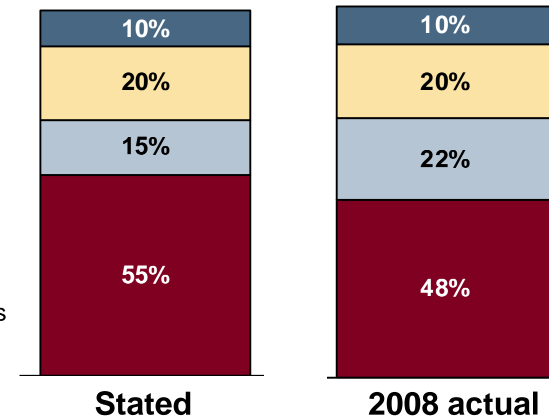
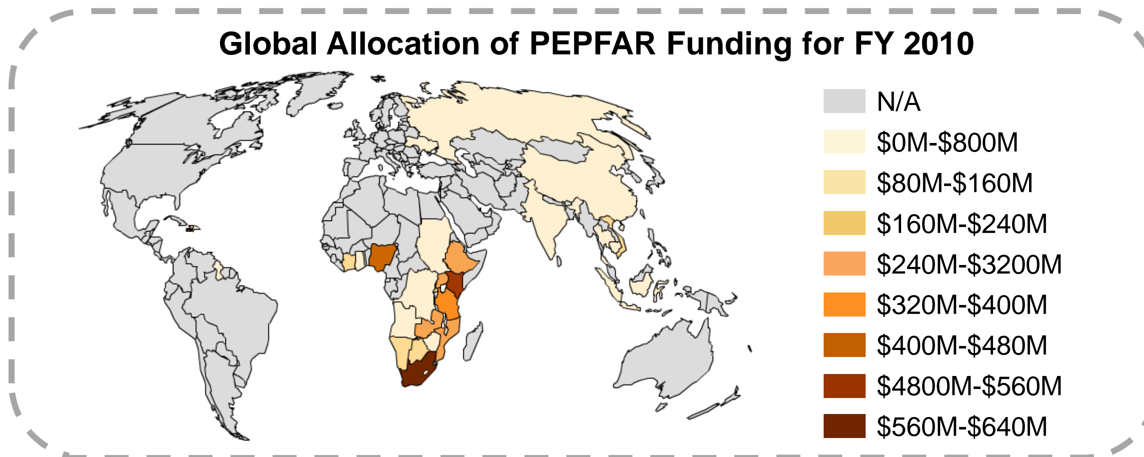
10% of the PEPFAR Funding Goes to OVC Efforts, Mainly in Sub-Saharan Africa







Top Recipients of Total PEPFAR Funds, 2004-2010	
South Africa	$2.4 B
Kenya	$2.3 B
Nigeria	$1.8 B
Ethiopia	$1.4 B
Uganda	$1.4 B
Tanzania	$1.3 B
Zambia	$1.2 B
Mozambique	$1.0 B
Rwanda	$0.6 B
Haiti	$0.5 B

In 2008, PEPFAR was reauthorized for an additional 5-year period and up to $48 billion to combat HIV, TB, and malaria

Source: KFF Global Health Facts PEPFAR funding website; USAID, "President's Emergency Plan for AIDS Relief Funding and the Global Economic Crisis" December 15, 2008; Celebrating Life: PEPFAR 2009 Annual Report to Congress

