



**JOINT LEARNING INITIATIVE ON CHILDREN AND HIV/AIDS**  
**LEARNING GROUP 3: EXPANDING ACCESS TO SERVICES AND PROTECTING HUMAN RIGHTS**



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**The Implementation Gap in Services for Children  
Affected by HIV/AIDS:**

**Supporting families and communities in caring for and  
protecting vulnerable children**

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This report is dedicated to Dr. Julius Richmond (1916-2008), whose life as a leader and pediatrician was dedicated towards closing the implementation gap for children living in poverty. His model of the “Development of Public Policy” has served as a guiding light for many throughout the world who have ventured down the long tunnel of social justice and the “War on Poverty.” Dr. Richmond’s model is highlighted in this report.

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This paper was prepared for the Joint Learning Initiative on Children and HIV/AIDS (JLICA). The JLICA is an independent, interdisciplinary network of policy-makers, practitioners, community leaders, activists, researchers, and people living with HIV, working to improve the well-being of HIV-affected children, their families and communities.

The named authors alone are responsible for the views expressed in this publication.

## CONTENTS

Acronyms .....	4
I. Executive summary .....	5
II. Background .....	9
A. The implementation gap: Factors and statistics .....	9
B. Improving children’s lives: From human rights to human health .....	10
C. Benefits of identifying and understanding gaps and barriers .....	12
D. Rationale for immediate intervention .....	13
1. The science of human development .....	14
2. Economic rationale .....	14
III. Addressing the bottleneck: Opening barriers and closing gaps .....	15
A. The role of integrated global health care systems .....	15
B. Increasing access to lifestage-appropriate services .....	18
1. Introduction .....	18
2. PMTCT .....	19
3. HIV treatment .....	21
a. HIV testing access .....	21
i. Testing: Infants .....	21
ii. Testing: Adolescents .....	21
b. Cotrimoxazole .....	22
c. Treatment access (ART) .....	22
d. Adherence promotion .....	23
4. General pediatric care, nutrition, clean water, and sanitation .....	24
5. Education and early childhood development (ECD) interventions .....	26
a. ECD Interventions .....	26
b. Access to education .....	27
c. Relationship between educational attainment and HIV/AIDS risk .....	28
6. Social stressors, mental health risks, and psychosocial support .....	29
a. Stressors and strategies for support and intervention .....	29
b. Psychosocial factors and HIV risk .....	32
7. HIV prevention: Youth and young adults .....	35
C. Cross-cutting themes for advancing access and quality of services for HIV-affected children and their families .....	38
1. Policy, the legal framework, and political will .....	38
2. Overcoming economic gaps and barriers: Strategies for funding .....	39
a. Macro-level funding .....	39
b. Micro-level funding .....	41
i. Role of micro-credit .....	41
ii. Cash transfers .....	42
3. Decentralizing services .....	44
4. Community-based support and the community health worker model .....	44
5. Family-centered services .....	46
6. Strengthening the physical and human resource infrastructure .....	48
IV. Conclusions and guidelines for action to advance access to services and improve health outcomes among children affected by HIV/AIDS .....	48
V. References .....	52

## ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral therapy for HIV (triple therapy)
ARV	Antiretroviral drugs for treatment and/or prophylaxis of HIV virus
AZT	Zidovudine
CDVC	Care delivery value chain
CHW	Community Health Worker
CSDH	World Health Organization's Commission on the Social Determinants of Health
DBS	Dried Blood Spot testing for HIV
ECD	Early Childhood Development
EFA	The 1990 World Conference on Education for All
GFATM	Global Fund to Fight AIDS, TB, and Malaria
GHDP	Global Health Delivery Project at Harvard University
HIV	Human Immunodeficiency Virus
JLICA	Joint Learning Initiative on Children and HIV/AIDS
LG3	Learning Group 3 of JLICA: Expanding Access to Services And Protecting Human Rights
OVC	Orphans and Vulnerable Children
PEPFAR	President's Emergency Plan For AIDS Relief
PMTCT	Prevention of mother-to-child transmission of HIV
PREFA	Protecting Families Against HIV/AIDS
UDHR	Universal Declaration of Human Rights
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNICEF	United Nations Children's Fund
WHO	World Health Organization
VCT	Voluntary Counseling and Testing

## **I. Executive summary**

Despite increasing investment in HIV research and treatment since the 1980s, there is a persistent failure to implement effective prevention and treatment for children in the world's poorest settings. The World Health Organization refers to this failure to translate known medical knowledge into practice as the "know-do gap," the divide between what we know to be effective and what is implemented in practice. The factors that contribute to this failure are sometimes called the "implementation bottleneck," since they slow the flow of interventions to those in greatest need. Even after a quarter century of research, there is still no *cure* for HIV/AIDS; effective response to prevent morbidity and mortality requires both *prevention* of transmission among those at risk and lifelong *treatment* for individuals who are HIV-positive. As a result of this gap in applying existing knowledge on prevention and treatment to action, millions of families and communities are burdened with debilitating morbidity and mortality that are destroying their social stability and hope for the future.

