The Joint Learning Initiative on Children and HIV/AIDS **Learning Group 3**

Expanding Access to Services and Protecting Human Rights

Compiled by Learning Group 3 Co-Chairs **Jim Yong Kim** (François-Xavier Bagnoud Center for Health and Human Rights, Harvard University) and **Lydia Mungherera** (Mama's Club and The AIDS Support Organization); and by **Susan R. Holman** (FXB Center for Health and Human Rights, Harvard School of Public Health) and **Mary C. Smith Fawzi** (FXB Center for Health and Human Rights, Harvard School of Public Health)

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JLICA JOINT LEARNING INITIATIVE ON CHILDREN AND HIV/AIDS

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Acronyms

AMPATH	Academic Model for the Prevention and Treatment of HIV
BTS	Breakthrough Series
CHW	community health worker
CDVC	Care Delivery Value Chain
CM	case management
EFA	Conference on Education for All
CROI	Conference on Retroviruses and Opportunistic Infections
ECD	early childhood development
IFFIm	International Finance Facility for Immunization
HC	health centre
IMB	Inshuti Mu Buzima Rwanda
IAS	International AIDS Society
OVC	orphans and vulnerable children
PCR	polymerase chain reaction
PIH	Partners In Health
PMTCT	prevention of mother-to-child-transmission of HIV

Introduction

The Joint Learning Initiative on Children and HIV/AIDS (JLICA) is an independent, time-limited network of researchers, practitioners, policymakers, community leaders and people affected by HIV and AIDS. Its goal is to improve the well-being of children, families and communities affected by HIV and AIDS by mobilizing the scientific evidence and producing actionable recommendations for policy and practice.

Launched in October 2006, JLICA brings together experts from more than a dozen countries. To date, the initiative has produced more than 50 original review and research papers and reports. These outputs mobilize knowledge from a broad spectrum of disciplines with the aim of enabling evidence-informed policy decisions to improve children's lives. JLICA addresses itself in the first instance to national policymakers in heavily-burdened countries and those who advise them. Many of its findings apply to low-prevalence and highly concentrated epidemics. JLICA also speaks to donors; international agencies concerned with children and AIDS; international and national non-governmental organizations; and local civil society organizations and movements.

JLICA's research activities are conducted by four thematic Learning Groups, organized according to the main recommendations of the widely endorsed *Framework for the Protection, Care, and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS* (UNICEF/UNAIDS, 2004). Learning Groups have undertaken a programme of work involving reviews of existing research; the commissioning of strategic studies in under-researched areas; disseminating results among stakeholders; fostering public debate on key policy issues; and providing information to decision-makers and national, regional and global policy forums. Each Learning Group is bringing together its key findings and recommendations in an integrated synthesis paper. Learning Group synthesis papers serve as key inputs to the JLICA final report. As they are completed, all JLICA research products will be freely available on the initiative's website at **http://www.jlica.org**.

JLICA's four Learning Groups are structured and led as follows:

- **Learning Group 1: Strengthening Families,** chaired by Linda Richter (Human Sciences Research Council, South Africa) and Lorraine Sherr (University College London, United Kingdom)
- **Learning Group 2: Community Action,** chaired by Geoff Foster (Family AIDS Caring Trust, Zimbabwe) and Madhu Deshmukh (CARE USA, United States of America)
- **Learning Group 3: Expanding Access to Services and Protecting Human Rights,** chaired by Jim Yong Kim (François-Xavier Bagnoud Center for Health and Human Rights, Harvard University, United States of America) and Lydia Mungherera (Mama's Club and The AIDS Support Organization, Uganda)
- **Learning Group 4: Social and Economic Policies,** chaired by Alex de Waal (Social Science Research Council, United States of America) and Masuma Mamdani (Research on Poverty Alleviation, Tanzania)

JLICA was created in response to the enduring neglect of children in the context of HIV and AIDS. Many factors have contributed to this marginalization. In part, it has been perpetuated because children lack power, organization and voice to defend their interests politically. In part, it is because the responsibility of caring for affected children in the context of HIV and AIDS has been unobtrusively absorbed by families and communities on the front lines of the epidemic. A guiding aim of JLICA's analysis is to identify the specific ways in which national governments and other actors can most effectively support families and communities, as the latter must remain at the heart of any sustainable response to children's needs in the context of HIV and AIDS.

Shared values underpin JLICA's work. Most importantly, JLICA is committed to a human rights-based approach to issues of children and AIDS. This includes the right of children, young people and families to participate in key decisions that affect their lives.

A number of methodological and definitional principles are also shared across all Learning Groups. JLICA uses the Convention on the Rights of the Child to define a "child" as a person under 18 years of age. JLICA's research has highlighted the confusions caused by the definition of "orphan" adopted by United Nations agencies and used to generate international statistics. JLICA has called for the official UN definition to be reviewed and applauds recent indications that such a review may be imminent (Richter, 2008; Sherr et al., 2008).[1] Because of the associated definitional ambiguities, JLICA discourages reliance on the term "orphans and vulnerable children" and, in particular, the reifying acronym "OVC." The preferred inclusive term within JLICA is "children affected by HIV and AIDS."

The inclusive quality of this term has both practical value and ethical significance. Indeed, JLICA argues that, in addition to the categories specified under the UNAIDS and UNICEF definition, the term "children affected by HIV and AIDS" must be understood more expansively. In settings characterized by high HIV prevalence and widespread poverty, the meaning of this term extends to include:

- Children indirectly affected by HIV and AIDS because they are living in communities heavily burdened by HIV and AIDS, and
- Children especially vulnerable to exposure to HIV due to their circumstances.

JLICA is committed to the disaggregation of child-related data by gender, age, household economic level and other relevant stratifiers. Equally important, JLICA emphasizes that the information derived from disaggregated data should be, not merely reported, but also *used* to better understand the specific needs and risks faced by vulnerable groups, including girls and young women, and to develop appropriate responses.

1 See UNICEF's recent call for a reevaluation of the UN definition of 'orphan': UNICEF (2008). 'Orphans'. Press statement published online, available at: http://www.unicef.org/media/media_44928.html (accessed 13 September 2008).

Executive Summary

Despite increases in national and international investment in HIV-focused programs in developing countries, resources for families and communities affected by HIV and AIDS targeted at vulnerable women and children are not reaching their intended beneficiaries. Millions of families and communities in resource-poor settings lack access to needed services, and suffer unnecessary morbidity and mortality.

Children affected by HIV and AIDS often live in communities characterized by economic and social instability, since many caregivers — health workers, teachers, and village leaders — are sick or have died (Foster & Williamson, 2000). In addition to basic health risks, such settings pose a high risk of what human development and education experts have termed "toxic stress," that is, unmitigated psychological and developmental stressors that impair developing brain architecture and learning potential (Shonkoff & Phillips, 2000; Center on the Developing Child at Harvard University, 2007). In such settings children can survive and thrive only when they receive the care and services necessary for a healthy life, and receive it early enough and in a manner that such care will make a practical difference. Research confirms the importance of early childhood development (ECD), suggesting that "child survival and health agendas are indivisible from ECD" (Irwin, Siddiqi & Hertzman, 2007). Thus, in resource-poor settings where HIV is a significant problem, prevention and treatment of HIV for children must be delivered along with other children's services, such as vaccinations and ECD interventions, in order to give children a chance at a healthy, productive life.

This report provides a synthesis of the findings and practical recommendations of the Joint Learning Initiative on Children and HIV/AIDS (JLICA) Learning Group 3 (LG3), "Expanding access to services and protecting human rights." Results from eight papers were synthesized for this report. These papers included comprehensive literature reviews to describe and assess:

- the "implementation gap" in service access and delivery;
- access to prevention of mother-to-child transmission of HIV/AIDS (PMTCT) programs and their potential integration with early childhood development activities;
- the role of primary/secondary education in reducing HIV/AIDS health risks;
- case studies of specific programs and policies that have worked in resource-poor settings;
- cross-cutting themes, innovative health- and funding-related models and tools that reflect "best practices" for policy makers, health workers, families, and communities; and
- the role of an innovative global health delivery framework that promotes positive lifelong health by advancing access and quality of services to affected and vulnerable children, women, families, and communities around the world.

In addition, to understand the details of specific HIV-focused programs and the lessons they provide for global health practitioners, LG3 researchers utilized the "care delivery value chain" framework to identify the elements of specific efforts that are essential to ensuring that programs actually deliver "value" to their intended beneficiaries. This method is more commonly used in the fields of management and business strategy but was found to be very helpful in understanding HIV-related programs such as PMTCT. Another team adopted the Breakthrough Series "Learning Collaborative" model for quality improvement of health care services for a demonstration project in Rwanda to improve the delivery of PMTCT services and link them to early childhood development-focused interventions.

Findings from these papers suggest program models, tools, and resources for a strategic approach to increasing access to services within a human rights framework. Although external funding is needed to sustain and enhance current HIV prevention and treatment efforts, these disease-specific interventions should be closely linked with financing for poverty reduction, such as promoting microfinancing initiatives, increasing access to formal education, and offering cash transfers to the most impoverished families.

LG3 Findings: An Integrated Summary

Certain key themes appear as consistent threads throughout Learning Group 3 projects. These are summarized below.

First, while it is obvious that needs far outstrip available services and resources, effective interventions in resource-poor settings can make a dramatic difference. The Botswana example demonstrated, for instance, that even when HIV prevalence seems overwhelming on a national level, national leadership complemented by conducive policies and effective intervention reduced HIV prevalence dramatically within five years. Effective intervention can incorporate both major changes (e.g., in this case, increasing the uptake of PMTCT services from 30 percent to 85–90 percent, which contributed to reducing the mother-to-child transmission rate to 4 percent) as well as more specific programmatic changes (e.g., in this case, offering routine HIV testing). The Rwanda case also demonstrated that regional and local leadership played a critical role in advancing services for orphans and vulnerable children.

Second, both the literature reviews and the Learning Collaborative model demonstrated that gaps and barriers in access and implementation must be recognized and clearly identified before they can be addressed effectively. The existence of available services does not ensure their effective delivery. At the outset of program initiation or scale-up it is imperative to understand the context and level of local capacity so that the implementation can account for these factors and critical bottlenecks can be overcome.

Third, there are five very specific factors that were consistently mentioned as hindering improved access to services for children affected by HIV and AIDS in resource-poor settings. The consistency of these themes suggests that effective targeted and integrated interventions are possible. The recurrent factors are:

a. The lack of basic resources: Widespread poverty characterizes many developing country settings and presents myriad challenges. Insufficient funds prevent families from accessing preventative and curative commodities, such as mosquito nets and drugs, and undermine their ability to travel to clinics and hospitals. In many areas, food and clean water are also inadequate, which jeopardizes the health of all family members. Poverty can also impact school enrollment, particularly for countries that have school fees. The impact of these hardships is amplified when breadwinners fall ill and must reduce or cease their productive activities.

b. Limited access to available resources: In some settings existing health-related resources that cannot be accessed by the populations for which they are intended. There may be programs already in place, such as routine HIV testing, PMTCT and pediatric HIV services, that provide optimal treatment regimes and integrated care, but logistical problems, system constraints, transport difficulties, and many other factors conspire to limit access to them.

c. Barriers created by knowledge gaps and societal norms: Low demand for services can often arise from a lack of knowledge or confusion about the available options. For instance, many women are unaware of the benefits of PMTCT care and do not present themselves for services, or do so only late in their pregnancies when it is too late to receive all needed services. This problem is compounded for women because girls often face gender-based discrimination that limits their access to formal education. Many women are also fearful of accessing HIV-related care because of the social stigma attached to infection and/or because of the threat of intimate-partner violence.

d. Limited access due to system limitations and inadequate service capacity: Human resources are often insufficient, and also tend to be centralized and therefore difficult to access for

the vast majority of citizens. Lack of laboratory capacity needed for diagnosis, CD4 counts, and other services delays or denies health care in almost every developing setting. The absence of nutritional support in many areas undermines overall child health for the neediest families.

e. System gaps prevent receipt of needed services: Poor or non-existent follow-up systems lead to poor patient compliance and interruptions in care. The lack of service integration, e.g., the integration of PMTCT and early childhood development activities into other programs, means that opportunities to deliver more services are missed. The need for advanced laboratory equipment to perform specialized techniques such as PCR testing for HIV detection in infants and young children often presents problems in caring for clients.

While these factors are widely recognized, LG3 findings also suggested that health care providers' perceptions and explanations of barriers to service access may differ from patients' perceptions of the factors causing such gaps. For example, health care providers identified among key barriers the fact that women were sometimes turned away at the clinic or failed to come to the clinic due to ignorance, shame, fear, or misconceptions. The patients themselves, however, described key barriers as including: poor experiences at the clinic, difficult access to services due to travel and financial constraints, and being uninformed. Such subtly different views on where the problems lie suggest the importance of communication in improving services. Improved access to care that results in lifelong health critically depends on addressing and managing all the factors—social and economic—that presently hinder such access.