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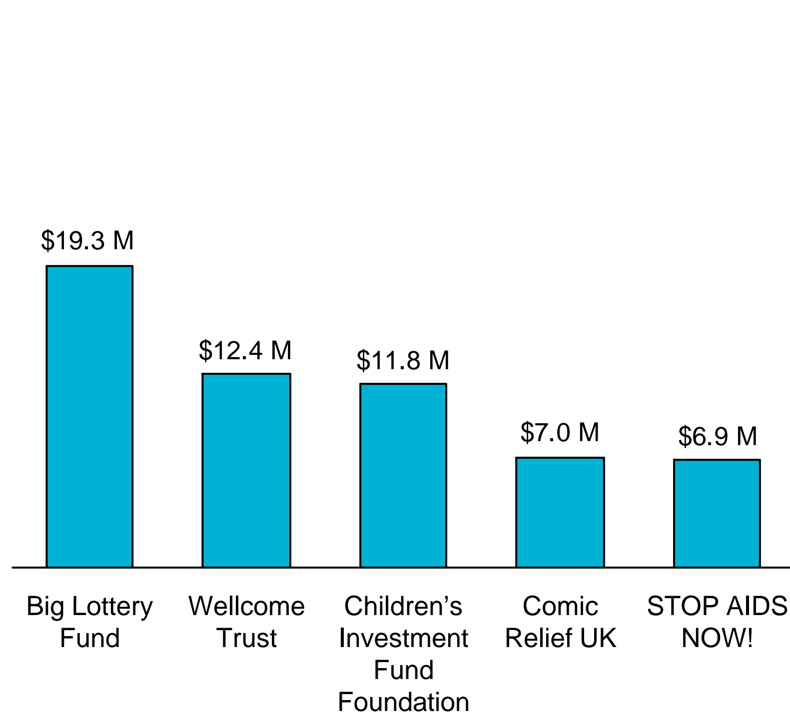
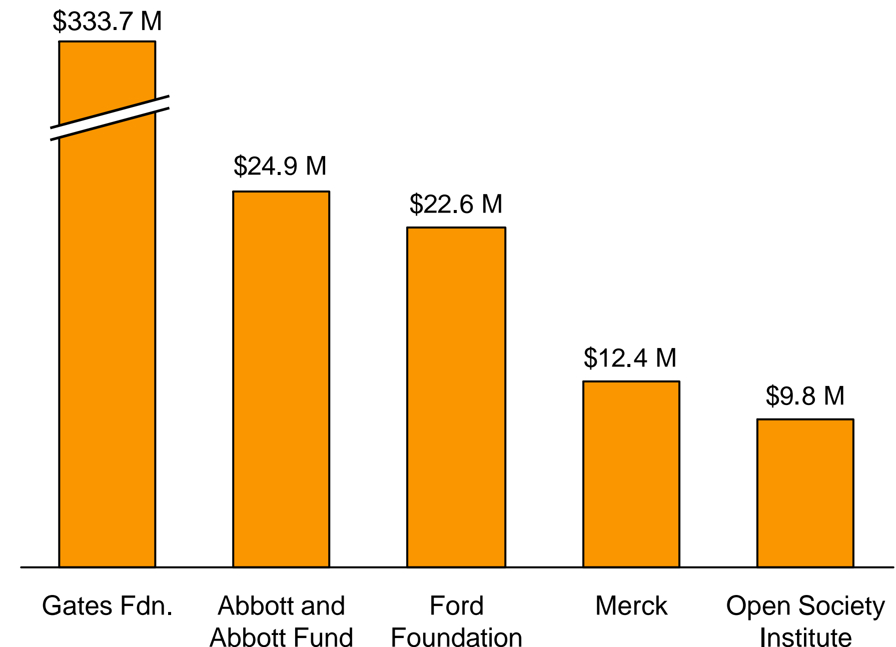
Philanthropic Funding for HIV/AIDS Is Highly Concentrated; the Ten Largest Donors Worldwide Account for 83% of Private HIV/AIDS Funding

Contributions of the Top Five **European Private Funders** of International HIV/AIDS Efforts, 2009



Contributions of the Top Five **U.S. Private Funders** of International HIV/AIDS Efforts, 2009



Source: Funders Concerned About AIDS, *U.S. Philanthropic Support to Address HIV/AIDS in 2009*; European HIV/AIDS Funders Group, *European Philanthropic Support to Address HIV/AIDS in 2009.*