These implementation gaps and access barriers to health care for families occur at several different levels in society. This is often exemplified by responses that are fragmented and patchy in nature, and inconsistent across sectors and donors, producing a dilemma concerning the boundaries of what to include in any systematic analysis. The absence of effective strategies to deliver proven interventions often combines with a sense of exceptionalism that disregards lessons from local settings as of little value and use. The poorest are most vulnerable to the pernicious impact of HIV, and many interventions are necessary for those with, as well as those families without, HIV in high-burden settings. How can a program navigate between a family focus to alleviating poverty and very specific HIV interventions that, by themselves, will not work without stronger general support? The global health service access goal—to narrow the gap between aspirations and actions—remains a daunting challenge. It is already evident that existing funders and programs need to monitor progress more vigorously, make midcourse corrections more quickly, and work together more effectively. But how?

In countries that face high disease burdens, there is strong evidence to support a successful investment in protecting vulnerable children within a full context of also providing support to their families and communities (Richter, Sherr & Desmond, 2008). Such an approach promotes integrating maternal diagnosis, treatment, and support of HIV-positive women with every measure possible to ensure equitable disease prevention and treatment that advances human rights for current and future generations.

Children affected by HIV/AIDS often live in communities that are characterized by economic instability because key caregivers, health workers, 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 such as Jack Shonkoff and colleagues have termed "toxic stress," that is unmitigated psychological and developmental stressors that impair developing brain architecture and learning potential (Center on the Developing Child at Harvard University, 2007). In such settings children can survive and thrive to revitalize their world only when they receive a broad spectrum of services necessary for a healthy life, and receive it in time for such care to make a practical difference. Research confirms a strong association between child survival and early child development (ECD), suggesting that "child survival and health agendas are indivisible from ECD" (Irwin, Siddiqi & Hertzman, 2007). Lifelong health requires social, educational, and health care services that work, and that address critical needs before they have "toxic" effects on physical and social development. The health of the individual makes good economic sense since healthy children and families can learn, teach, and work creatively to build their communities and societies.

This paper argues that the implementation bottleneck and "know-do gap" in effective health care delivery is preventable. Effective discussion of specific bottleneck issues can optimally be placed within an approach that systematizes the study of global health delivery and enables rapid diffusion of new knowledge.

One of the more recent care delivery initiatives that is outlined briefly in this paper and is detailed elsewhere (Porter et al., 2006; Kim, Rhatigan, Jain & Porter, 2008) describes implementation success as “value for investment” where “value” is defined as lifelong health outcome per dollar spent. Programs that result in good “value for investment” must be programs that deliver what they promise. Effectively applying optimal care and treatment systems to a local program is central to delivering value in care that gives a child a chance to live a normal, healthy life. Implementation research has the potential to strengthen HIV care and treatment scale-up in resource-limited settings (Hirschhorn, Ojikutu & Rodriguez, 2007; Sanders & Haines, 2006). But effective implementation is only part of the answer. HIV prevention must be closely linked with broad-based policies that promote poverty reduction (such as, but not limited to, cash transfers) and that build comprehensive, integrated health delivery systems to work effectively in resource-poor settings.

Against the background of this new approach to global health delivery, and building firmly on a human rights foundation of practice, this paper explores ways that address the bottleneck by examining, first, ways to increase access to lifestage-appropriate services and, second, themes that cut across the life stages to advance quality of services for HIV-affected children and their families.

### *Lifestage-appropriate services*

Programs for children are typically organized into three developmental categories: prenatal through age five; school-aged children (whether they are actually attending school or not); and adolescents/young adults. Each group is associated with particular HIV/AIDS-related risk factors and lifestage-appropriate health issues.

Services for children between the prenatal period and age five face the challenge of simultaneously serving two interdependent patients: mother and child. Considering that less than 25% of HIV-positive pregnant women in the world have access to PMTCT services, access issues here are addressed most effectively in the context of PMTCT programs within maternal-child health; such programs can maximize the strength of health synergies when they include and integrate: early childhood development (ECD); consistent provider-initiated testing and counseling (PITC) for both mothers and fathers that contains a clear opt-out option; and consistent long-term access to treatment, including cotrimoxazole whenever indicated. In accordance with recent WHO recommendations, treatment access should also include ART for all infants under 12 months of age who have either confirmed HIV infection regardless of clinical or immunological stage (if virological testing is available) or clinically diagnosed presumptive severe HIV (if virological testing is not available) (WHO, 2008a).

Services for school-aged children promise evidence-based effects when, in addition to appropriate testing and treatment, they also ensure that a child is able and equipped to attend school; when they address gender-related risks that can compromise physical and psychological health; and when they provide for other factors that may compromise a child’s ability to learn, including nutrition and access to clean water/sanitation. Access to education in much of sub-Saharan Africa falls far below the 1990 goal of universal access to primary education, and gender gaps persist, with disproportionately low numbers of girls in secondary school. There is consistent and increasing evidence that access to education significantly improves health outcomes and, particularly, that female education increases use of maternal care services. While there has been mixed evidence about the relationship between educational attainment and the risk of HIV/AIDS, recent studies are more likely to find a protective effect of education on HIV/AIDS risk, especially at higher levels of attainment (Hargreaves et al., 2008, de Walque et al., 2005). “Family-focused” HIV/AIDS prevention for school-aged children can effectively address the education barrier by providing age-appropriate counseling for children who face the stresses of family illness, bereavement, and loss of primary caregivers. Cash transfer and other innovative opportunities can overcome economic gaps to provide school fees, supplies, and transportation. Successful programs also model opportunities for children to learn coping skills from one another in settings that address the risk of

sexual encounters school-aged children face, including abuse or engagement in other high-risk behavior. Youth who have participated in these psychosocial interventions reported fewer incidences of risky sexual behavior (such as fewer sexual partners and unprotected sexual encounters) and enhanced coping skills (Rotheram-Borus et al., 2001b). Interventions that promote treatment adherence will consider and engage household and community members, ensuring that the school is not a source of stigma and discrimination for HIV-positive students.