Each of the cases and products demonstrated that improving access to services that will result in effective lifelong health for children affected by HIV and AIDS is a complex process that requires sensitive, consistent, and informed integration of many factors. As the diarrheal disease outbreak in Botswana demonstrated, safe formula feeding depends on more than just clean water. Complex issues of hygiene and access to safe water, electricity and refrigeration must be considered in provider plans to design effective and safe infant feeding components in resource-limited settings. The integrated health care delivery system case studies demonstrated that the most effective intervention will provide food and financial support for entire households, not just infected or orphaned children. PIH-Rwanda demonstrated the complexity of rapid scale-up and identified five key components vital in such complex integration:

a. partnership with public health authorities;

b. maternal health support;

c. building/strengthening pediatric AIDS services;

d. operational research; and

e. promoting basic social and economic rights that include fair remuneration for health care providers, including community health workers (CHWs).

The access to education review demonstrated that the relationship between education and HIV/AIDS risk is likewise complex, but that improved education for women and girls is vital to provide them with the necessary skills to safeguard their own health and minimize HIV risk.

Findings consistently reiterate the importance of supporting existing structures, not creating new parallel structures. This theme applies to both existing programs and health centers as well as existing communities and family units. Multiple funders can work together as facilitators in attaining these common goals. Community programs are most effectively led by community members, including affected children and adolescents. Innovative funding strategies, innovative models, and service delivery integration may work most effectively when they strengthen existing programs.

Recommendations for Immediate Action

What can be done immediately? We suggest that the following activities, when they are applied without resource and/or political constraints, have the potential to reduce the impact of HIV on children:

1. Advance a framework and methods to increase access and improve quality of care and prevention services. Helpful framework/methods can include the "care delivery value chain" and learning collaborative models; these can promote local ownership and cultivate a work culture focused on developing local strategy for quality improvement;
2. Offer Provider Initiated Testing and Counseling (PITC) as broadly as possible, within a human rights framework, with the option to "opt-out" of testing easily. This approach could potentially have a tremendous impact on the epidemic if it promotes and supports women's safety in the context of disclosing testing results;
3. Consistently link PITC with adequate access to antiretroviral therapy (ART), and continue to promote funding to make universal access to ART a reality;
4. Link HIV testing to identification and treatment of other sexually transmitted infections;
5. Pursue strategies (e.g. eliminate or provide school fees or apply complementary strategies) to increase enrollment in primary as well as secondary school; support education for girls to overcome the existing gender imbalance in schooling access/education, and thereby reduce HIV risk for both boys and girls;
6. Link HIV prevention and treatment programs to poverty reduction strategies that quickly and measurably reach needy individuals in families and communities, especially women and their children. Cash transfers are a proven intervention and are strongly recommended as part of a poverty reduction program;
7. Link HIV prevention and treatment programs with nutrition and food security for families and communities;
8. Offer transportation fees where distance and cost are barriers in access to care. Ensure that these resources are available to the households' primary caregivers, particularly women;
9. Integrate care in existing services to address all family members and health problems to enhance efficiency of care and improve outcomes;
10. Expand access to community health workers and employ other strategies of "task shifting" of health care responsibilities to ensure broader access to care; compensation for CHWs should be a priority.

In conclusion, JLICA Learning Group 3 suggests that implementing the recommendations above will positively impact the lives of children, their families, and communities by ensuring effective service delivery in the health care system. Integrating services that encourage local initiatives, build on existing programs, and put resources directly into the hands of those who need them, offers a realistic model for hope in the face of daunting implementation gaps and access barriers. Decentralized, integrated health care services that build permanent "bridges" to improve access lay the foundation for economic success that can serve as models to the global community even as they give new life and hope to each individual family and child. The application of learning collaborative lessons, "value chain" analysis, integrated health care delivery models, each consistently driven by providers within the affected communities can, when adequately funded, reduce the burden of poverty and promote the well-being of children affected by HIV and AIDS.

Overview

Learning Group 3 (LG3) of the Joint Learning Initiative on Children and HIV/AIDS (JLICA) focuses on expanding access to services and protecting human rights. The overall goals of LG3 are: to identify implementation gaps for providing health care and related services for children affected by HIV and AIDS; and to identify strategies for closing these gaps, increasing access to services, and improving outcomes for children affected by HIV and AIDS.

These goals are based on the underlying principle that access to health care, including prevention programs and other basic services, is a fundamental human right. Examination of existing efforts and conditions indicates that these human rights are violated for the large majority of the HIV-affected children and youth living in the developing world. Poverty alleviation, such as social protection and microcredit initiatives, is discussed within the context of enhancing health-related outcomes among children affected by HIV and AIDS.

These goals are achieved according to the following objectives for LG3:

1. Describe the "implementation gap" in services for children affected by HIV and AIDS according to the current medical and public health literature available, as well as information available from community settings in the developing world;
2. Identify cross-cutting themes on how to enhance access to services;
3. Provide an innovative framework for advancing access to and quality of services for children affected by HIV and AIDS that focuses on "value," i.e., positive lifelong health outcomes that result from specific programs and initiatives;

4. Offer new models and tools that can result in faster and more efficient "learning" processes among global health practitioners, so that individual field innovations can be more quickly integrated into existing programs, future planning efforts, and policy development;
5. Provide a description of successful "case" examples of policies and programs that have worked to close the implementation gap effectively in a specific context;
6. Describe the critical roles of integrative, family-centered services and access to education in advancing care and HIV prevention for children affected by HIV and AIDS.

Summarized Papers and Methods

1. The Implementation Gap

The methods for this paper included a comprehensive search in PubMed on the terms "child," "HIV," and "intervention." This allowed us to examine any intervention for which there is currently published information that may have relevance for children affected by HIV (including those infected). This same strategy was used for a review of abstracts from IAS 2006/2007, and CROI 2007/2008. Overview documents (such as the *Children and AIDS — A Stocktaking Report* published by UNICEF, as well as UNICEF's *State of the World's Children*, and the *Framework* document) were also reviewed. Finally, relevant gray literature was accessed through sites such as Population Council's Horizons, the Better Care Network, and the Child Rights Information Network, among other relevant sources. This paper provided the background data necessary for LG3's first and second objectives outlined above.

2. Integration and Expansion of Prevention of Mother-to-Child Transmission (PMTCT) and Early Childhood Development (ECD) Intervention Services

The methods used for this paper included a comprehensive review of published and gray literature of PMTCT and ECD sources. PubMed and relevant gray literature were reviewed for both topics. For PMTCT, relevant UN documents (e.g. WHO report on PMTCT, 2006) as well as abstracts from IAS 2006, IAS 2007, CROI 2007 and CROI 2008 conferences were reviewed. For ECD, additional relevant search engines were also used, including PSYCHInfo and ERIC. Also included were references cited by Engle et al. (2007) in their *Lancet* review of ECD interventions in developing countries. LG3 members' programmatic experience in both areas as well as representative field "cases" from the literature provided additional resources. This paper, based on a review of PMTCT-related "implementation gaps" (LG3 objective 1) focused on themes for enhancing access to services (LG3 objective 2) and provided brief, context-specific "case examples" (LG3 objective 5) of policies and programs that work.

3. The Care Delivery Value Chain in the Prevention of Mother-to-Child HIV Transmission

The *care delivery value chain* (CDVC), developed by Porter et al. (2006), is a strategic framework that facilitates systematic analysis of how health interventions deliver *value* for patients. Value—defined as long-term health outcomes achieved per dollar spent—is created across the cycle of care for a particular medical condition. The value chain maps the sequence, organization, and interdependence of activities required to deliver care. For PMTCT, a successful outcome was defined as a healthy, HIV-free two-year-old child with healthy parents. As a result, the PMTCT care cycle begins *before* pregnancy with HIV prevention, and continues through the second year of the infant's life.

Consistent with LG3's third objective, PMTCT value chain analysis provides an innovative framework for expanding service access that protects human rights. The CDVC elucidates whether the sequence of activities are aligned with value; how information is shared between entities involved in PMTCT care; how human resources and health commodities are deployed; and how integration is achieved with other services, including maternal health and broader child health services. Value chain analysis demonstrates that the failure of global PMTCT delivery is primarily a strategic failure. While improved operations and additional resources may lead to short-term successes under current metrics, revised strategic thinking is essential for successful PMTCT health outcomes, including HIV-free child survival at 24 months and healthy mothers able to care for their children. Delivery science studies will become increasingly important to help understand the successes and failures of global health programs.

4. The LG3 Learning Collaborative (LC)

It is difficult to extract practical, service-provision details using only published literature. LG3 members consequently chose to launch a quality improvement project that had two objectives. First, such a project would improve one specific example of HIV/AIDS-related service delivery (i.e. improve access to and quality of care for integrated PMTCT and early childhood development (ECD) services in Rwanda). Second, the project would generate important information on low-level barriers to implementation while simultaneously evaluating a quality improvement methodology that other implementers could potentially use or further refine.

The Rwanda Learning Collaborative chose to test the Breakthrough Series (BTS) Learning Collaborative method, developed by the Institute for Healthcare Improvement in the early 1990s (IHI, 2003). The BTS promotes peer-to-peer, horizontal joint learning and problem solving, and can operate at the grassroots level. The collaborative method is useful for accommodating diverse organizations, improving procedures, and rapidly spreading best practices. LG3 adopted the BTS methodology and formed a Learning Collaborative focused on improving PMTCT and ECD services and rapidly spreading best practices.

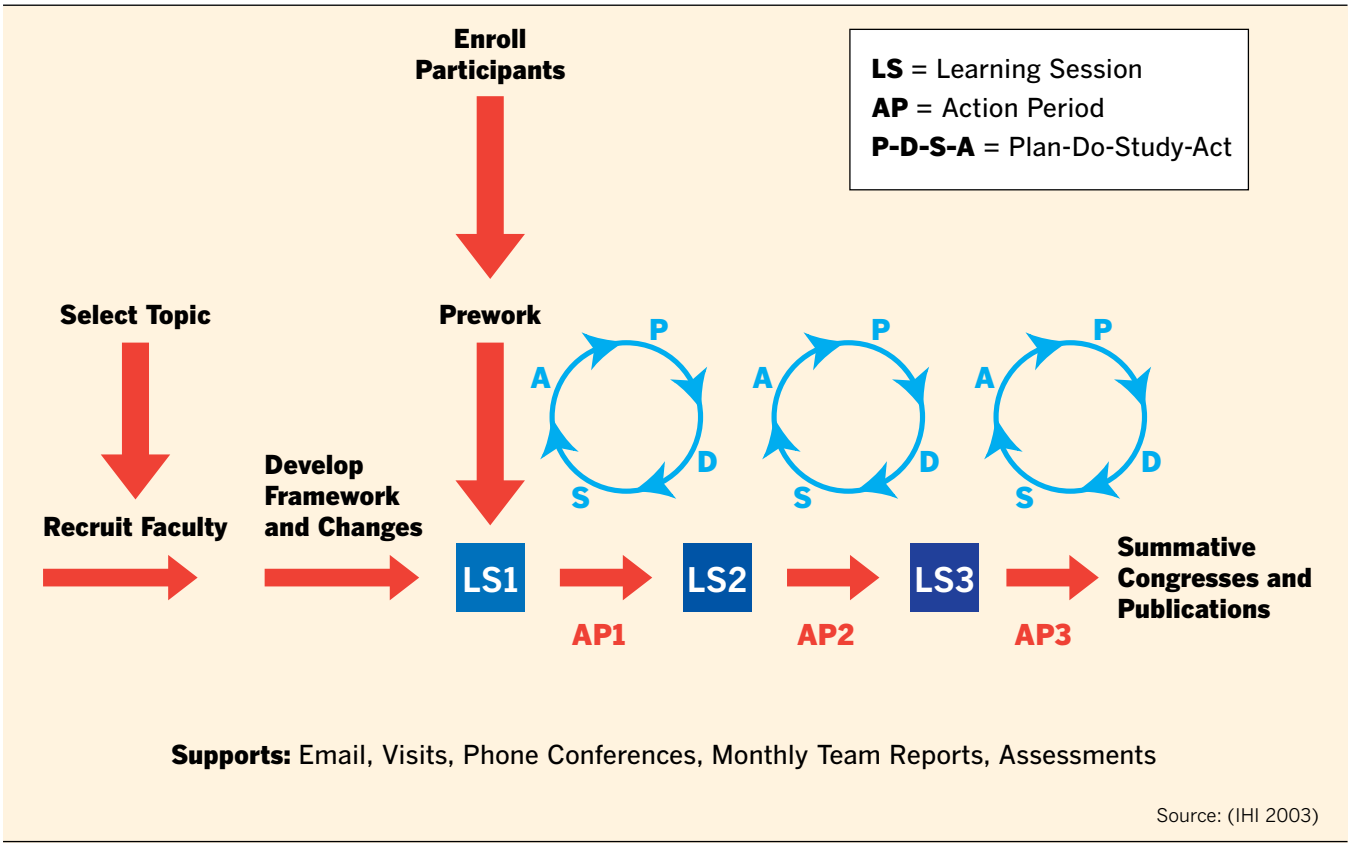
Seventeen Rwandan health centers volunteered to participate, using the BTS methodology of "Plan-Do-Study-Act" (PDSA) cycles in which problems are identified, solutions tried, results analyzed, and improvements then incorporated into standard working procedures (see Figure 1) (IHI, 2003). Three learning sessions facilitated the sharing of problems and solutions, and promoted relationships that are anticipated to sustain process improvement beyond the end of the formal LC experience itself.