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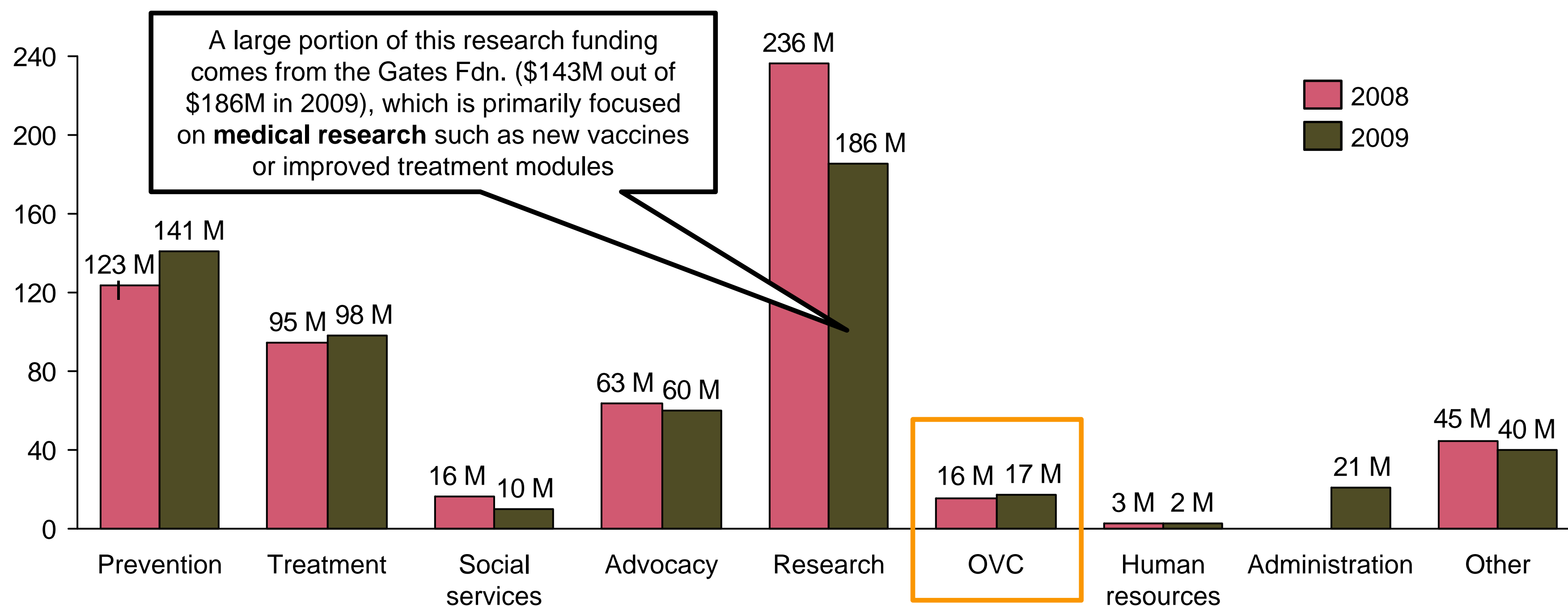
Private Spending Focuses Primarily on Medical Areas (Research, Prevention, and Treatment)

Intended Use of European and U.S. Private Funders' Contributions to International HIV/AIDS Efforts, 2008-2009 (in $ millions)



Meanwhile, OVC-related efforts receive a very small proportion of private HIV/AIDS funding

Note: This data excludes contributions from a few funders that did not meet the timeline required; data comes from combining findings from FCAA's *U.S. Philanthropic Support to Address HIV/AIDS in 2009* report and EFG's *European Philanthropic Support to Address HIV/AIDS in 2009* report; European data for international-specific HIV/AIDS efforts was not available in the report, and was estimated by multiplying total funding distribution by the portion not spent in Western and Central Europe.