In developing countries, 20% of people do not use safe drinking water sources, and about 50% lack adequate sanitation, with estimates of both risks higher in sub-Saharan Africa. Yet water, sanitation, and hygiene services are affordable, sustainable, can mitigate the impact of HIV/AIDS, and offer health benefits for the entire household leading to increased economic and educational opportunities. Promising models that integrate sanitation services with HIV/AIDS programs have been shown to alleviate the impact of opportunistic infections affecting those living with HIV/AIDS (Lule et al., 2005).

Services for adolescents/young adults should include all of the above health care components, further tailored specifically to promote emerging adult maturity. Adolescents can be primary caregivers of their own children or younger siblings, and they may benefit from training and engagement in ECD. Secondary education and support groups for adolescent girls can effectively strengthen health choices. A number of school-based HIV-prevention interventions have demonstrated effectiveness in developing countries. Since many adolescents are not in school, educational strategies can drive mass media communications and community-based initiatives. For example, a community-based intervention in Nigeria using peer educators and health clubs was found to reduce the burden of STIs among youths aged 12-21 (Okonfua et al., 2003). A television and radio media program implemented in South Africa was shown to be effective in reducing HIV prevalence, demonstrating the potential for mass media to be used as an effective HIV/AIDS educational tool targeting adolescents (Pettifor et al., 2004). HIV-positive adolescents who know their HIV status and the specifics of optimal treatment are best able to make safe choices. Employment counseling, job training, and cash transfers further enable them to advance the economic stability of their family, community, and society.

### *Cross-cutting themes*

These lifestage-specific approaches also contain a number of cross-cutting themes for advancing service access and quality of care. Two of these, political will and scientific knowledge, are equally essential for program success. Each of these in turn depends on the effective integration of innovative social strategy.

Another cross-cutting theme is that of innovative funding. A number of funding strategies offer pragmatic ways to overcome economic gaps and barriers. Microfinancing programs for women have been shown to decrease intimate partner violence as well as the need for high risk sexual behavior such as trading sex for food, money, or medications. Cash transfer programs are effective at keeping children in school, and secondary-level education has a demonstrated protection effect on HIV risk. Cash transfers also are effective in reducing poverty, and have been found to increase access to health care and decrease rates of malnutrition (Devereux et al., 2007). New and unprecedented opportunities in macro-level funding in global health offer a number of models for innovative and sustainable economic support from the international community. An International Drug Purchasing Facility, UNITAID, is one example of an innovative global initiative in macro-level funding.

The persistent barrier posed by transportation problems that hinder effective health care access in resource-poor settings is another cross-cutting theme. To address this, decentralizing services can be paired effectively with cash transfers that enable necessary transport in tandem with trained CHWs who visit patients in their homes. Properly trained and adequately supported CHWs can be as effective as health professionals in providing basic care and the vital resources that promote maternal-child health and child survival.

Finally, decentralized services that are family-centered may further advance access to care. Families offer irreplaceable strengths in the context of HIV/AIDS, but they also face many challenges as the epidemic decimates support structures. Effective family-centered services can integrate HIV testing of couples and families; engage male partners in PMTCT services; and include ECD programs that also offer support to caregivers which in turn can promote their children's cognitive and physical development.

The ultimate success of such programs depends on strengthening the human resources infrastructure of nations and communities that face the daunting challenges of delivering health care to children affected by HIV/AIDS and poverty. Building integrated global health care delivery systems that deliver care using a comprehensive approach is an essential key to addressing implementation gaps and barriers in a manner that ultimately supports families and communities. The discrete activities recommended in this paper will succeed most effectively, we suggest, when they take place within an integrated health delivery system that creates value in global health.

## **II. Background**

### **A. The implementation gap: Factors and statistics**

In 2007, it was estimated that approximately 290,000 children died from AIDS-related causes worldwide (UNAIDS, 2008). Although high, this level of mortality is likely to be a significant underestimate, given that less than 25% of HIV-positive pregnant women receive prevention of mother-to-child transmission (PMTCT) services; without this preventive treatment approximately 20–45% of infants born to HIV-positive mothers will acquire HIV infection (De Cock, Fowler et al. 2000; Cooper, Charurat et al. 2002). The rate of vertical transmission can be reduced to less than 2% with the appropriate PMTCT regimen (WHO, 2006a). When services are available they often do not offer a comprehensive approach, such as inclusion of early childhood development (ECD) programming as a follow-up to PMTCT services. In addition to the lack of access to PMTCT and ECD interventions, other significant factors related to high HIV-related mortality in children include: limited access to HIV testing, particularly polymerase chain reaction (PCR) testing prior to 18 months of age (ideally performed at 4-6 weeks of age), and the low level of antiretroviral therapy (ART) access among children—only 10% of children who need ART are currently receiving this life-saving treatment (UNAIDS, 2008).

In addition, while programs targeted at prevention of HIV infection among youth exist throughout the developing world, there is a significant need to expand *access* to evidence-based HIV prevention initiatives among pre-adolescents, adolescents, and young adults. Greater than 40% of all new HIV infections occur among people under the age of 25; almost 5.4 million youth are living with HIV/AIDS (UNAIDS, 2006). While there have been some interventions that have demonstrated effectiveness in developing country settings, those interventions have not been made widely available. Integrated programming of family planning initiatives that are coupled with HIV prevention programs for women and men of reproductive age can serve to reduce risk of HIV, other STDs, and unplanned pregnancy, which in turn will improve health outcomes for women as well as infants and young children (Berer, 2004).