The Learning Collaborative project focused on LG3's fourth objective: offering a new field model to aid "learning processes" for global health practitioners. In addition, it also served as a "case" example (objective 5) and, together with the other LG3 reports covering field-based projects, identifies cross-cutting themes on *how* to enhance access to services (LG3 objective 2).

5. Botswana — PMTCT Case Study

Botswana offered an example of a successful PMTCT intervention (LG3 objective 5) in a country with a high HIV burden, and merited further research to assess its usefulness for similarly-affected settings. This case study places Botswana's PMTCT program

Figure 1: Standard Elements of the Breakthrough Series (BTS)



Source: (IHI 2003)

in the appropriate context by reviewing literature that describes the country's history, demographics, health system and progression of the HIV/AIDS epidemic. Field staff then interviewed key stakeholders in Botswana to identify factors that facilitated the improved access to PMTCT services in that setting, and discussed factors that impeded progress. A range of individuals were interviewed, including those representing the National AIDS Coordinating Agency in Botswana, the Botswana-Harvard Partnership, Baylor-Botswana Children's Center of Excellence, as well as the U.S. Centers for Disease Control and Prevention (CDC).

6. Rwanda — Orphans and Vulnerable Children: Planning and Programming Case Study

This case study (which addresses LG3 objective 5) is based on materials being gathered in close collaboration with the National AIDS Control Commission (NACC) in Rwanda. They include primary policy documents from NACC, documents from the Rwandan NACC website, and other gray literature (such as that found on the "AIDSportal" website). A comprehensive review of government documents was performed based on these sources. In addition, documents from non-governmental organizations working in Rwanda were reviewed. Field staff interviewed key stakeholders in Rwanda to describe the policy development as well as the program implementation of the Rwandan OVC program.

The goal of this case study was to examine how initial ideas about advancing services for orphans and vulnerable children develop into policy and then into implementation. In the final version of this paper, we intend to document explicitly the steps involved and the factors that sustain this progressive system. One approach is to examine the aspects of accountability and transparency of this initiative, and how such characteristics might enhance follow-through on a cash transfer program; that is, how can this model of governance be translated to other aspects of care for children in high HIV burden countries?

7. Family Centered Integrated Services Review

This paper (which addresses LG3 objective 6) focuses on a comprehensive review of existing published, internet, and gray literature that addresses the broad relevance of family and community-centered integrated care services. The study used data from websites, such as the Better Care Network, USAID, the World Bank and UNICEF; from medical journals; and from the case study programs themselves. Research addresses the following issues: 1) empowerment, self-esteem and development of children affected by HIV and AIDS; 2) integrated health and social service delivery related to children affected by HIV and AIDS, their infected parents, and other caregivers; 3) challenges to scale-up; and 4) the importance of compensation to family and community caregivers in the context of salaries or other forms of remuneration.

Data include internal and external descriptive and analytical program studies and reports about three programs: AMPATH, PIH and CARE, using third-party program evaluations, research and policy documents, conference abstracts, program monitoring documents, project descriptions, work plans, and reviews.

8. HIV and Access to Education Review

This paper (which also targets LG3 objective 6) provides a comprehensive literature review. The first section of the paper, on the impact of education on HIV risk, draws on studies reviewed by Hargreaves et al. in a recent paper in *AIDS*, as well as a number of other studies. The emphasis is on studies that explore and demonstrate a causal relationship between the level of education and HIV. The second section of the paper examines the mechanisms for the effect of education on HIV, with a selective review of papers from the health psychology literature. The final two sections discuss issues of educational access and review recent gray literature, drawing particularly on the UNESCO *Education for All Monitoring Reports* and the recent UNICEF/PCD review of programs that provide educational access for orphans and vulnerable children.

LG3 Peer Review Process and Validation

The LG3 peer review process is on a par with what is typically done with peer-reviewed medical and public health journals. Established researchers and practitioners in the papers' respective fields have been identified and approached. In order to reduce the potential for bias, we ask all reviewers to sign a conflict of interest form.

The LG3 peer review process differs from a peer-reviewed medical journal process in that the reviewers are not anonymous. This rationale will allow for open communication between the writers and reviewers in order to refine the information and arguments in the document in a collaborative manner. Due to the lack of reviewer anonymity, the conflict of interest form serves an important function in facilitating unbiased review of LG3 products.

Findings

LG3 activities and research yielded a broad range of findings. The following highlights from each resulting LG3 product/paper offer key points that may advance access to and quality of care for children affected by HIV and AIDS. An integrated summary of findings that can be traced in common across all LG3 papers concludes this section.

1. The Implementation Gap

Improving access to services for HIV/AIDS-affected children requires a broad consideration of needs. The manuscript describing the "implementation gap" in services for children affected by HIV indicated that needs far outstrip available services and resources. A central focus on identifying, understanding, and addressing the "implementation gap" in services for children affected by HIV and AIDS will facilitate analysis and action toward closing those gaps; this is in contrast to a focus emphasizing achievements. While it is important to learn from successful outcomes, by attempting to uncover existing gaps at the local, regional, national, and international levels, strategies to close these gaps can be developed to enable effective program implementation.

Taking a human rights approach, we reviewed the implementation gap in services for children affected by and living with HIV, including: PMTCT; HIV testing and treatment; general pediatric care (clinical and public health measures); early childhood development interventions; education; psychosocial support; and HIV prevention.

The Implementation Gap and PMTCT

The services and programming related to PMTCT offer a good example of the broad range of factors that contribute to the wide implementation gap. These factors include lack of access to services for women that can take several shapes: limited availability of HIV testing during pregnancy; lack of access to reproductive health care (e.g. prenatal care, delivery assisted by a "skilled" attendant, and

postnatal care); limited access to the most effective ARV regimens, including appropriate HIV treatment for the women themselves; limited knowledge of PMTCT among women (in part related to women's educational levels); poverty (e.g. lack of funds for transport for services); HIV-related stigma; as well as fear of domestic conflict (including violence). Limitations in access to PMTCT services persist for infants and young children, including: lack of access to clean drinking water and free formula (to prevent transmission through infant feeding); limited access to the appropriate ARV regimens, including ART for all HIV-positive infants under 12 months of age (WHO, 2008); and in many cases lack of access to adequate food. Health systems limitations also contribute to the implementation gap, including: inadequate integration of PMTCT into existing HIV treatment and reproductive health programs; limited availability of material or human resources; and over-centralized programming at district hospitals (Manzi et al., 2005; Perez et al., 2004; Abrams et al., 2007; Kominami et al., 2007; Medley et al., 2004).

Evidence from Uganda, illustrating the PMTCT implementation gap in a specific context, indicated a number of other gaps in PMTCT care. Health sector financing is very limited and is about US $9–12 per capita per year, inclusive of donor funds (Racalbuto et al., 2007). Human resources are inadequate. Overburdened staff do not have time to provide labor-intensive interventions, including HIV/AIDS follow-up care for mothers and children (UNICEF/WHO, 2004). The lack of appropriate clinical infrastructure hampers ART care. Basic laboratory equipment is unavailable in many districts, precluding even basic analyses (GoU, 2003). PCR testing is only available centrally, which causes further diagnostic delays for many infants and young children under 18 months of age who live in rural areas. These limitations amplify the challenges posed by pediatric ARV formulations, which require special handling and storage and adequate providers' knowledge of dosing and combining ARVs for children. Supply chain problems further complicate the provision of treatment; and further gaps in service provision result from challenges related to coordination between the major providers of HIV/AIDS care and treatment in Uganda.

Infrastructure limitations and technical problems have been exacerbated by the fact that in the past pediatric HIV/AIDS treatment had been a low priority. Political will has improved, but awareness and availability of services remains very low at the community level. Families must travel to hospitals and advanced health centers, making it more difficult to access services. Stigma and discrimination associated with HIV/AIDS also limit disclosure and isolate caregivers and patients from familial and communal support systems.

Cross-Cutting Themes

Beyond PMTCT and follow-up of HIV-exposed infants, themes that cut across service categories emerged that would facilitate access to services and enhance quality. These themes include: ensuring political will and having a social strategy; relying on a strong scientific base as the rationale for program design and service provision; developing innovative strategies for funding to initiate as well as sustain programs (including macro- and micro-level funding, such as direct cash transfers to vulnerable families); decentralizing services; engaging communities and recruiting community health workers; increasing the capacity of health care system through the strengthening of physical infrastructure, supply chain processes, recruiting adequate personnel, and training/re-training of personnel; offering family centered services; and integrating service delivery. It was also observed that poverty and gender inequality are key drivers of the epidemic in high HIV burden settings, with some evidence indicating that improving access to education and economic opportunities (particularly for women and girls) may reduce the burden of HIV in some environments. Consideration of these structural issues is necessary for optimal outcomes of HIV prevention efforts as primary prevention of HIV remains a significant priority for PMTCT and for the overall epidemic.

Role of Community Health Workers

While community health worker programs are frequently initiated in order to address a lack of trained health professionals, CHWs have often proven more effective than professionals in supporting individual and community responses to health challenges that require sustained and constant efforts or that disproportionately affect poor or vulnerable communities (Haines et al., 2007). CHWs can serve in a variety of roles as effectively as health professionals, for instance in providing basic care for endemic diseases with

straightforward treatment. None of the studies we examined showed CHWs providing sub-standard care. For example, in a study of community-based distribution of injectable contraceptives, the CHWs' clients had equivalently low rates of problems with injection site inflammation and slightly higher rates of follow-up than did clinic clients. Further, 95 percent of the CHWs' clients reported themselves satisfied or highly satisfied with the services provided (Stanback et al., 2007). In Zaire, malaria prevalence and incidence fell 50 percent in the CHW intervention area versus a control area (Delacollette et al., 1996). With a constant community presence, CHWs can provide the fastest responses in areas where health clinics are not easily accessible. A study of malaria treatment in rural Ethiopia reported that people with access to CHWs sought treatment earlier than those who went to public facilities (Deressa et al., 2007). An intervention in Nigeria aimed at utilizing CHWs to diagnose and treat malaria in remote rural areas found that they managed to improve geographic equity in access to malaria drugs (Onwujekwe et al., 2007). In studies in Bangladesh and Pakistan of directly observed therapy (DOT) for TB (Islam et al., 2002) and in Ecuador of immunization coverage (San Sebastián et al., 2001), CHWs were found to be significantly more cost-effective than health professionals and hospital-based strategies.

LG3's review of CHW-based health care and disease prevention strategies concluded that elements of a successful CHW strategy include the following: (1) high-quality training and regular refresher or additional training; (2) specialization in a few areas, but the ability to address and refer for key health concerns of the community; (3) awareness within the community of the services CHWs provide; (4) strong linkages and referral system between CHWs and formal health care institutions; and (5) provision of payment or meaningful incentives to ensure that CHWs prioritize the needs of their patients and make a long-term commitment to the program. These issues related to CHWs are relevant for all service areas that were reviewed.

Innovative Financing

Several recent innovative funding mechanisms are outlined that have resulted from competition and cooperation among national governments, private industry actors, international institutions, NGOs, and non-profit institutions. For instance, in 2006 France introduced a levy on the purchase

of international airline tickets, known as the Airline Solidarity Contribution, to benefit an International Drug Purchase Facility (IDPF), UNITAID. The program's strengths derive from easy implementation, a limited economic impact for the country enacting the levy, and the progressive nature of the levy (*The Airline-Ticket Solidarity Tax Report,* 2007). Other countries have joined France, including Chile, Brazil, Norway and the United Kingdom among others, in this initiative (UN, 2006). In addition, promising activities outlined in The Landau Report in September 2004 include: a levy at a very low rate on a fraction of international financial transactions; a levy on capital flows to or from countries that practice banking secrecy; and a levy on the fuel used by air and maritime transport (*The Landau Report,* 2004).

The recipient of the Airline Solidarity Contribution, UNITAID, is delivering another innovative method of financial support. At the nexus of private industry, governmental, and non-profit coordination, UNITAID has a two-fold objective: mobilizing resources in the mid- and long-term for the purchase of drugs and other medical products (e.g. diagnostic kits) needed for the treatment of the three killer diseases of the developing world (malaria, TB, and HIV); and structuring the drug market, particularly that of ARVs,

allowing for lower prices through better structured competitive mechanisms and by establishing reciprocal agreements between producers and buyers in the long term ("International Drug Purchase Facility," 2006). The leading proposed mechanism to achieve these objectives include pooling together drug orders received from beneficiaries and launching international and transparent tenders of which the volume would allow for significant reductions in prices ("International Drug Purchase Facility," 2006).

Other illustrative examples of innovative funding methods include the International Finance Facility (IFF), the Global Fund's Debt Conversion Initiative, and The Red Campaign. In November, 2006, the IFF's pilot program, the International Finance Facility for Immunization (IFFIm) declared a bond issuance intended to raise US $1 billion. It is estimated that this and similar financing efforts may generate US $4 billion over ten years to support disbursements for immunization and other health programs ("Spectacular Response to IFFIm's Inaugural Financing," 2006). This large upfront infusion of capital, provided by a bond issuance, anticipates many advantages and economic efficiencies, allowing for investments across a range of sectors. This initiative constitutes a "massive push" to boost access to essential services for children, encouraging countries to get ahead of rapidly growing problems; and catalyzing the transition to more costly yet more effective, medications (Bryden, 2006).