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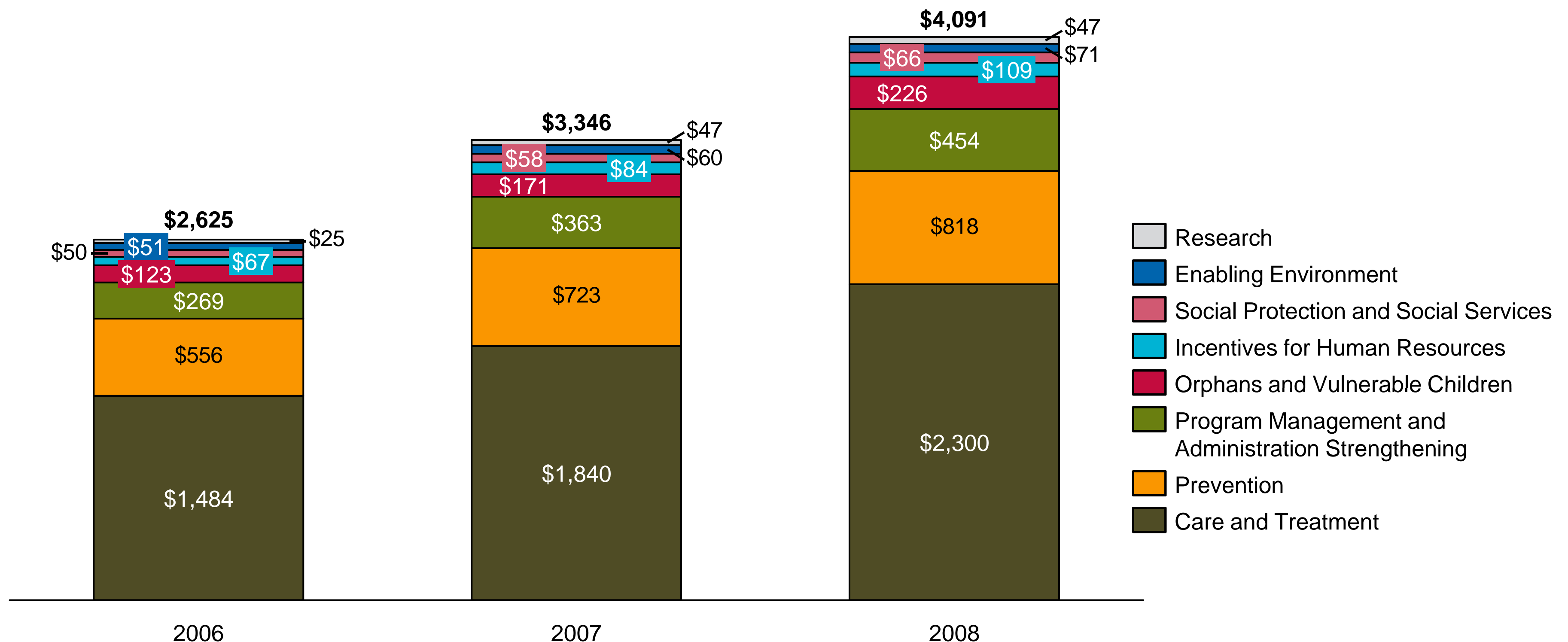
Medical Interventions – Including Treatment, Care, and Prevention – Receive By Far the Largest Amount of Overall Funding for HIV/AIDS

HIV/AIDS Spending by Programmatic Area in 43 Low- and Middle-Income Countries, 2006-2008 *(in $ millions)*



Meanwhile, direct funding for children affected by HIV/AIDS (listed as "Orphans and Vulnerable Children") represents only ~6% of overall funding for HIV/AIDS

Source: UNAIDS. Enabling Environment = advocacy efforts to reduce stigma and promote prevention, human rights programs that aim to protect the human and legal rights of those affected by HIV/AIDS, efforts to strengthen local organizations involved in this type of work, and programs meant to support AIDS-affected women and reduce gender violence. Incentives for human resources = training, recruitment, retention, deployment, and rewarding of quality performance by health care workers and managers in the HIV field. Some direct human resources costs are included in other categories; this category focuses on additional incentives that aim to ensure availability of health services