A broader question is: what are the systemic factors that are fueling the HIV epidemic? Gender inequality plays a key role. Although many girls and women are aware of the consequences of unprotected sex, they often do not have the power within a relationship to protect themselves from HIV or other sexually transmitted infections (Kalipeni et al., 2007; Sa et al., 2007). Gender roles are developed early on in most contexts and these inequalities are often “incorporated” before a girl reaches adulthood. Imbalance in the percent of children who attend primary school in the least developed countries is discussed further below (“Access to Education”). HIV prevention education for children and youth should also include discussion of gender roles and inequality as they relate to risk of infection. Gender issues are linked with poverty and limited education in a number of ways—through transactional sex, younger women and girls finding partners in older men, sexual violence against women and girls, and limited access to the media (Turmen 2003, Gupta 2000).

Economic inequality and poverty are other key drivers of the epidemic (Sahara, 2006). The HIV epidemic in turn promotes poverty. It is possible then that the “cycle of HIV” may be short-circuited by poverty reduction efforts (Fenton 2004; Lowenson & Whiteside, 2001). Efforts that directly improve economic conditions for impoverished families and communities may reduce the risk and impact of HIV. The implications are great for children since they experience a disproportionate burden of poverty. According to UNICEF’s 2008 “State of the World’s Children” report, under-five child mortality in the least developed countries (average GNI/capita of US\$438 per year) is 142/1,000 live births and infant mortality is 90/1,000 live births. This is in contrast to the child and infant mortality rates in industrialized countries, which were estimated at 6 and 5/1,000 live births, respectively, for the same time period (UNICEF, 2007). As a result of the high infant and child mortality rates in the least developed countries, over 4.1 million children under the age of five die per year, largely from preventable causes. High infant and child mortality rates result in low life expectancy (55 years). Food insecurity also has a tremendous impact on children under five years of age, with over one-third of children in the least developed countries at

moderate-to-severe levels of malnutrition and a low birthweight rate of 17%. With respect to basic services, 59% use an improved drinking water source and only 36% have access to adequate sanitation facilities. Overall adult literacy is 55% and only 65% attend primary school in the least developed countries; the orphan school attendance ratio is low at 82:100 (orphans: non-orphaned children). In this same set of countries, the overall adult (ages 15–49) HIV prevalence is 2.7%, with the highest rate in sub-Saharan Africa (overall 6.1%); some countries have much higher rates than this average, such as Mozambique (16.1%), South Africa (18.8%), and Zambia (17%). Even more startling is the estimate of HIV prevalence among young pregnant women (ages 15–24 years) in capital cities of least developed countries of approximately 7.5% (median), 9.7% for sub-Saharan Africa, and 13.5% for east and southern Africa (UNICEF, 2007).

Table 1 – Comparison of selected indicators between – least developed (LDC) and industrialized countries (IC) (UNICEF, 2007)

Indicator	LDC	IC
Under-five child mortality rate	142	6
Infant mortality rate	90	5
Number of deaths under age of 5	4.1 million	66,000
Life expectancy at birth	55	79
% of infants with low birth weight	17	7
% of population using an improved drinking source	59	100
% of population with access to adequate sanitation facilities	36	100
Primary school net enrollment	65	96

## B. Improving children’s lives: From human rights to human health

While statistics such as those summarized above establish the foundation of any science-based response to address the implementation gap, the social mandate that drives much of the contemporary global concern to address health care disparities is sometimes taken for granted even in human rights literature. The effective application of new care delivery initiatives that address concerns about human rights depends on an extensive practical-conceptual knowledge base that builds on models from science, anthropology, and business theory and practice in addition to statistics. Human rights have meaning only when they are realized, and this realization in individual lives depends on more than filling a knowledge gap. In this section we offer a brief overview of how human rights dialogue has influenced debates about best practices in addressing the health needs of children in low-resource settings.

The application of human rights concepts to these new initiatives to improve treatment access and health for children is not something that “just happened.” From the *Universal Declaration of Human Rights* (UDHR) to the *Convention on the Rights of the Child*, “rights” have been consistently understood as a concept intended for action. Yet the history of human rights dialogue in human health demonstrates a persistent “know-do gap” in the developing world that continues to influence how gaps are addressed in resource-poor settings. For example, the notion that every person on the planet deserves access to health care is a fundamental tenet of Article 25 of the UDHR: “Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control” (United Nations, 1948). Yet even in supporting and adopting this Article in 1948, Eleanor Roosevelt, as Chairperson, explicitly stated that such ideals did not “imply an obligation on governments to assure the enjoyment of these rights by direct governmental action” (Glendon, 2001, page 186). Indeed, the drafters debated most over the term that appears in the final version as simply “security” (originally “social security”), spending “far more time on the label they were to use to introduce the list of items than on the individual items themselves” (Morsinck, 1999, page 199).