Funding schemes that stabilize incomes, increase savings, and promote income-generating skills can strengthen social and financial safety nets, making it easier for households to cope with HIV/AIDS (Pronyk et al., 2005). Microcredit models operate by granting small, low-interest loans to the poor for income-generating activities. Often such programs are linked with training and education, and follow a group-lending model where a community shares responsibility for repayment. Reported loan repayment rates often exceed 96 percent, and most microfinancing institutions have been demonstrated to recover their administrative costs through interest rates and user fees (Auwal, 1996). Microcredit programs have been shown to be successful in reducing household poverty, promoting childhood education, and addressing gender norms by increasing women's autonomy and empowerment (Cheston and Kuhn, 2002). Microfinance participation has also been associated with improved health outcomes in child nutrition (Doocy et al., 2005), health promotion (Dohn et al., 2004; Hadi, 2001), and modern contraceptive use (Schuler and Hashemi, 1994; Steele et al., 1998).

While many wealthy countries provide basic social assistance for the poorest individuals in their populations, developing countries often lack such social support (Adato & Bassett, 2008). Cash transfers provide beneficiaries with flexibility that other forms of aid, such as food aid, may not provide (Devereux et al., 2007). Mexico's Oportunidades cash transfer program works in two ways: first, families receive a fixed sum (the funds are intended for food) provided they access medical care. Second, children receive educational scholarships beginning in the third grade (conditional on 85 percent attendance). Oportunidades was found to reduce headcount poverty by 17 percent and the severity of poverty by 46 percent (Skoufias, 2005). In Malawi, preliminary qualitative analysis of Concern Worldwide's Dowa Emergency Cash Transfer project, which provides direct cash transfers for poor individuals, has shown that cash transfers to individuals led to better access to health care in addition to increased ability to cover transportation and medication expenses (Devereux et al., 2007).

Management Tools for Addressing the Implementation Gap

Although standard medical and public health approaches are useful in identifying and addressing implementation gaps, two other models or conceptual tools offer important approaches to identify strategies to close the implementation gap. One is the care delivery value chain (CDVC), a business model that offers a useful tool for conceptualizing and delivering integrated PMTCT and ECD services. Focusing on the question of "how," the CDVC allows the attainment of LG3 goals and objectives through: (a) providing practical how-to guidelines for integrating services to improve follow-up; (b) careful planning (process management) that will lead to a successful integration of complex, interrelated activities; and (c) incorporating systems to manage data (knowledge management, such as electronic medical records) so necessary information is always available when it is needed for optimal health care decision-making. Value chain analysis examines activities in the full cycle of care, and

follows the patient through different channels of service delivery. This model defines value as maximized positive outcome, or health. It offers a system that can prevent the existing common challenge of loss to follow-up, since participants are followed closely. Designing an integrated PMTCT and ECD value chain would enable service overlaps for both women and infants that could result in more efficient and effective service delivery. A second tool is the learning collaborative model, described in Section (4) below.

2. Integration and Expansion of Prevention of Mother-to-Child Transmission (PMTCT) and Early Childhood Development (ECD) Intervention Services

The extensive review of the existing literature on PMTCT and ECD in this paper pre-dated and informed the Learning Collaborative described below in Section (4). The review identified a number of strategies and approaches described in the existing literature that would improve access to and quality of care. Decentralizing and integrating services to increase access to PMTCT and reproductive health care (particularly early prenatal care and the availability of skilled birth attendants) and offering routine provider initiated testing and counseling (opt-out method) for HIV testing may help to identify women who need PMTCT services and may promote their access to care earlier in pregnancy (see Box 1).

Other mechanisms for identifying HIV-positive pregnant women include re-testing women at 34–36 weeks of gestation (Nuttall et al., 2004) and offering routine intrapartum counseling and testing (Homsy et al., 2006). In addition, a family-based approach to HIV care offers opportunities to test other family members, including spouses and other children.

The above case emphasizes the need for community involvement in increasing access to care. Other findings similarly indicate that a peer-support model improves access and quality of care. For example, the mothers2mothers (m2m) program offers another successful strategy. In this case, "mentor mothers" who have prior experience with PMTCT programs are paid for their outreach and education efforts and offer support to new program mothers.

BOX 1

Challenge: Addressing Low Uptake of HIV Testing: Cameroon Baptist Convention Health Board (CBCHB) Case Study

The CBCHB PMTCT Program successfully integrated PMTCT into routine prenatal care services provided by CBCHB's outreach branch: the Life Abundant Primary Health Care Program. Beginning in 1982, CBCHB trained traditional birth attendants (TBAs) to assess obstetrical risk and perform low risk deliveries. Before starting the PMTCT component, CBCHB staff met with village health committees for input on and approval of the program. In 2002, they began training TBAs in confidential HIV counseling and testing using Ora Quick oral HIV tests. A typical first-time prenatal visit included a group education session on the importance of HIV testing and ARV prophylaxis, pre-test counseling, a prenatal exam with the midwife while waiting for the results, and then post-test counseling with the same provider when the results from the lab returned that same day. Over four years this program was expanded to 115 health facilities in six of Cameroon's 10 provinces, including large hospitals as well as remote clinics, training 690 health workers and testing 68,635 women. In this population, 63,094 women were screened (92 percent acceptance), of whom 9 percent were HIV-positive and were offered a PMTCT regimen. Important factors that may have contributed to this success rate include: HIV testing and PMTCT offered as a routine part of prenatal care; well trained educators, nurses and TBAs; HIV test results available on the same day; a decentralized and sustainable prenatal program; community support and awareness; as well as intensive follow-up, quality assurance, and supervision. The program is funded continuously by Elizabeth Glaser Pediatric AIDS Foundation (EGPAF), and received a grant from Columbia University's MTCT-plus program. Nevirapine (NVP) and HIV tests were donated from pharmaceutical companies, and the clinics are run by the government and faith-based organizations (Welty et al., 2005).

The program also addresses the contextual variability and challenges in considering infant feeding and HIV risk. Women in this program were counseled in both exclusive breastfeeding and exclusive formula feeding and were more likely to choose and adhere to exclusive formula feeding. The mentors were able to inform women of the

risks of different feeding strategies and the women were able to play an educated role in their infant feeding decisions (Khan et al., 2007).

Reducing transmission through breastfeeding involves either exclusive breastfeeding or exclusive infant formula feeding, with mixed feeding conferring a higher risk. However, even with exclusive breastfeeding some HIV transmission risk remains (Coovadia et al., 2007). Intensive community-based support can reduce the morbidity and mortality risks of formula feeding. For example, in Rwanda, Partners In Health works with community health workers to educate HIV-positive women and support them in efforts to safely offer formula to their children (Stulac et al., 2007). While there is evidence that infant formula can be used in resource-poor settings, contextual factors must be carefully considered in order to provide adequate support to women who formula feed. Formula feeding in some settings has resulted in increased risk of infant morbidity and mortality (Noel et al., 2006; Creek, 2006).

Another strategy to improve PMTCT outcomes is to offer the most effective regimen for reducing transmission. There are a number of different PMTCT regimens available, with outcomes that range from less than 2 percent to 8 percent transmission (without breastfeeding). Single-dose nevirapine results in 8 percent transmission (Jackson et al., 2003), whereas ART and a combination regimen developed by Lallemant et al. (2004) can result in less than 2 percent HIV transmission. Therefore, the rate of MTCT will vary based upon the regimen offered; in the Lallemant study, this includes the ability to ensure that women present no later than 28 weeks of gestation to receive treatment.

Supportive follow-up and quality assurance is critical in early infant care, for example, offering cotrimoxazole to HIV-exposed infants to promote survival (WHO, 2006). Early testing for HIV using PCR will improve infant outcomes for those who test positive (Mbewe et al., 2006) and the dried blood spot (DBS) method makes this achievable in remote areas (Brambilla et al., 2003). If infants test HIV-positive, offering ART improves HIV disease prognosis. However, it was found that there was need in resource-poor settings to offer more training and support for pediatric HIV treatment, particularly in locations with few pediatricians (Michaels et al., 2006).

Integrating early childhood development interventions with nutrition, primary health care, and other health care programs (e.g. vaccination campaigns) can enhance access to ECD efforts. In addition, offering home-based ECD tends to increase access as well. Having a parent-focused approach to ECD (e.g. identifying and addressing maternal depression) may also facilitate longer-term benefits. Improving access to ART for all family members has long-term developmental implications for the infants as well, since it minimizes the risk of infants being orphaned due to HIV. Finally, broader structural changes, such as improving women's literacy and access to education, poverty reduction efforts, and reducing HIV-related stigma in the community may further enhance access to care, increasing families' capacity / demand for care and potentially improving health outcomes.

3. The Care Delivery Value Chain in the Prevention of Mother-to-Child HIV Transmission[2]

Successful implementation of interventions to prevent mother-to-child transmission (PMTCT) of HIV have reduced transmission to less than 2 percent of at-risk infants in most high-income countries, including the United States. PMTCT efforts around the world, however, have failed to provide similar results. The current disparity in PMTCT outcomes represents a failure of delivery. Value chain analysis, a framework that allows for examination of the strategy, operations, resource allocation, and metrics involved in PMTCT programs globally, elucidates the reasons for this failure and suggests a new approach.

The *care delivery value chain* (CDVC) is a strategic framework that facilitates systematic analysis of how health interventions deliver *value* for patients (Porter and Teisberg, 2006). Value—defined as long-term health outcomes achieved per dollar spent—is created across the cycle of care for a particular medical condition. The value chain maps the sequence, organization, and interdependence of activities required to deliver care. For PMTCT, a successful outcome was defined as a healthy,

2 Pending publication in a peer-reviewed journal. Please contact Dr. Peter Drobac (pdrobac@partners.org) directly for more information.

HIV-free two-year-old child with healthy parents. As a result, the PMTCT care cycle begins *before* pregnancy with HIV prevention, and continues through the second year of the infant's life.

The PMTCT CDVC organizes care into six groups of primary activities: (1) screening and prevention of maternal infection; (2) diagnosing and staging pregnant women; (3) initiating antiretroviral therapy; (4) offering skilled attendance for labor and delivery; (5) ongoing maternal disease management; and (6) promoting child health. These primary activities are examined within the context of patient communication, access, information flow, and metrics. The CDVC elucidates whether the sequence of activities is aligned with value; how information is shared between entities involved in PMTCT care; how human resources and health commodities are deployed; and how integration is achieved with other health services. With regard to integration, the PMTCT CDVC encourages the inclusion and integration of maternal health and broader child health services.

Value chain analysis demonstrates that the failure of global PMTCT delivery is primarily a strategic failure. The focus by WHO and major programs on pediatric transmission of HIV during labor and the early postnatal period results in marginal value for mothers and infants, and for the donor programs supporting current efforts. Although operational and resource failures have played a part in PMTCT program failure, Botswana's program from 2002–2007 successfully addressed operational bottlenecks with sufficient financial and human resources, but still faced program failures, including increased infant deaths and loss to follow-up of mothers and infants. Recognition of the shortcomings of the conventional approach to PMTCT has led to a shift in program strategy in Botswana, which was delayed by a lack of appropriate outcome measures (Sullivan et al., 2008). Value chain analysis strongly suggests that the greatest loss of value in the PMTCT care delivery value chain occurs at the level of current global PMTCT strategy.

Global efforts to control and reduce pediatric HIV infection are unlikely to provide significant value based on current strategy. While improved operations and additional resources may lead to short-term successes under current metrics, revised strategic thinking is essential for successful PMTCT health outcomes, including HIV-free child survival at 24 months and healthy mothers able to care for them. New metrics will be necessary, as current metrics do not correctly identify successful PMTCT outcomes, nor enable program improvement cycles. Delivery science studies will become increasingly important to help understand the successes and failures of global health programs.

4. The LG3 Learning Collaborative (LC)

The Learning Collaborative paper describes initial findings that are currently resulting in quality improvement in PMTCT/ECD services in Rwanda. First, by supporting local staff to evaluate and improve their own programs, the LC revealed that the existence of services at health centers (HCs) was not always translating to the delivery of services to patients. Further, it was found that although clinic attendance numbers were within 20 percent of government targets, significant losses to follow-up meant that identified patients were not receiving services. Providers who participated in the LC process identified program challenges that included: 1) the tendency of women to access services too late and/or infrequently in their pregnancies to optimize intervention services; 2) insufficient human and financial resources to follow up identified women and children; and 3) insufficient service capacity at some of the HCs, including a lack of nutritional support, or the ability to offer CD4 testing.