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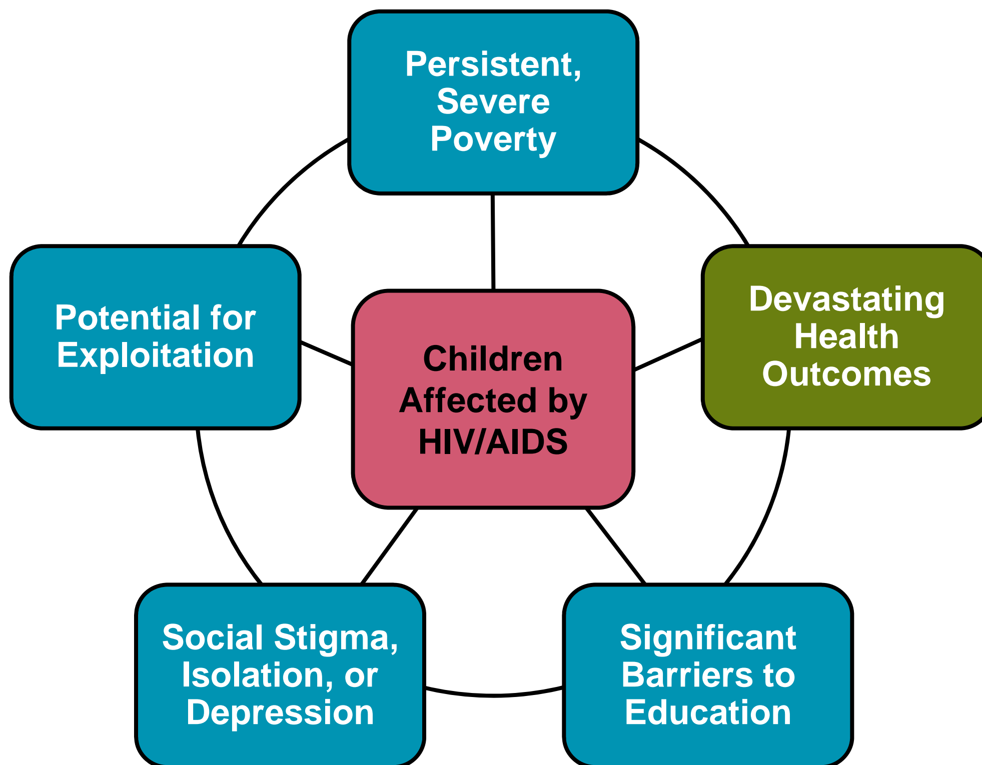
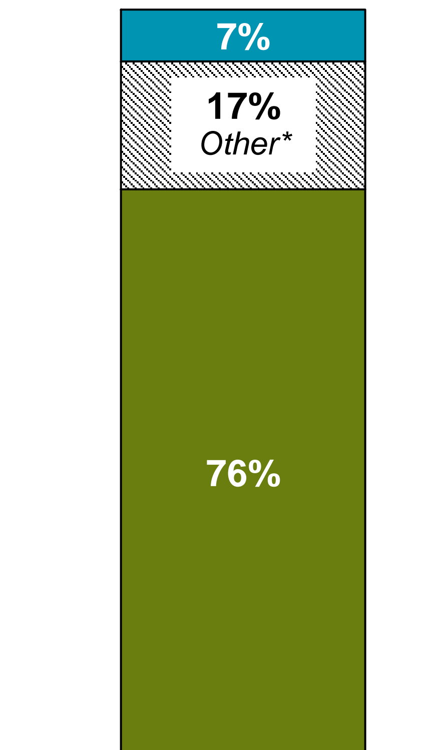
The Vast Majority of Funding for HIV/AIDS Is Spent to Address Health Outcomes, While Other Issues Receive Very Few Resources



HIV/AIDS Spending By Programmatic Area*



* Health outcomes includes funding for "care and treatment," and for "prevention." Other includes "Program Management and Administration Strengthening," "Incentives for human resources," "Enabling environment," and "Research." Source: UNAIDS

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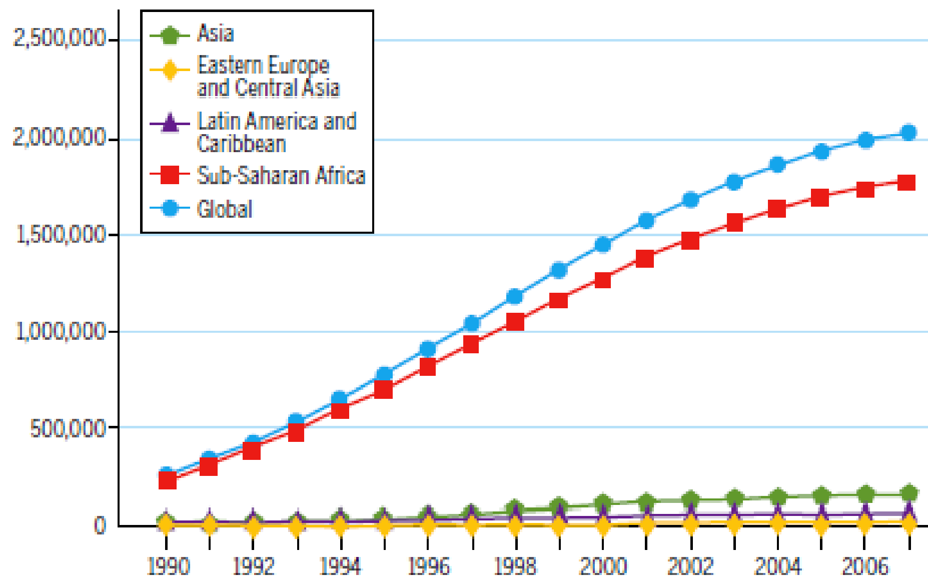
While the Number of Children Living with HIV Is Growing, this Population Is Less Likely than Adults to Receive Treatment



Antiretroviral therapy coverage is increasing but needs to be more equitable:

37% of **adults** eligible for treatment in sub-Saharan Africa were able to access life-saving medicines in 2009

26% of **children** under the age of 15 in sub-Saharan Africa received treatment in 2009

Source: UNAIDS 2010 Global Report; JLICA Final Report.