A more focused effort to achieve universal access to health care was launched at the International Conference on Primary Health Care in Alma-Ata in 1978 with the declaration “Health for All by the year 2000.” However, the declaration of this collective vision was not followed by substantial funding, nor did the apparent consensus reflect universal commitment to the right to health care (Gwatkin, 2000; Magnussen et al., 2004). In the first two decades following the declaration of Alma-Ata, debates over appropriate strategies to improve health in developing countries continued without clear resolution, in part due to the limited resources available. Articles 24, 27, 28, and 34 of the 1990 *Convention on the Rights of the Child* affirm children’s rights to: the highest standard of health and access to health services, to an adequate standard of living, to education, and to protection from sexual exploitation and abuse (United Nations, 1989). These remain unrealized ideals for many children affected by HIV/AIDS in poor countries today.

The application of explicit human rights concepts to HIV/AIDS service access in resource-poor settings began in the 1990s. In a chapter on “Human Rights and AIDS,” published posthumously in 1999, Jonathan Mann noted the difficulty of moving beyond identifying the simple fact that there is a social dimension of contextual risk factors and influences that fuel the HIV/AIDS epidemic, to new conceptual territory that develops models and methods that identify these dimensions in ways that can effect measurable change (Mann, 1999). Mann located the state of global public health research at that time at a crossroads: between accepting current limits (that is, shifting to a view of the disease as “endemic” and thus socially and politically tolerable) or else—Mann’s advice to his readers—following the path to “refuse to accept the unacceptable.” Mann called for a quest to identify “How, or more precisely, through which conceptual prism can we best identify and act positively upon the factors, beyond the individual, that constrain, limit, and interfere with the making and carrying out of free and informed choices about behavior?” His answer, new at that time, was to incorporate a human rights dimension into HIV/AIDS prevention. Linking health issues with the “mobilizing power” of human rights, Mann argued, would enhance the capacity for cross-disciplinary work and revitalize global thinking. It would enable an empowerment built on specific knowledge (social and scientific). And it would enable those who had previously considered themselves powerless, to act on a “belief, faith, and confidence that the world can change.” The next step, he said, “will require a leap of confidence based on analysis, reflection, and hard work.”

A decade beyond Mann’s tragic death this confidence—that human-rights based action can improve the world for those affected by HIV/AIDS—is no longer an ideological “leap.” It has been realized, however imperfectly, by a number of practitioners in global health who have dedicated their lives to a similar vision. Yet for children, mothers, families, and communities in the majority of resource-poor settings, the language of “human rights and human dignity” persistently fails to translate into improved choices about health. This failure has profound economic implications. As today’s teachers, health workers, parents, and other community leaders in low-resource settings get sick and die of HIV/AIDS, the resulting social disorder heightens mortality and risk for those of tomorrow—infants and children (Richter, 2004). Civil rights are violated because social and economic rights are ignored (Parker & Aggleton, 2003). Such “structural violence” poses particular challenges for clinical medicine (Farmer, Nizeye, Stulac & Keshavjee, 2006). Responses that limit aid in a “pragmatic” hesitation that “to attempt too much is to achieve too little,” risk taking the fatalistic path that Mann rejected. As Paul Farmer puts it, “the hesitation of many in the human rights community to cross the line from a rights activism of pure principles to one involving transfers of money, food, and medicine betrays a failure, I think, to address the urgent needs of the people we are trying to defend” (Farmer, 2005, pp. 9–10).

Thus Mann’s vision persists for all who share his concern for translating public health policies into effective, practical action on the ground. His legacy, and the legacy of HIV/AIDS and community health research in poor communities around the world since 1999, now enables us to move through Mann’s “conceptual prism” to map out new territory for building health systems that translate human rights into action.

This territory is enriched by the new focus within global health delivery on the cross-disciplinary approach that Mann understood to be fundamental for change. Learning Group 3's recommendations emerge from this conceptual focus, offering practical examples of what has worked in selected settings, and reflections on how such examples might be applied in other settings and scaled up. As this and other LG3 reports demonstrate, cross-disciplinary approaches that integrate services and promote improved access include examples such as the Learning Collaborative in Rwanda, based on a well-accepted business model. Other programs support a rationale for enhancing economic and human development potential in low-resource societies by integrating PMTCT services with early childhood development (ECD). Building and sustaining such programs requires thoughtful yet aggressive application of findings from implementation science and global health delivery case studies that are built on partnerships between science and business theory, as well as an openness to other innovative approaches. Examples and conceptual approaches can be knit together with existing programs and resources into funding packages that draw on new funding initiatives and that also include direct cash transfers to families within affected nations and communities. Such programmatic integration—coupled with a sensitive consideration of where existing programs succeed or fail, and why and how—will succeed in attaining JLICA goals only if it is based in a firm commitment to maintain long-term continuity. Thus examples of such cross-disciplinary integration, models, and “lessons learned” are already immediately available to empower existing programs, improve access to services, and deliver human rights that save lives.

### **C. Benefits of identifying and understanding gaps and barriers**

Bottlenecks are not resolved with Band-aids; they must be examined and opened. When timely prevention and treatment is hindered by access barriers and implementation gaps, the most effective first step is to understand what is not working, and why (see Case Description 1). Improving access to health care services mandates a close examination of all of the factors that create barriers and implementation gaps between those who need health care services in a particular community, and the community's actual delivery. Emergency programs may successfully “force” essential resources into the community for short-term delivery, but may fail to effectively “open” key access barriers and “close” implementation gaps in a manner that effectively ensures long-term value. The opportunity for human life to thrive depends on broad, consistent, systemic dialogue that is seamlessly coupled with action. An honest understanding of successes, limits, and failures in existing access delivery programs offers those who run, maintain, and receive services in such programs to identify and act on opportunities to build change. Admitting shortcomings makes it possible to construct foundations strong enough to overcome limits within the most appropriate cultural context. A clear-sighted management approach enables the realization of human rights “on the ground.” It does this through improving access to health care delivery services that, while never perfect, “refuse to accept the unacceptable” and thus generate a dynamic energy for increasingly optimal service delivery.