According to patients' perspectives, barriers to care included: 1) poor past experiences; 2) long waiting times for services; 3) difficulties in transport to the clinic (in terms of money, time and effort, particularly inability to travel when ill, caring for a newborn, or in third trimester of pregnancy); and 4) limited awareness of the services available. According to providers' perspectives, patients often "fell through the cracks" when they were referred from one center to another for different aspects of care; greater coordination of services across field sites would potentially reduce this loss to follow-up. Box 2 outlines some of the reasons that, according to community health workers, women do not attend, or attend infrequently, antenatal care (ANC) clinics and/or prefer to deliver at home. These responses are listed in descending frequency and are based on a survey by Rwinkwavu HC, one of the LC member HCs.

BOX 2

Reasons Why Women Do Not Attend Antenatal Clinics and/or Prefer Home Delivery: Results from a Survey of 118 CHWs by Rwinkwavu HC

1. **Women are turned away:** Lack of clinic capacity led to women being turned away. Word of negative experiences spread in the communities, further discouraging other clients, especially those who live far away. CHWs expressed concern that women were coming from outside of the catchment area which increased the risk that local residents would be turned away. Women were also turned away sometimes because they did not come with their husbands. Some of these women did not have husbands and some husbands did not want to come.
2. **Ignorance:** CHWs believe that women do not know or understand the importance and relevance of prenatal consultations and giving birth at the clinic.
3. **Shame:** Many women are ashamed that they are pregnant again or are having children out of wedlock, so they attempt to hide it by not coming to the hospital.
4. **Poverty:** Women without a change of clothes or clean clothes are ashamed to come.
5. **Poor Preparation:** People are not used to preparing and because they are not organized, giving birth at home is an easier option.
6. **Husbands' Opinion:** Husbands discourage women from attending prenatal consultations because they fear HIV testing.
7. **'That's not how we did it'**: Older generations pressure women to deliver as they did.
8. **Illiteracy:** Some women don't know how to read or write, so they cannot refer to appointment cards and forget visits, or come on the wrong day, which often means they are denied services.
9. **Mutuels (health insurance coverage)**: People without insurance cards think they cannot come.
10. **Cultural Attitudes**: In Rwandan culture there is an ideal of 'standing strong and alone.' CHWs cited this attitude to explain why many women do not avail themselves of prenatal consultations or want to give birth at the clinic.
11. **Misconception**: According to CHWs there have been rumors that health professionals may poison them and their babies.
12. **Fear**: According to CHWs, the local belief exists that excess preparation can cause harm to the baby.
13. **Traditional Birth Attendants** do not encourage women to come to the clinic.

The Learning Collaborative process led to new activities that facilitated an increase in capacity to offer PMTCT at the health center (that is, decentralized) level. During the implementation of the learning collaborative, which included distribution of stipends for community health workers' efforts and families' transport to health facilities as well as the quality improvement cycles described above, improvements were observed for vaccination coverage; bed net distribution; first trimester antenatal clinic (ANC) attendance; PMTCT services; administration of appropriate regimens, including regular cotrimoxazole prophylaxis; and infant feeding counseling. Increased capacity also involved the following: the introduction of blood drawing for CD4 counts at some health centers where this had not occurred; additional nutrition counseling; and recruiting a local doctor to provide weekly visits for prescribing ARVs. Strategies for integrating service delivery also included: 1) combining appointments for mothers and infants when feasible; 2) ensuring that patients receive all needed services when they arrive for any health appointment; 3) offering counseling and growth monitoring on immunization days; and 4) delivering bed nets at outreach vaccination sites rather than asking patients to come to the health center to collect them.

Local strategies were also developed to increase patient encounters and improve follow-up. Some of these locally-developed strategies included providing appointment cards, combining appointments, increasing the number of outreach vaccination sites, scheduling services at convenient times (e.g. market days, extending hours), offering incentives to CHWs and/or women to facilitate ANC visits, and using CHWs to remind families of follow-up appointments or to perform home visits when infants miss vaccinations.

There were several persistent challenges noted. These included the cost of obtaining food for infants six months of age and older; the cost of formula when women opt to formula feed their infants; stock-outs of supplies; insufficient human and material resources (e.g. insufficient human resources for home visits); identifying all pregnant women and infants who need care; and difficulties with systematic ECD monitoring while implementing initial efforts to enhance patient follow-up. Two health centers (Kiziguro and Kabarondo) made group screening for ECD a PDSA

objective, monitoring growth and development for malnutrition. ECD monitoring was found to be very limited outside the centers that offered the comprehensive feeding program. A reference card based on ECD guidelines from WHO's "Integrated Management of Childhood Illness for High HIV Settings" (World Health Organization, 2006a), along with screening questions and guidelines on infant feeding, was developed and tested. The program planned to do pilot testing of these cards with nurses at the health centers, and then train CHWs to use them on home visits. The final report of the Learning Collaborative is pending at this time.

5. Botswana — PMTCT Case Study[3]

Findings from the Botswana PMTCT case study (Sullivan et al., 2008) revealed factors potentially related to the successes and challenges that the program encountered. Botswana has one of the highest rates of HIV prevalence worldwide (24.1 percent). However, the rate declined from 38.8 percent in 2001 to 24.1 percent in 2005 (UNAIDS, 2007). This decline can be partially attributed to a change in the method for calculating HIV prevalence; applying UNAIDS recommended corrections, the Ministry of Health reported an HIV prevalence rate of 26.9 percent in 2007 (Sullivan et al., 2008). The Government of Botswana (GoB) has been proactive in addressing the HIV epidemic; former President Festus Mogae's tenure was characterized by a resolute commitment to battle HIV/AIDS. In addition, given its relatively high GDP per capita (US $11,200) compared to other sub-Saharan African countries, it has been able to invest more government resources to prevent and treat HIV. For example, in 2005, roughly 6 percent of the government's total domestic budget was spent on HIV/AIDS.

In 2002, the GoB offered the first national antiretroviral treatment (ART) program in Africa providing free treatment. This resulted in an increased demand for voluntary counseling and testing for HIV. Botswana was also the first country in Africa to offer Routine Provider-Initiated HIV Testing (PITC) in 2004 (also known as the 'opt-out' strategy). Although there was much controversy surrounding this strategy, a pilot study was conducted in 2003 by BOTUSA/the Center of Excellence and Operational Research (Francistown) that demonstrated that women found PITC acceptable. During the first year of PITC implementation, Botswana's health facilities tested more than 69,000 clients for HIV.

The PMTCT program was piloted in the country's two largest cities in 1999, prior to the advent of the national ART program. However, the program suffered from limited uptake, with 2002 statistics demonstrating that only 30 percent of women attending prenatal clinics were tested for HIV. Approximately one-third of pregnant women were HIV-positive, which made it imperative that access to treatment and PMTCT services be promoted among pregnant women. A number of factors may have contributed to this low uptake or limited program performance, including human resource constraints related to voluntary counseling and testing for HIV; HIV-related stigma and fear; difficulties with patient follow-up; and until the advent of the national ART program in 2002, women testing positive for HIV during pregnancy did not have access to ART after they delivered.

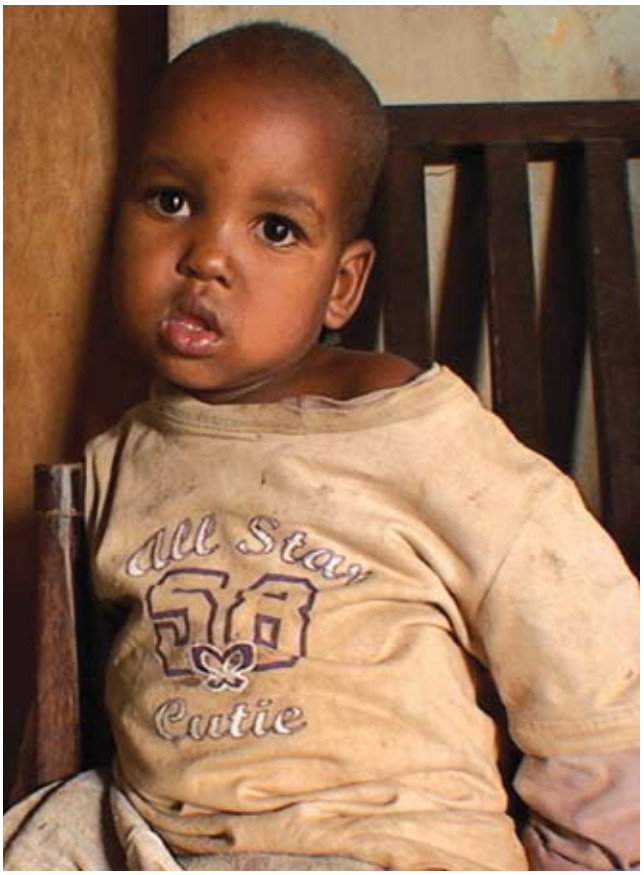
Due to a number of programmatic and policy changes, the uptake of PMTCT services increased from 30 percent to 85–90 percent (2006), and the rate of mother-to-child HIV transmission was lowered to 4 percent in 2007 (Tlale et al., 2008). Factors that may have enhanced uptake and outcomes include access to routine HIV testing (all pregnant women receiving antenatal care were offered an HIV test); introduction of rapid HIV testing in antenatal clinics and the labor ward; improvements in counseling education; increased access to ART for adults, including pregnant women; initiating PMTCT services at 28 weeks of gestation rather than 34 weeks; and adoption of an easier way to obtain blood specimens for HIV testing for infants, using the dried blood spot (DBS) method.

The success of Botswana's PMTCT program was challenged with a diarrheal disease outbreak in 2006. The investigation of this outbreak demonstrated that formula-fed infants were at a greater risk of morbidity and mortality. Since adopting a formula feeding policy for infants born to HIV-positive mothers, it had been thought that

3 For more information on the teaching case, "Botswana's Program in Preventing Mother-to-Child HIV Transmission," please contact Global Health Delivery at Harvard University at info@globalhealthdelivery.org.

all citizens generally had access to clean water; thus, it was assumed that there was a limited need to consider hygienic practices, access to refrigeration and electricity. In the aftermath of the outbreak, and with the publication of new PMTCT guidelines in 2008, Botswana had re-evaluated its formula feeding, counseling and support program for HIV-positive mothers. Changes were made to improve outcomes, including enhanced support and education of women using infant formula, training programs for water monitoring, and public health campaigns that focused on boiling water and other safe hygiene issues. New guidelines dictated that for HIV-exposed babies, infant feeding decisions should be made according to the WHO AFASS criteria (recommending replacement feeding only if it was affordable, feasible, acceptable, sustainable and safe). Historically, the infant formula feeding program had also been challenged by a lack of inventory, problems with distribution, and ordering systems. Additionally, the set allocation of 10 tins of formula per month was not enough for some infants, and had resulted in some cases of malnutrition; to remedy this, new PMTCT guidelines were more flexible in terms of the allocation of formula.

From examining Botswana's PMTCT program, it is evident that a series of changes in both process and policy have increased the program's uptake and



success levels. Looking forward from 2008, one of the program's main strengths is its integration with maternal and child health care services. Botswana is working on determining the safest infant feeding strategy for HIV-positive mothers, primarily through conducting a number of studies to determine ways to decrease infant mortality and morbidity. As a mature program, it faces a number of challenges as it strives to move toward eradicating childhood HIV, one of which is determining the best measure of "success" in PMTCT care.

6. Rwanda — Orphans and Vulnerable Children: Planning and Programming Case Study

The case to expand access to basic services for orphans and vulnerable children in Rwanda is informed and strengthened by the tremendous political will following that nation's 1994 genocide. After the genocide, Rwandans at all levels of government and society resolved to build a national governance mechanism that would be fully representative, highly participatory, and completely transparent. To meet these goals, high priority was placed on including groups that are often marginalized, such as the poor, orphans and vulnerable children and those living with HIV/AIDS. Poverty reduction was made a high priority, with the goal of achieving sustainable economic growth and social development to improve the quality of life of all citizens. Addressing HIV/AIDS across all sectors is an essential element of this plan. Rwanda's commitment to inclusive, comprehensive care empowered the government to conceptualize and implement new approaches to difficult challenges. The government established its first national policy for orphans and vulnerable children in 2003; and in 2007 adopted a Strategic Plan for OVC 2007–2010. The government worked in close collaboration with the OVC Technical Working Group and other stakeholders, including the United States President's Emergency Plan for AIDS Relief (PEPFAR), Global Fund to Fight AIDS, Tuberculosis, and Malaria (GFATM), and the World Bank's Multi-Country HIV/AIDS Program (MAP) to define a "minimum package" to support orphans and vulnerable children. The goal is to offer a basic package of care that includes health care, nutrition, education, protection, psychosocial, and socioeconomic services. The package is intended

to be holistic, whereby development partners are directed to offer funding for all services for a given number of children, as opposed to offering only one element, such as access to education.

A number of initial themes/ priorities were identified in this Rwandan case examining the comprehensive program for orphans and vulnerable children that may help promote program success in other settings as well. These include the following: financial investment at international and national levels; political will at all levels of governance; development of a national policy and action plan; decentralization of accountability; performance-based funding allocation; transparency; community involvement; and support of families to enable them to offer adequate care and protection of children.