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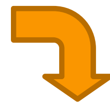
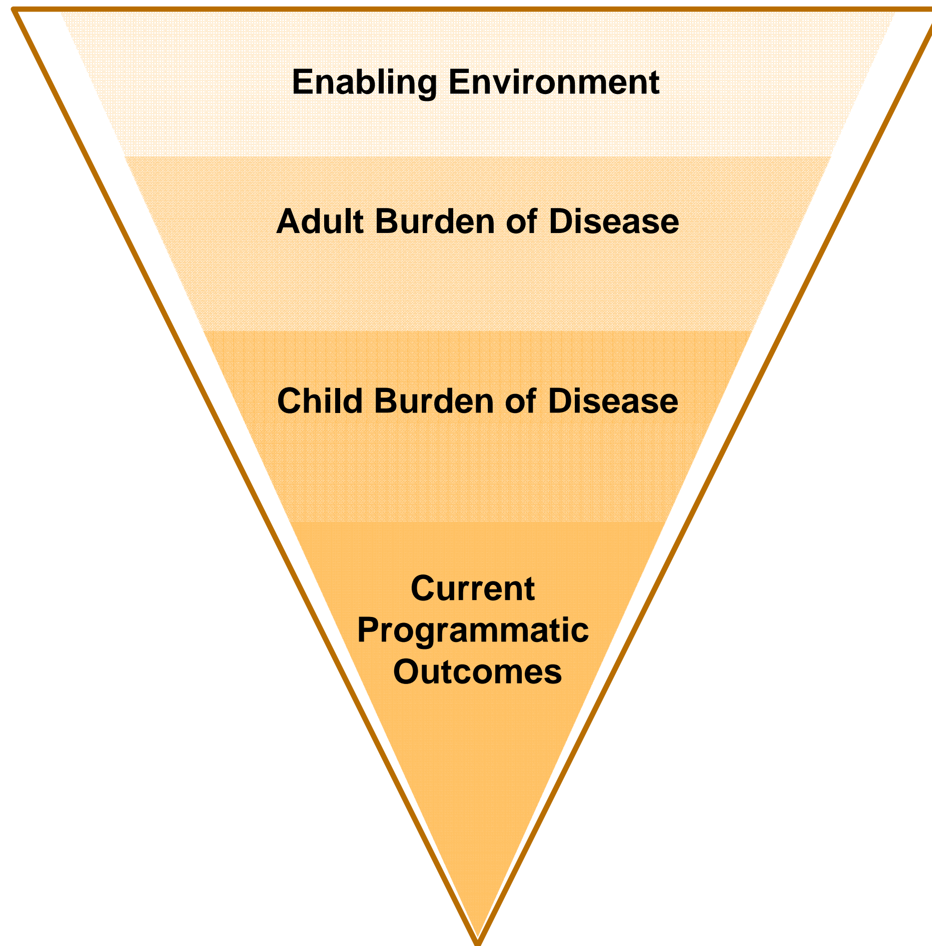
Criteria to Assess 42 Sub-Saharan African Countries and Determine a Preliminary Set of Geographies for Further Research

42 Countries





Rationale

A country has to be relatively stable

The adult burden of disease should be high, representing overall high need and high opportunity for impact

Countries where there are large numbers of children affected by HIV/AIDS to address