This opportunity—to use problems encountered to design change—is developed in more detail in LG3's paper on the Learning Collaborative model. Such examples demonstrate how shortcomings in service delivery can be overcome when, recognized and caught immediately—and addressed with targeted funding for specific interventions—they serve as leverage for cyclic re-evaluation and new action. In such cycles, change is often implemented in small steps, making it “do-able” even in resource-challenged health care settings. Such a cyclic approach improves care even as it trains providers and other health care workers, advancing programmatic success through local trouble-shooting and sharing of lessons learned (LG3, “A Learning Collaborative on Child Health in Rwanda,” 2008, draft in revision).

The global health community is just beginning to understand the unique challenges of addressing implementation gaps and access barriers in HIV/AIDS care delivery. Whereas mass vaccination campaigns are carried out in episodic fashion to large populations, programs to treat HIV must deliver lifelong continuous individualized care. HIV programs must carry out large-scale diagnostic testing, track individual patient information over time, provide reliable and continuous supplies of medications, ensure uninterrupted adherence to these medications, identify and manage complications and treatment failures,

and provide counseling and preventive services (Schwartlander, 2001). Lessons learned from HIV/AIDS programs can be used to build integrated approaches that address other chronic global health issues, such as tuberculosis (including drug-resistant varieties), maternal and child health, improving obstetrical services, and creating basic surgical capacity. To confront such issues successfully, global public health programs will have to move beyond a focus on building successful “projects” and become fully functioning health care delivery organizations. This new model, of building integrated global health care delivery infrastructures, is discussed in detail elsewhere (Kim, Rhatigan, Jain & Porter, 2008) and in the LG3 Synthesis Paper (LG3, “Synthesis Paper,” 2008).

***Case Description 1***

**Implementation gaps in Uganda: Local initiative to evaluate factors impeding access to and quality of care for HIV-exposed and HIV-positive infants and children**

Implementation gaps and access barriers frequently overwhelm existing programs, impeding success despite the best intentions. In one attempt to better understand these issues, several researchers, who are part of the LG3 group, including Dr. David Serukka, and who work with Protecting Families Against HIV/AIDS (PREFA) in Uganda, assessed perceived barriers to pediatric HIV care in that context. They visited eight participating HIV/AIDS programs in Uganda and asked staff members how they perceived these barriers. Specifically, respondents were asked to rate ten barriers to HIV prevention scale-up that have been identified in the literature as issues in developing nations, including Uganda.

The ten identified barriers considered were:

1. Inadequate health sector financing
2. Inadequate human resources for health personnel trained in pediatric AIDS care and treatment
3. Lack of appropriate clinical infrastructure
4. Delayed HIV diagnostic testing
5. Disintegrated HIV/AIDS services
6. Lack of appropriate pediatric ARV drug formulations
7. Appropriate pediatric dosing and formulation of ARV drugs
8. Lack of prioritization of pediatric HIV/AIDS care
9. Limited availability of pediatric HIV/AIDS services at the health sector and community level
10. Stigma and discrimination

Representatives from participating HIV programs expressed the greatest concern about four major barriers: lack of clinical infrastructure, delayed HIV testing of children below 18 months, limited availability of pediatric HIV care services, and stigma among health workers.

This investigation is an innovative approach to trouble-shooting for improving health outcomes for HIV-exposed and HIV-positive children and reflects an example of a local quality improvement effort. Such initiatives open related opportunities for health care providers within a defined geographic region to begin collaborative discussions that can lead to practical problem-solving and re-evaluation of how to make systems work better (Serukka, 2008).

**D. Rationale for immediate intervention**

While there are many obvious reasons to improve effective access immediately to HIV/AIDS services for children, two interdependent processes compel immediate investments that will build the integrated health care delivery services that we suggest. The first is the science of human development. The second is the economic rationale of immediate intervention.

## **1. The science of human development**

The science of both human development and the biologic viral transmission of HIV/AIDS in young children demonstrates the critical importance of early intervention. Immediate early intervention maximizes health care value, that is, a social justice measured by lifelong health. To realize their rights, children must attain an optimal quality of life and have the opportunities to realize their full learning potential. Addressing barriers and gaps in early infancy allows children the chance to strengthen communities and societies into the next generation.

Recent work by Jack Shonkoff and colleagues demonstrates how early experience, including social stressors, literally shapes the brain (Shonkoff & Phillips, 2000; Center on the Developing Child at Harvard University, 2007). Neurobiological science demonstrates that the brain makes on average 700 new synapses per second during the first three years of life, and that measurable differences in learning can be linked to socioeconomic status (SES). In developed nations, for example, children in high SES families had three times the vocabulary of those in low SES families. These discrepancies could be improved by early childhood intervention activities. Neurobiology also demonstrates that learning behaviors are directly related—positively and negatively—by stress hormones.