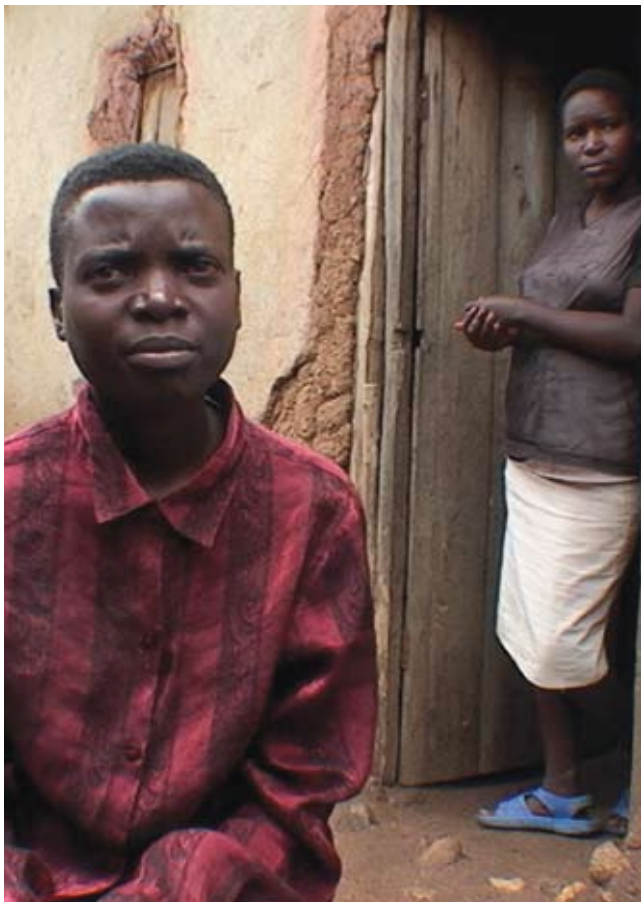
The Rwandan case offers both a detailed description of the planning and initial implementation stages for supporting orphans and vulnerable children in a comprehensive manner. By examining what facilitated this process, other governments, non-governmental organizations, and community-based organizations can adopt similar strategies or adapt them to their specific context. Examples of "facilitators" include multiple funders of the initiative, involving internal as well as external funding; a collaborative approach (e.g. National AIDS Control Commission and the Ministry of Gender, Child Protection, and Promotion of Family); mapping operations onto existing structures, rather than creating parallel structures; and involving communities and the children themselves to ensure targeting of appropriate children.

Lessons Learned

In describing the roles and approaches of authorities at the decentralized level and NGOs working to improve the lives of orphans and vulnerable children, it became clear that certain specific factors helped to facilitate the implementation of support mechanisms for this population. These factors are listed and discussed below. Some of the ongoing challenges in these areas are also identified.

1. Political Will to Address the Problem

Rwanda has demonstrated its commitment to supporting children and families that have been made vulnerable due to the genocide, HIV/AIDS,



and overwhelming poverty by recognizing the importance and relevance of community-based support of orphans and vulnerable children in its policy and programming. All ministries engaged in such work, whether directly or tangentially, should recognize the importance of their individual participation in development of program planning going forward.

2. Decentralization of the Program

Decentralization of responsibility for programmatic activities targeting orphans and vulnerable children (e.g. concrete work plans developed at the district level) has facilitated success through promoting local ownership, enhancing district autonomy, and engaging communities, including vulnerable children themselves.

3. Strong, Widely Accepted Program Leadership

Robust leadership at all levels (from the national coordinating authority to the decentralized level) has fostered transparency and accountability in the system in financial as well as programmatic terms. This process has engendered in local actors a sense of responsibility for and motivation to assist orphans and vulnerable children. Strong

leadership has encouraged participation in open forums to exchange ideas and solve problems collaboratively. These findings suggest that Rwanda's Ministry in charge of Gender, Child Protection, and Family Promotion (MIGEPROF) should focus on initial consultation with leadership at the district level on programmatic decisions concerning orphans and vulnerable children. Packaging this information in a way to make it accessible to communities, particularly illiterate populations, is an ongoing challenge for leadership at the decentralized level.

4. Linking Programming with Poverty Reduction and Economic Development

A central priority of Rwanda's national government is poverty reduction and economic development. Policy and program initiatives benefiting orphans and vulnerable children were spearheaded in this context, promoting uptake and expansion of new efforts. Those efforts are implemented within the context of Rwanda's Economic Development and Poverty Reduction Strategy and should be treated as an essential part of the district development plan.

5. Trust and Buy-in of Local Stakeholders and Beneficiaries

Gaining the trust of people in the community and beneficiaries can be achieved by promoting active participation of the child in support services for orphans and vulnerable children. Child-centered committees at the decentralized level and children's involvement in the Nkundabana initiative have shown success and sustainability. The high level of community involvement promoted program follow-through and fostered accountability for achieving program targets.

6. Strategic Alliances

Networks of service providers at all levels with informed knowledge and experience of the problems faced by orphans and vulnerable children are integral to helping them navigate the referral system and to reducing the number of children who either receive duplicate services or are not accessing them at all. Multiple support mechanisms delivered simultaneously allow children to fare better overall; for example, children who receive psychosocial support tend to have better performance in school. Reliance on volunteers to deliver services to orphans and vulnerable children is an integral part of service delivery, but this also poses a challenge in terms of their level of commitment. Harmonization and dissemination of best practices across NGOs and district offices have not yet occurred on a broad scale. Competing priorities of involved ministries and other key stakeholders may have slowed the rate of progress in this regard.

7. Development of Comprehensive Programs to Address Root Causes of the Problem

Comprehensive programs that address underlying causes of problems for orphans and vulnerable children exist in Rwanda and the use of a community-centered definition of vulnerability as a targeting mechanism has enabled service providers to reach a greater number than previously. However, set criteria are needed for determining when children and families have "graduated" from a support program or entered into a less/more severe state of vulnerability. The minimum package of services in its entirety has not been implemented widely enough due to budget constraints and coordination challenges. This is in part due to the fact that one organization cannot typically offer all six elements of the minimum package. Donors should lessen restrictions on use of funding for operating costs (such as not allowing compensation for community volunteers or motorbikes for transportation) and eliminate the beneficiary age cap in order to make services more accessible to all orphans and vulnerable children.

8. Challenges Maintaining the Monitoring and Evaluation System

The monitoring and evaluation system is an excellent example of data collection used for the purpose of improvements in program implementation. In this sense it is a strong system. The main challenge will involve maintaining and building capacity of the system in terms of cost, staff training, and equipment/software upgrades. Thus far, it appears as if the technical expertise is available but it is unclear if there will be adequate funding in the future to sustain the system.

9. Leadership and Future Financing of the Initiative

Feedback from the field interviews indicates that the need is far greater than the current program capacity. Strong leadership and advocacy have allowed the program to advance to its current form and it is anticipated that these strengths will serve to enhance future funding to sustain and expand the program. Allocation of additional funds will allow for a greater likelihood of all elements of the "minimum package" being offered to all orphans and vulnerable children and promoting dissemination and uptake of "best practices."

In summary, the purpose of this case study was to describe the framework or architecture of a program from the outset, starting with the initial vision and ending with program implementation. The vision of aggressively moving Rwanda's economic situation out of poverty is an underlying force that drives the process and it is this vision that characterizes the type of leadership that is motivated by the democratic process and the promotion of human rights, particularly of those most vulnerable. The mechanics of operationalizing the vision of offering orphans and vulnerable children the services and resources to which they are entitled were rooted in policy development, which provided the framework for the national strategic plan of action. The guiding principles of the strategic plan were based on content from Rwanda's National Policy on OVC (2003) and the UN Convention on the Rights of the Child (GoR, 2006).

However, in the Rwandan case, the process did not stop with the national strategic plan; implementation was possible because this national plan was translated into district-level plans in which district officials, such as the local mayors, were responsible for program plans, implementation, and evaluation. The process of decentralization was facilitated by raising local awareness through information campaigns; fostering capacity building at the local level by supporting local community-based organizations and structures; and by establishing mechanisms for coordination, to ensure program consistency, prevent duplication, and identify gaps in services. In terms of future progress of this ambitious plan, feedback from program implementers indicated a need to strengthen efforts of communication, capacity building, transparency and coordination between national and local/district levels of operation. As more capacity building occurs at the district level, the local government will be able to develop a more coordinated response (e.g. across government entities and civil society organizations [CSOs]) to address the needs of orphans and vulnerable children, since they may vary in different geographical areas of Rwanda.

Rwandan policy makers were able to set the agenda with development partners, such as PEPFAR, Global Fund, World Bank, etc., given the fact that they had engaged local communities as well as orphans and vulnerable children to offer feedback on how those children could be assisted. Policy makers developed the "minimum package" program in part based on this feedback and negotiated with development partners to fund this program, rather then allowing outside funders to set the agenda. As a result, the Rwandan government was able to make its own decisions on allocation of this external funding and also was able to develop a monitoring and evaluation system that mirrored its internal goals and objectives for the program. In the immediate-term, this has sustained the system and program activities. It is clear that greater external funding for the program is currently required to meet the great needs of orphans and vulnerable children; however, as Rwanda transitions into its vision of a middle-income nation, it is anticipated that more resources will be generated internally by the very youth who benefited from the existing program.

7. Integrated Health Care Delivery Systems for Families and Children Impacted by HIV/AIDS: Case Studies from Rwanda and Kenya

The primary responsibility for care and support of children affected by HIV and AIDS continues to fall to communities and immediate families of the sick and vulnerable. Caregivers in such settings are predominantly women, ironically the very group who is (along with children) often functionally viewed as invisible, second-class citizens by traditional and, to some extent, civil laws. Such caregivers often also donate time and labor outside their homes, contending with daily physical and economic stresses. And yet there is strong evidence that family-centered ART delivery and care may have the potential to cultivate unity,

continuity, knowledge, and strength for pediatric patients and other HIV-infected family members (Reddi et al., 2008). This LG3-sponsored paper, on integrated health care delivery systems for families and children, provides evidence to illustrate key program components that enable decentralized integrated health care delivery systems to flourish in family and community settings. The four programs highlighted in this report—AMPATH in Kenya, CARE International's 5x5 Model for Early Childhood Development in Rwanda, the CARE Rwanda Case Manager Model, and the Partners In Health/Inshuti Mu Buzima (PIH/IMB) Rwanda program—are in resource-poor settings where a vast majority of clients live in poverty and often experience malnutrition and insufficient access to health care and education. Interventions must thus simultaneously address poverty, hunger, gender discrimination, and stigma, among other factors (Einterz et al., 2007).

Case Study 1

AMPATH: Treating HIV-Positive Kenyans and Providing Integrated Nutritional, Health and Social Support to Their Children and Families

Based in Kenya, AMPATH is one of Africa's premiere integrated health delivery models. It provides free ARVs to 42,000 HIV-positive patients, weekly food assistance from six local farms to 30,000 people, and annual prenatal care to 25,000 women. AMPATH enrolls 2000 new patients each month. Founded in 1990 as a partnership between the Indiana University School of Medicine (IUSM) and Kenya's Moi University School of Medicine, AMPATH operates under the auspices and direction of the Ministries of Health and Education and has been supported by PEPFAR funds since 2004.

AMPATH was confronted with the insufficiency of its early approach to HIV/AIDS treatment and care when many patients refused ART treatment after learning that AMPATH's strategy did not provide food and nutrition (Mamlin et al., 2007). Concluding that scaling up ART without an integrated food and anti-poverty strategy would have only limited impact, the program began to offer nutritional support with ART. After several months AMPATH found that clients also wanted and needed technical assistance to increase their productivity and improve their economic condition. AMPATH decided that the most effective intervention should include ART in combination with food and financial support for

the entire household (Food Assistance Initiative for ART, 2005). Although AMPATH reports that delivery of services is challenging with food distribution sites based throughout the country (Mamlin et al., 2007), their operating principles of collaboration and long-term partnership with the government, the local university, and communities provide the foundation for successful engagement of trouble-shooting obstacles when they occur.

Promoting Food Security

In the AMPATH program, all HIV-infected patients undergo comprehensive nutritional assessments, and those found to be malnourished or food-insecure are given nutritional counseling and a nutrition prescription that benefits the entire household. The assessment includes documenting the patient's anthropometrics, clinical symptoms, economic status, most recent food intake, and food security indicators. A patient must meet a combination of the following factors for his/her family to become a beneficiary of food assistance: BMI<19, CD4<200, poor economic status, and household food insecurity. Patients that meet the above criteria receive monthly prescriptions for full nutritional support for themselves and all dependents that live in the same household.

Promoting Economic Security

The vast majority of AMPATH's initial patients were women with children who had been widowed by HIV/AIDS and did not have the capital or skills necessary to support their families. It soon became obvious to AMPATH leaders that economic security was as important as food security, and it subsequently launched its Family Preservation Initiative (FPI). FPI provides skills training, micro-

credit, agribusiness support, a fair-trade-certified crafts workshop and membership in agricultural cooperatives to recovering patients who are rebuilding their lives as healthy HIV-positive citizens.