Countries that are not currently seeing significant outcomes on CABA programs

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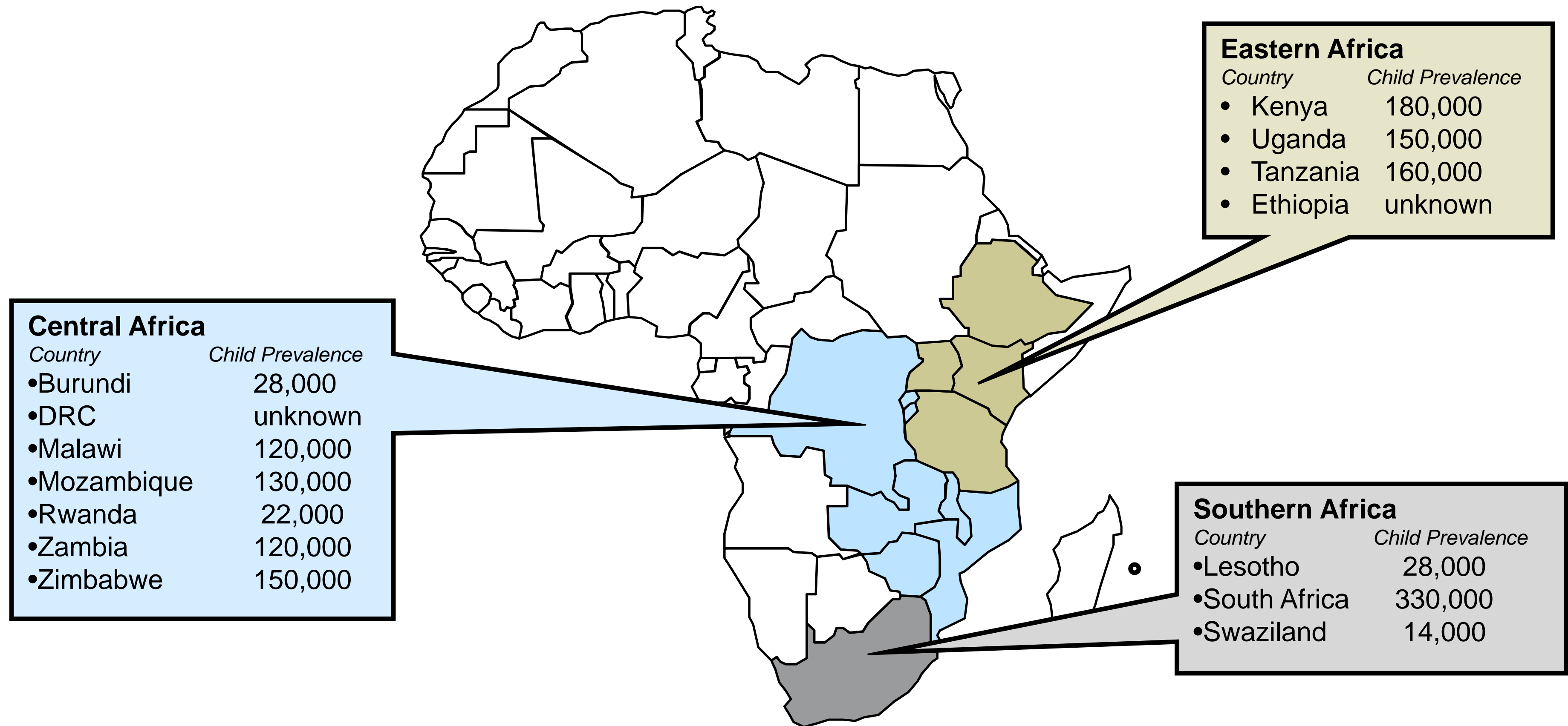
Filter Criteria Pointed to 16 Potential Priority Countries that Were Grouped into Three Clusters (According to Geographic, Cultural, and Political Similarities)



See appendix for further information on geographic criteria.
Sources: UNICEF, USAIDS, The Economist, United Nations Development Project

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A Preliminary Set of Countries with a High Disease Burden, Enabling Environments in Which to Work, and Poor Outcomes

Country	Children with HIV	Adult HIV prevalence	Political stability**	Domestic Investment Priority Index***	Development outcomes****
Eastern Africa					
Tanzania	160,000	5.6%	High	-	Low
Uganda	150,000	6.5%	Medium	High	Low
Ethiopia	-	2.1%	High	-	Low
Kenya	180,000	6.3%	Medium/Low	Medium	Medium
Central Africa					
Mozambique	130,000	11.5%	High	Low	Low
Burundi	28,000	3.3%	Medium	-	Low
Zimbabwe	150,000	14.3%	Low	Low	Low
Zambia	120,000	13.5%	Medium/Low	-	Low
Malawi	120,000	11.0%	High	Low	Low
Rwanda	22,000	2.9%	High	-	Low
DRC	7,900*	-	Low	Medium	Low
Southern Africa					
Swaziland	14,000	25.9%	High	-	Medium
Lesotho	28,000	23.6%	Medium	Medium	Low
South Africa	330,000	17.8%	Medium	Medium	Medium

Note: *While there is limited available HIV/AIDS data on DRC, it is included for now based on qualitative factors and will be researched further in Phase II. **The political instability index published by the Economist was used to measure political stability, countries that have higher political stability were preferred over lower ***The DIPI is a measure of the extent of investment priority governments give to the AIDS response, higher was preferred over lower ****The Human Development Index was used to measure development outcomes and lower was preferred over high scores.
Sources: UNICEF, USAIDS, The Economist, United Nations Development Project