The findings of these neurobiological studies, particularly on positive versus “toxic” stress, have important implications for designing interventions for infants and children affected by HIV/AIDS in resource-poor settings. “Positive” stress—moderate, short-term elevations in cortisol or cytokine levels—is associated with children’s experiences of increasing self-mastery and self-control, for example in meeting new people or dealing with frustration. Environmental crises (such as death of loved ones, divorce, and natural disasters) impose additional stress on children that may be “tolerable” if the child receives support to cope, either from parents, informal community support, or professional assistance. When stress hormones are allowed to return to baseline levels, the brain can recover from otherwise overwhelming threats and long-term learning potential is not impaired (Shonkoff & Phillips, 2000).

“Toxic” stress, however, is associated with “strong and prolonged activation of the body’s stress response systems in the absence of the buffering protection of adult support” (Center on the Developing Child at Harvard University, 2007). Persistently high stress hormones disrupt the child’s brain architecture and chemistry. This in turn can impair learning, memory, and the social-behavioral learning process, and even increase lifetime risk of physical and mental diseases. While these findings reflect results from studies in neurobiological science performed among children in developed nations, the social and physical circumstances of HIV/AIDS in poor communities present a picture-book case of risks for “toxic” stress. The greatest difference between tolerable and “toxic” stress is not cause, but the presence or absence of buffering factors. As Jack Shonkoff noted in his remarks at the 2007 JLICA International Symposium, “This is not about other people’s children. It is about everybody’s future” (Shonkoff, 2007).

## **2. Economic rationale**

Children’s bodies are perpetually shaped by the resources, stabilities, or crises of their world. Social justice that enables and supports optimal lifelong health depends on economics. For example, each occasion when a postpartum woman lacks the funding, transport, food energy, and childcare services she needs to make a clinic visit to obtain rapid HIV testing and services for herself and her newborn, the risk increases for her own morbidity and reduces her child’s potential for health and development. Similarly, any barrier to education (such as money for transport, clothing, supplies, and release from the need to care for younger siblings), likewise increases a child’s chances for high risk behaviors and a life of economic poverty. Access barriers and gaps have long-term economic impact on family productivity and community development. While further research is needed, studies on cash transfers, part of the ongoing work of JLICA Learning Group 1, strongly suggest that the economic costs of inaction outweigh the costs of immediate intervention (Adato and Bassett, 2007; Schubert and Huijbregts, 2006). Such costs cannot be separated from the individual biologic rationale of development science.

The opportunity to address such costs with targeted economic interventions in global health has never been better. The past decade has seen bold health-related commitments such as the Millennium Development Goals and the 2005 pledge by heads of state and government to press toward universal access to HIV/AIDS treatment. Substantial new resources are flowing into the global health field. Between 2003 and 2005 alone, global spending on HIV/AIDS almost doubled, from US\$4.2 to US\$8.3 billion (UNAIDS, 2006). Effective strategies have been developed to treat and prevent many of the greatest contributors to the global burden of disease. Investment in medical research and programs by governments and by donors like the Bill and Melinda Gates Foundation brings the promise of a new generation of initiatives that, within eight to ten years, may dramatically bolster the world's arsenal in the fight against disease (Bloom, 2007). At the same time, there is a marked increase in broad public interest in the health and well-being of poor and marginalized people in the developing world (Kim, 2007).

Encouraging as this is, an enormous gap persists between growing interest and the actual health outcomes of vulnerable groups. In the face of new investments in global health, the persistence of poor outcomes for so many is an ongoing tragedy. Providing access to care, a central focus in today's global health landscape, is the starting point, but is not sufficient. Following practice in business, the focus must shift to value, defined as actual health outcomes experienced by patients. Value must become the central goal that drives global health delivery.

Dramatically improving the value of care will be necessary if the new resources for global health are to be used effectively to meet the pressing needs of the developing world. Demonstrating value, not just expanding volume, will also be necessary to ensure that funding from both the donor community and from local governments is sustained at sufficient levels. In global health delivery, it is time to move beyond our laudable humanitarian efforts to provide care to the poor and begin focusing much more attention on the details of delivering results. This vision for a new approach to global health care delivery is discussed in further detail below.

### **III. Addressing the bottleneck: Opening barriers and closing gaps**

#### **A. The role of integrated global health care systems**

When considering HIV/AIDS programming, it is essential to also invest in the broader strengthening of health systems, a recent topic of interest in global health. Health systems strengthening has been shown to be valuable in HIV programming in Haiti that simultaneously invested in the primary care system administered through the Ministry of Health (Walton et al., 2004). When considering children and youth affected by HIV/AIDS, it is important to expand consideration beyond health systems, to consider the role of other sectors, including those that address basic education, legal issues, child care and protection, as well as economic and food security, among other dimensions that may have an impact on children's well-being. This holistic approach may allow ministries of health and their collaborators to consider vertical and horizontal approaches simultaneously, noting the strengths and limitations of each strategy (Reich et al., 2008). A multi-sectoral, integrated approach to service provision in high HIV burden countries will be necessary to provide the maximum benefit with respect to health outcomes and well-being of children, youth, and their families in these settings.

Integrated approaches can be organized by deliberately relating existing services to one another in many different ways. The model that LG3 offers, summarized briefly below and described elsewhere at length (Kim, Rhatigan, Jain, & Porter, 2008) is based on effective integration systems that proceed from proven business theory.