Agricultural Initiatives

Designed to combine measures for food security and economic independence, AMPATH also launched a variety of agricultural initiatives. Community-based social workers identify vulnerable patients and invite them to farm higher-value crops, such as passion fruit and soybeans, which are part of AMPATH's staple food program stocks. Paying a registration fee of US $15, HIV-positive farmers who have regained their health are trained to farm new crops using methods that are inexpensive and sustainable. The success of the program lies in the ability of the crops to generate greater yields and profits for the small-scale farmer.

The Role of Social Workers and Community Health Workers

AMPATH's paid social workers and CHWs facilitate care, support, and referrals to increase the access of children affected by HIV and AIDS to a wide range of essential services including food and nutrition, education, health care, protection, psychosocial support, housing, and economic security. CHWs work closely and intensively with communities and serve as a point of contact for community members to refer HIV-impacted families in need of services. The CHWs are identified through existing community structures; for example, chiefs, village elders, church leaders and women's groups. Their role is to identify and refer the households of children affected by HIV and AIDS to the program, complete household and individual assessments at the home, and provide follow-up. The AMPATH model thus offers a number of useful entry points for integrating health care delivery systems for families and children.

Case Study 2
CARE's 5x5 Model in Rwanda: Promoting ECD for Children in Need

CARE's 5x5 Model pilot program intentionally streamlines early childhood development (ECD) into general health-related service delivery to families affected by HIV/AIDS. According to its 2007 program report (CARE, USAID, and Hope for Children, 2007), the 5x5 program advances child-centered interventions in the areas of: food and nutrition, child development, economic strengthening, children's health, and children's rights and protection. As of July 2008, CARE was working with three communities in Rwanda to establish and operate ECD centers for children ages 2–4, and also supports two nursery schools for children ages 4–6. Each ECD center: provides at least one nutritious meal daily to each child; emphasizes the use of quality ECD curricula to build the capacity of teachers and caregivers for interventions alongside play and learning in childcare settings; engages caregivers in numerous economic-strengthening practices; uses the ECD center to mobilize and link health workers with children and families and as a vaccination site; and leverages existing community resources to advance children's rights through advocacy initiatives and training.

The existence of these ECD centers has enabled some older sisters serving as caregivers to attend school more regularly. The centers have the potential to help increase and stabilize household earnings; and can help to support a stable home environment for healthy psychological development of children and family members. The pilot program advances numerous innovative strategies for increasing ECD resources and access in poor communities (Zoll, 2008). These include funding ECD programs through microenterprise loans to women to establish home-based daycare centers and to finance related income-generating projects such as ECD-center-associated gardens, handicraft sales, and supplementary endowments to ensure that teachers are paid more regularly.

Case Study 3
CARE International's Case Management (CM) Model in Rwanda

Of an estimated 190,000 HIV-infected Rwandans, 100,000 are women and 27,000 are children (UNAIDS, 2007). Established in 2004, CARE's Case Management (CM) integrated model aims to holistically address the many and complex needs of HIV-affected households with a specific focus on enhancing ART and adherence, combined with social and economic support through PLWA Support Groups (CARE, 2008). This model builds on the finding that case managers can be used to successfully integrate formal care services into informal delivery systems.

CARE uses case managers (who are either nurses or social workers) who are based in and employed by health facilities that are receiving financial support from CARE. After assessing the health, psychosocial condition and economic situation of their patients, case managers work with patients and their families to develop individualized plans that help affected families cope by linking them to additional health care, legal assistance, nutrition and food support, housing and shelter assistance, psychosocial services, and financial or in-kind support for transportation, school fees and clothing. CARE's CMs fulfill a role similar to CHWs in that they provide a bridge between families and health care facilities; CMs in the Rwanda program maintain an average caseload of 63 clients.

While CARE compensates its case managers, it does not compensate home-based care volunteers who deliver services to patients and their families in their homes. This compensation policy is responsible for much turnover. Since community volunteers are often poor and in need of basic support themselves, incentives and motivation were cited as pressing concerns in a 2006 evaluation (Thurman et al., 2006).

Case Study 4

Partners In Health Rwanda: Building a Rural Integrated HIV/AIDS Treatment and Health Care System in Rwanda

In 2005, the Rwandan Ministry of Health invited Partners In Health (PIH) to bring its model of linking community-based services with clinical resources (Farmer et al., 2008) to Rwanda, where, at the time, limited HIV/AIDS treatment was concentrated primarily in the capital city of Kigali. Together with its local partner, Inshuti Mu Buzima (IMB), the PIH/IMB team began with two of six designated health clinic sites, Rwinkwavu and Kirehe, which ostensibly served a population of nearly 500,000, although no medical doctors were on staff at that time.

Rwinkwavu Hospital had been in disrepair for years and was staffed by only a handful of nurses working without most basic supplies. Within two years of introducing the PIH model, more than 2,500 HIV patients were enrolled on antiretroviral therapy, more than 800 villagers—many of whom are HIV-positive—were trained and hired as community health workers, and nearly 100,000 patients visited the hospital. In the first year, hospital reconstruction generated five dedicated inpatient wards with more than 80 beds, a general pediatric ward, and a separate inpatient center for children suffering from severe malnutrition.

Challenges to Scale-Up

Rapidly scaling up HIV/AIDS and general health services in this setting revealed many of the limitations that existed within the national health system. Common barriers to access included transportation problems, a lack of services and staff, and social stigma. PIH estimates that approximately 6,000 nurses are needed to fully scale up comprehensive care, about twice as many as are available nationally. PIH/IMB plans to bridge this human resource gap by training and employing local villagers to serve as community health workers. PIH estimates the financial cost of providing a comprehensive health care system at about US $280 million annually (PIH, 2008).

PIH Programs for Children and Families Affected by HIV and AIDS

Rapidly scaling up programs for families affected by HIV and AIDS requires a multi-faceted approach to address the many pressing needs common to resource-poor settings where HIV disease is endemic. For instance, psychosocial support for children is an important complement to ARVs, as is systematic counseling, support, and educational assistance. Around Rwinkwavu, PIH Rwanda staff and patients conduct HIV education programs at primary and secondary schools. Food security and proper nutrition are also integral to their service package and essential to successful HIV treatment. PIH Rwanda distributes 1,500 food packages per month to HIV and TB patients and their families, and has signed an agreement with the World Food Program for another 1,000 per month.

PIH has identified five key components for implementing comprehensive, community-based child survival programs that include linkages with HIV services. These include: working in partnership with public health authorities to provide comprehensive child survival interventions; supporting maternal health; initiating and/or strengthening pediatric AIDS services; supporting operational research; and promoting social and economic rights.

The PIH Community Health Worker Model

PIH recruits, trains, and pays CHWs to meet the human resource challenges of delivering high-quality care in difficult settings. PIH's model of community-based care is rooted in its commitment to training and hiring from within the local community. Community members are recruited, trained, and compensated to fill jobs as counselors, educators, treatment providers, and advocates. Community health workers help health care systems overcome personnel and financial shortages by providing high-quality, cost-effective services to community members in their homes, and by identifying serious conditions at an early stage, before they become more dangerous and expensive to treat. By delivering services to patients in their homes, community health workers improve patient adherence to treatment and reduce the burden of time and money on both patients and health care systems. Because contact with their patients is so frequent, CHWs are able to monitor and advocate for patients' needs for food, housing, and safe water, lead education campaigns, and empower community members to take charge of their own health.

As members of the communities they serve, community health workers are able to establish relationships of trust with their patients, bridging the gap between the clinic and the community. PIH/IMB recently recognized the need for more formal supervision structures that capitalize on experienced senior CHWs, and introduced supervisory CHW Leaders. Supervisory responsibilities vary in different PIH contexts; leaders in Rwanda supervise 15–25 CHWs and meet regularly with health center staff to determine specific needs, desires, and resources.

Program scale-up in Rwanda is challenged by a variety of factors, including general health issues (malaria; maternal mortality; tuberculosis; hunger, malnutrition, and poverty; and various barriers to assessing care and treatment), human resources, and financial resources.

This LG3-sponsored report on four case examples of family- and community-centered care identified a number of key components for success that may be applicable to other settings and contexts. These include:

- a philosophy rooted in social justice and the human rights of patients to access health care services regardless of ability to pay;
- a broadened definition of health care that includes the linked provision of nutrition, psychosocial support, education, economic security, legal protection, clean water, and basic shelter;
- integrated ECD;
- CHWs (including HIV-positive individuals) at the center of the program's architecture;
- a sustainable, integrated, food and nutrition component that is considered an essential patient right and of equal importance to ARV and other life-saving medications;
- community-based comprehensive health care delivery;
- a strong commitment to hire within the community, including compensation of community health workers;
- a program focus on reciprocal partnerships with a range of actors;
- a cross-disciplinary approach to health care delivery;
- transparent, experimental, and flexible management style; and
- a large infusion of operating costs from external donors.

Of all of these essential points, nutritional supports, ECD practices, and compensation/cash transfers/pensions to caregivers—both family and community members—appeared to be uniquely critical to program success.

8. HIV and Access to Education Review

The goal of universal access to primary education was first established in 1990 at the World Conference on Education for All (EFA). According to EFA's 2002 assessment, however, 89 countries are in danger of failing to meet the 2015 deadline of universal completion of primary education (UNESCO, 2002). At the secondary school level, only 30 percent of children in sub-Saharan Africa currently enroll in secondary school (UNESCO, 2007), and only five sub-Saharan African countries have female secondary enrollment rates greater than 50 percent, reflecting the persistent gender gap in many high-HIV-burden countries. In cases

where advances in enrollment have been achieved, such gains risk being undermined by the poor quality of education and the presence of school fees that pose additional barriers to access (Global Campaign for Education, 2007). As Table 1 illustrates, many of the highest HIV prevalence countries continue to struggle to provide primary and secondary school education to their populations.

Table 1. Illustrative HIV Prevalence and Primary and Secondary School Gross Enrollment Rates

	Adult HIV Prevalence (2005)	Gross Enrollment Rate (Male/Female) (2006 unless otherwise noted)	
		Primary	Secondary
Zambia	17.0	118/116	31/25 (2002)
Mozambique	16.1	113/97	18/13
Tanzania	6.5	112/109	7/5 (1999)
Uganda	6.4	116/117	21/17 (2002)
Nigeria	3.9	98/78 (1999)	24/22 (1999)
India	0.9	114/109	55/41 (2002)

Source: UNESCO Institute for Statistics, last accessed 05/10/2008: http://stats.uis.unesco.org/unesco/TableViewer/document.aspx?ReportId=198&IF_Language=eng

In addition to the challenges in accessing education that face all children, such as cost, distance and household responsibilities, children affected by HIV and AIDS often face stigma and discrimination, and more serious financial barriers to education (Foster 2002; Cohen et al. 2006). Nyamukapa and Gregson (2005) found that increased barriers to schooling are most severe among maternal orphans (rather than paternal or double orphans), and concluded that placement in a female-headed household often results in a higher priority placed on continued education for orphans. These HIV-specific disadvantages are in addition to the lower overall health outcomes that are associated with less education (Caldwell, 1979).

Relationship Between Educational Attainment and Risk of HIV/AIDS

Strong evidence exists to support the impact of formal education on health outcomes (Grown et al., 2005). The strongest evidence supports the connection between female education and increased use of maternal care services (Malhotra et al., 2003). However, evidence for the relationship between level of education and HIV incidence for both women and men has been mixed. Some studies of HIV prevalence have found that higher education is associated with higher levels of HIV prevalence (Gregson et al., 2002), while others have found a protective effect of education, particularly at higher levels of attainment (Jewkes et al., 2003; Malhotra et al., 2003; Silveira et al., 2002). A review of evidence from a study of HIV risk in four African cities revealed no association between schooling and HIV infection for men or women in Kisumu or Ndola, but a did find relationship between increased schooling and reduced HIV risk for women in Yaounde and men in Cotonou, concluding that this relationship is context-dependent (Glynn et al., 2004).

However, a recent systematic review of published peer reviewed articles on the relationship between educational attainment and HIV status found a reversal in this relationship after 1996. Studies before that time generally found no association or the highest risk of HIV among more educated individuals, while studies after 1996 were more likely to find lower risk of HIV among the more educated groups (Hargreaves et al., 2008). Ajari et al. (2007) presented similar findings at the 2007 International AIDS Society (IAS) Conference, reporting on recent data that indicates a positive relationship between completion of secondary education for young women and reduced risk of HIV in Nigeria. A study of a rural Ugandan population also noted a changing trend, observing that in the period from 1999 to 2000 a statistically significant relationship existed between higher educational attainment and lower HIV risk among 18–29 year old females ($p = 0.01$); however, among the same age category of women from 1989 to 1990 there was no association between level of education and HIV (de Walque et al., 2005).

The shortfall in educational attainment holds particularly serious consequences for girls and women. According to UNAIDS, in 2007 women comprised 61 percent of HIV positive adults in sub-Saharan Africa, and this proportion was growing

at varying paces across regions (UNAIDS, 2007). Women and girls are at an increased biological and social risk of contracting HIV in many cultures where their abilities to control when and with whom they have sex are limited. In the most severe circumstances women's control over their sexual health is limited by physical and sexual violence. The 2005 WHO multi-country study on violence against women found that in most sites studied, between 10 and 50 percent of women reported experiencing sexual violence by an intimate partner in their lifetimes. In all sites except Ethiopia, women who reported experiencing violence from an intimate partner were significantly more likely to report that they knew their partner had had sexual partnerships with other women during their relationship (García-Moreno et al, 2005). Although education, particularly beyond the primary level, has been shown to be protective against both HIV and violence, gender gaps in enrollment and completion increase with the level of attainment, further constraining women's abilities to safeguard their own health (UNESCO, 2002). While education alone is insufficient to enable many women to protect themselves from HIV due to other socio-cultural risks, including violence, it is a necessary foundation to give women and girls necessary skills to control their choices and health risks.