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High Child, Infant, and Neonatal Mortality Rates Afflict These Geographies

Child and Infant Mortality Rates (deaths per 1,000 live births)

Country	Child (under-five) mortality rate	Infant mortality rate	Neonatal mortality rate*
Eastern Africa			
Tanzania	103	67	32 (2004)
Uganda	135	84	29 (2006)
Ethiopia	109	69	39 (2005)
Kenya	128	81	33 (2004)
Central Africa			
Mozambique	130	90	37 (2004)
Burundi	168	102	35 (1987)
Zimbabwe	96	62	24 (2006)
Zambia	148	92	34 (2007)
Malawi	100	65	27 (2004)
Rwanda	112	72	28 (2008)
DRC	199	126	42 (2007)
Southern Africa			
Swaziland	83	59	22 (2007)
Lesotho	79	63	46 (2004)
South Africa	67	48	15 (2003)

For comparison, the child (under-five) mortality rate in the U.S. was 8 deaths per 1,000 live births in 2008, while the infant mortality rate was 7 deaths per 1,000 live births

*Note: Neonatal mortality data is compiled from latest reported data in WHO Country Profiles, which span a broad range of years; thus, the year of collection has been included
Sources: World Health Organization Global Health Observatory Database, WHO Country Profiles; all child and infant mortality data is from 2008 or 2009, except for the DRC's statistics which are from 2005

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Key Principles to Guide Strategic Decision-Making Going Forward

Priorities for Developing Strategic Recommendations

- Large number of CABA
- Most vulnerable CABA
- Greatest possible impact relative to dollars spent
- Evidence-based interventions
- Build upon existing Conrad N. Hilton Foundation experience
- Partnership opportunities with other key players
- Ability to leverage public and private funds

Sources: FSG interviews, literature review, and analysis

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Next Steps to Guide Phase II of Children Affected by HIV/AIDS Strategy

- ✓ All children affected by HIV/AIDS, including orphans
- ✓ Prenatal to age 5
- ✓ Eastern, Central, or Southern Africa

Phase II

Identify **strategic options** to address all CABA and to effectively serve the prenatal to age 5 age range

Conduct **additional geographic research** to examine country-specific needs and current efforts

Identify **potential partners** to make a leveraged impact

Host a **funders convening** and a **site visit to Africa** to deepen understanding of potential options for impact

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Appendix

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Glossary

- **AIDS:** Acquired immunodeficiency syndrome
- **ART:** Antiretroviral therapy
- **ARV:** Antiretroviral
- **CABA:** Children affected by HIV/AIDS
- **CBO:** Community-based organization
- **FBO:** Faith-based organization
- **GFATM:** Global Fund for AIDS, TB and Malaria
- **HIV:** Human immunodeficiency virus
- **Incidence:** The number of new infections
- **MTCT:** Mother to child transmission
- **NGO:** Non-governmental organization
- **Orphan:** Child who has lost one or both parents
- **OVC:** Orphans and vulnerable children
- **PEPFAR:** U.S. President's Emergency Plan for AIDS Relief
- **PMTCT:** Prevention of mother to child transmission
- **PrEP:** Pre-exposure prophylaxis
- **Prevalence:** The number of people living with disease
- **SSA:** Sub-Saharan Africa
- **STI:** Sexually transmitted infections
- **TB:** Tuberculosis
- **UNAIDS:** The Joint United Nations Programme on HIV/AIDS
- **WHO:** World Health Organization

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Organizations That Participated in the Landscape Research

Service Providers

- ***CARE***
- ***Child Fund***
- ***Firelight Foundation***
- ***FXB International***
- ***Save the Children***

Funders

- ***Bernard van Leer Foundation***
- ***Children's Investment Fund Foundation***
- ***ELMA Foundation***
- ***Global Fund for Children***
- ***Hewlett Foundation***
- ***PEPFAR***
- ***USAID***

Multilateral Organizations

- ***UNAIDS***
- ***UNICEF***
- ***WHO***
- ***World Bank***

Others

- ***Cal Poly State University, San Luis Obispo***
- ***Coalition on Children Affected by AIDS***
- ***The Consultative Group on Early Care and Childhood Development***

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