In summary, the findings from this paper indicate that:

1. Research from the past decade suggests a trend towards a protective effect of education on HIV risk;
2. In particular, access to secondary education for girls may reduce the burden of HIV in high prevalence settings;
3. School enrollment may have an immediate protective effect on HIV risk (e.g. girls attending school are less likely to have an early sexual debut) as well as a long-term effect of education, through increased knowledge, enhanced self-efficacy, and an impact on sexual networks and power dynamics within relationships;
4. In many high HIV-burden countries, poverty is one of the most common factors that prohibit school enrollment. Elimination of school fees or payment of the fees, as well as poverty reduction strategies may have an impact on school enrollment and have an effect on HIV risk among youth;
5. A number of studies have demonstrated that children affected by HIV are at higher risk of not being enrolled in school, dropping out, and demonstrating poor performance, suggesting that programs targeted to improve enrollment and the successful completion of school are needed for children affected by HIV;
6. Findings also suggest that children affected by HIV may be at a higher risk of HIV infection themselves and may benefit from targeted HIV prevention efforts as well as promotion of enrollment/completion in formal educational opportunities.

Conclusions and Recommendations

Conclusions

Poverty plays a critical role in driving the HIV/AIDS epidemic. Poverty also undergirds most of the major barriers that limit access to care. Results from the Learning Collaborative in Rwanda, for example, found that, in addition to other provider-perceived access gaps, food insecurity and difficulty traveling to the clinic/hospital served as major barriers in access to care. Poverty also limited CHW volunteer resources and children's educational access, even though both CHWs and children's education are shown to be effective tools for HIV/AIDS prevention and improving family and community access to HIV/AIDS services. Gender inequality and HIV-related stigma are often related to poverty and reflect broader structural challenges in addressing the epidemic. Poverty reduction efforts may thus increase access to care, enhancing patients' ability to reach health centers and improving nutrition for mothers and children.

Innovative funding mechanisms at the international level (e.g., the International Finance Facility for Immunization) are required to meet the broad needs of children affected by HIV and AIDS. Under the current systems, children's access to ART lags behind that of adults, and PMTCT access remains low. Funding mechanisms to address these inequities should be spearheaded by the major multilateral and bilateral organizations. Such formal mechanisms should be put into place, operated, and maintained in a transparent manner, with active involvement of national governments of high HIV-burden countries, civil society organizations, and beneficiaries.

Strong leadership at the national and regional levels has resulted in rapid scale-up of quality care and HIV services in countries such as Botswana and Rwanda. In this regard, the leadership in national governments should determine prioritization of services and allocation of funds based on their own HIV/AIDS policies, rather than deciding upon resource distribution based on funding organizations' procedures and constraints. Transparency, accountability, and decentralization of responsibility have demonstrated to be key elements of effective leadership.

In this regard, political will is essential to HIV/AIDS programs. It must be sought out and encouraged and/or generated at the national and community levels. A concrete social strategy should stem from this political will, as evidenced by the OVC program in Rwanda, where initial ideas were translated into national policy, a national plan of action, and detailed work plans developed and directed at the local/district level. Decentralization of services, including promotion of local responsibility and ownership, was an important element of Rwanda's initiative.

A focus on "value" and health outcomes and not purely the "process" of providing services can be an important feature of advancing access to care and quality of services for children affected by HIV and AIDS, their families, and their communities. The care delivery value chain analysis, applied to global health delivery, can be one such innovative tool for developing guidelines, planning interventions, and managing service delivery.

Food security and poverty reduction are essential interrelated components of successful ART. Interventions for children affected by HIV and AIDS that center on families and communities should include both a sustainable, integrated food and nutrition component that is viewed as an essential human right, as well as tools for building economic resources for families and communities that reduce local poverty.

Community health workers are vital links to improving household access to care. Their role supports families and communities most effectively and consistently when their own personal needs for food, shelter, and economic security are addressed through adequate compensation, recognition, job support, and training opportunities.

The health of female caregivers has a significant impact on household welfare indicators; the death of adult women heightens food insecurity, decreases children's opportunities for schooling, increases the household work burden for survivors, and increases household poverty. Governments and donors should prioritize strategies that realize the priority of women's and children's rights.

Integration of services, as in the case of PMTCT and ECD, can facilitate greater continuity of care as well as improve access to related services among family members (e.g. maternal and child health care, PMTCT, and pediatric care).

Investing resources in strengthening the health system will be necessary for HIV-related programming for children to have the maximum effect. Increased resources for related services (e.g. education, clean water, sanitation) will also be warranted to achieve optimal health outcomes and promote the well-being of children affected by HIV/AIDS.

The Learning Collaborative model was successful at spreading best practices and provided an opportunity for staff members to meet their peers and make public contributions. Ownership and motivation were increased.

Recommendations for Immediate Action

While the above conclusions provide a multifaceted vision for effectively achieving LG3's goals and objectives, a central question remains: "What can be done now, immediately?" To address this question, we suggest that the following activities have the potential to reduce the impact of HIV on children when they are applied without resource and/or political constraints:

1. Advance a framework and methods aimed at increasing access and improving quality of care and prevention services. Framework/methods that are helpful can include the care delivery value chain and learning collaborative models; these can promote local ownership and cultivate a work culture focused on local strategy development for quality improvement;
2. Offer Provider Initiated Testing and Counseling (PITC) as broadly as possibly, consistently and sensitively within a human rights framework. The option to "opt-out" of testing should be easily available to each individual, and the approach should promote and support women's safety in the context of disclosure of testing results; promotion of PITC could potentially have a tremendous impact on the epidemic and may have been one of the factors that helped reduce the burden of HIV in Botswana;
3. Consistently link PITC with adequate access to ART, and continue to promote funding to make universal access to ART a reality, in order to prevent a future generation of children orphaned by HIV and AIDS;
4. Link HIV testing to identification and treatment of other sexually transmitted infections;
5. Eliminate school fees or pursue complementary strategies (e.g. provide school fees) to increase enrollment in primary as well as secondary school; support for primary and secondary education for girls can overcome the existing gender imbalance in schooling access/education, and thereby reduce HIV risk for both boys and girls;
6. Link programs for HIV prevention and treatment to poverty reduction strategies that quickly and measurably reach the needy individuals in families and communities, especially women and their children. Cash transfers are a proven intervention and are strongly recommended as part of a poverty reduction program;
7. Link programs for HIV prevention and treatment with nutrition and food security for families and communities;
8. Offer transportation fees for those to whom distance and cost are barriers in access to care, ensuring that these access fees are available to the households' primary caregivers, and particularly women;
9. For existing services, integrate care for all family members and health problems—which has the capacity to enhance the efficiency of care and improve outcomes;
10. Expand access to community health workers and employ other strategies of "task shifting" of health care responsibilities to ensure broader access to care; compensation for CHWs should be a priority given the implications for reducing staff turnover, creating employment opportunities, and enhancing sustainability of the program.

The Learning Collaborative process indicated that rapid program improvements in PMTCT service delivery (e.g. increasing access to prenatal care services, ARV delivery, and improving feeding counseling and follow-up) are possible with some methodological adaptations and the addition of resources.

In addition, the findings from the Learning Collaborative suggested that the existence of services and adequate facilities alone was insufficient for patients to access care. Increase in access to care required closer links with the community, active engagement of CHWs, as well as education and incentives for patients (e.g. offering fees for transport to clinic or hospital).

Service delivery designed for the patient's needs was more successful than delivery centered on the needs of existing health systems. Examples from the Learning Collaborative included extended service hours, outreach sites, and combined appointments for all necessary services.

Implementation of the recommendations above will positively impact the life chances of children, their families, and communities by promoting effective service delivery in the health care system. It will do this through an integration of services that encourages local initiatives, builds on existing programs, puts resources directly into the hands of those who need them, and offers a realistic model for hope in the face of daunting implementation gaps and access barriers. Addressing gaps and barriers as opportunities for informed change is an approach that supports community systems even as they seek to build society for the next generation. Decentralized, integrated health care services that build permanent bridges to improve access lay the foundation for economic success and can serve as models to the global community even as they give new life and hope to each individual family and child. The application of Learning Collaborative lessons, value chain analysis, and global integrated health care models—each consistently driven by providers within the affected communities can, when properly funded and effectively implemented, reduce the burden of global poverty and promote the well-being of children affected by HIV and AIDS.

JLICA
JOINT LEARNING INITIATIVE
ON CHILDREN AND HIV/AIDS

Appendix: Learning Group 3 Reports

Author(s), Organization(s)	Title	Description	Status
Primary authors: Jim Yong Kim,[1] Lydia Mungherera,[2] Myron Belfer,[3] Theresa Betancourt,[1] Susan R. Holman,[1] Mary C. Smith Fawzi.[4] Other contributing authors: Anna Casey,[1] Adrienne Chan,[1] Rosha Foreman,[1] Arlan Fuller,[1] Michelle Li,[1] Younsook Lim,[5] Timothy Williams,[1] Sandra Zaeh.[1]	Integration and Expansion of Prevention of Mother-to-Child Transmission (PMTCT) of HIV and Early Childhood Intervention Services	Comprehensive literature review. LG3 members' programmatic experience as well as representative field "cases" from the literature provided additional resources.	Draft completed May 2008
Florence Baingana,[6] Arlan Fuller,[1] Anya Levy Guyer,[1] Susan R. Holman,[1] Jim Yong Kim,[1] Michelle Li,[1] James McKeever,[3] Lydia Mungherera,[2] Stephanie Psaki,[1] Barbara Sematimba,[7] David Serukka,[8] Mary C. Smith Fawzi,[4] Sandra Zaeh.[1]	The Implementation Gap in Services for Children Affected by HIV/AIDS: Supporting families and communities in caring for and protecting vulnerable children	Comprehensive literature review	Draft completed May 2008
Erin Sullivan,[9] Peter Drobac,[10] Katherine Thompson,[11] William Rodriguez[9]	Botswana's Program in Preventing Mother-to-Child HIV Transmission	Case report (business school format)	Draft completed May 2008 (a business case for the Global Health Delivery Project at Harvard University; contact **info@globalhealthdelivery.org** for information regarding this case)
Kashif Khan,[9] Erin Sullivan,[9] William Rodriguez,[9] Peter Drobac[10]	Redefining Success in the Prevention of Mother-to-Child Transmission of HIV Infection (PMTCT): A Value-based Approach for Resource-limited Settings	Care Delivery Value Chain analysis and literature review	Draft completed August 2008 To be published in peer-reviewed literature
Please see p. 2 of paper posted on website (**www.jlica.org**) for listing of contributors and affiliations.	A Learning Collaborative on Child Health in Rwanda: Applying the Breakthrough Series Model to PMTCT-plus and early childhood development	Report synthesizes: performance data generated by providers and health centers; learning session insights; and interviews with participants	Draft completed September 2008
Agnès Binagwaho,[12] Julia Noguchi,[4] Marie-Noëlle Senyana-Mottier,[13] and Mary C. Smith Fawzi[4]	Community-Centered Integrated Services for Orphans and Vulnerable Children in Rwanda	Case description; relevant policy documents reviewed; primary interviews with program staff on site	Draft completed September 2008

Author(s), Organization(s)	Title	Description	Status
Miriam Zoll[14]	Integrated Health Care Delivery Systems for Families and Children Impacted by HIV/AIDS: Four Program Case Studies from Kenya and Rwanda	Case study analysis	Draft completed September 2008
Matthew Jukes,[15] Stephanie Simmons,[15] Mary C. Smith Fawzi,[4] Donald Bundy[16]	Educational access and HIV prevention: Making the case for education as a health priority in sub-Saharan Africa	Comprehensive literature review	Draft completed September 2008
Primary authors: Jim Yong Kim,[1] Lydia Mungherera,[2] Susan R. Holman,[1] and Mary C. Smith Fawzi.[4] Other contributing authors: Florence Baingana,[6] Myron Belfer,[3] Theresa Betancourt,[1] Agnès Binagwaho,[12] Jesse Bump,[1] Peter Drobac,[10] Arlan Fuller,[1] Anya Guyer,[1] Matthew Jukes,[15] Kashif Khan,[9] Michelle Li,[1] Younsook Lim,[5] James McKeever,[3] Julia Noguchi,[4] Stephanie Psaki,[1] William Rodriguez,[9] Barbara Sematimba,[7] David Serukka,[8] Stephanie Simmons,[15] Erin Sullivan,[9] Sandra Zaeh,[1] and Miriam Zoll.[13]	Expanding access to services and protecting human rights: LG 3 Synthesis Report	Synthesis report	Draft completed September 2008

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