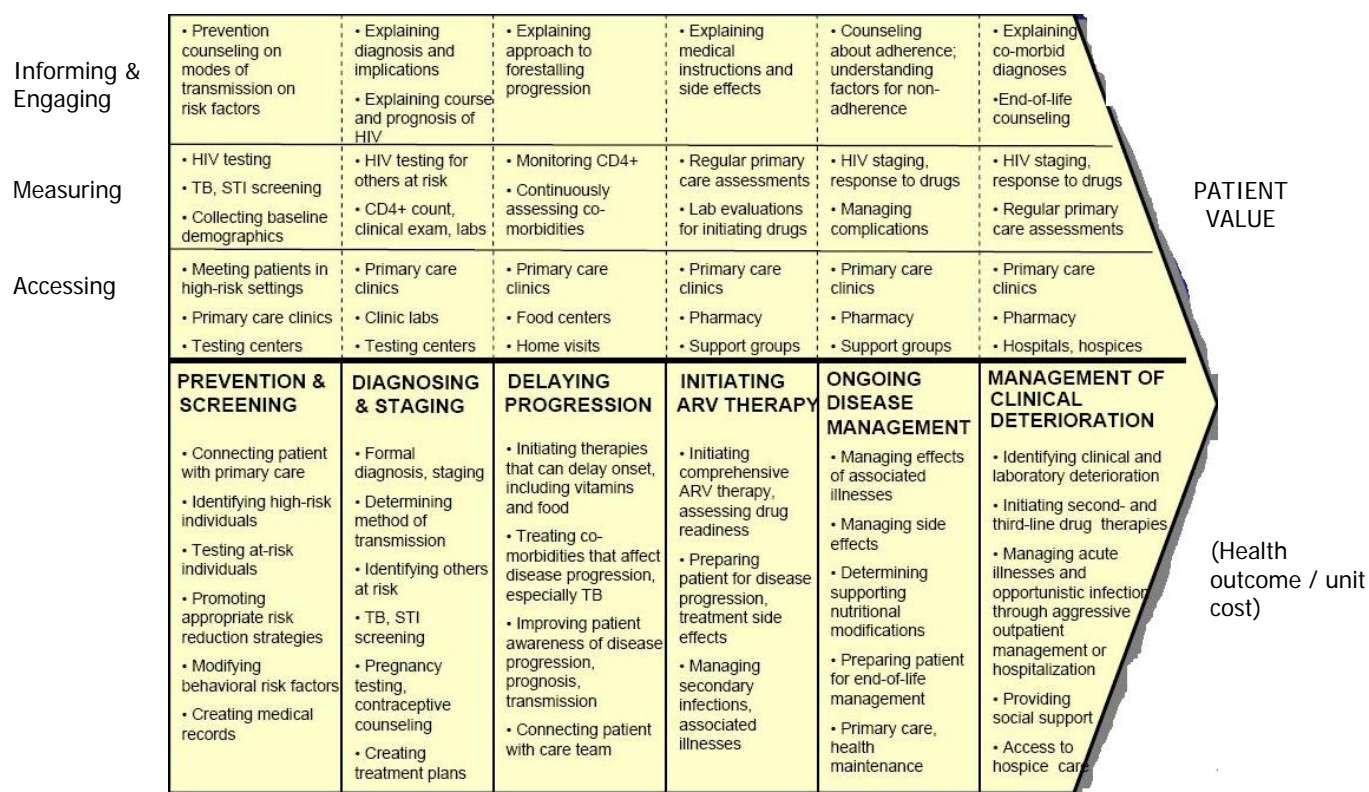
Existing strategic frameworks developed to deliver health care were first developed for advanced economic settings (Porter & Teisberg, 2006), but can be modified and applied for resource-poor settings.

Such a strategic approach to health care delivery must begin by recognizing that “value” (defined as optimal lifelong health per dollar spent) for the patient is ultimately generated by the overall set of interventions in treating a medical condition. Instead of looking at discrete interventions (such as providing antiretroviral therapy for HIV), the value of any individual intervention can only be understood in relation to the overall system of activities to treat the complete medical condition. This system of activities constitutes the “cycle of care” for the medical condition.

Building a new framework for designing global health delivery systems involves activities at three levels. First, the care for each medical condition must be viewed as a system in itself, which we term the care delivery value chain (CDVC). Second, the delivery of care across medical conditions must leverage shared delivery infrastructure that improves value through better utilizing personnel and facilities, and capturing the synergies in caring for related medical conditions. Third, the design of care delivery value chains and shared delivery infrastructure must embrace the external patient and community conditions that will improve value (Kim, Rhatigan, Jain & Porter, 2008).

To apply this to HIV/AIDS, one would begin with the care delivery value chain, the core of any delivery system. The CDVC defined as the set of activities involved in the full cycle of care for an individual medical condition, in this case HIV/AIDS. For each medical condition, the cycle of care within this system begins with prevention and screening, and ends with ongoing disease management and prevention of recurrences. The CDVC provides a tool for improving the outcomes and efficiency of each activity involved in care, and hence its value. Value arises from the integration of the entire chain, not just from individual interventions or services.

### HIV/AIDS CARE DELIVERY VALUE CHAIN



In advanced economies, such “value” is often enhanced by minimizing duplication of services and aggregating care for specific medical conditions in dedicated and tailored facilities. In resource-poor settings, however, health care facilities and personnel are scarce, and patients have multiple health and

social problems that make it difficult for them to access the appropriate services. In these settings, value is thus increased through shared delivery infrastructures in which the care of multiple medical conditions is coordinated and integrated. HIV/AIDS interventions are most effective when they are coordinated with other conditions served by the same resource settings.

The third step of creating value in global health delivery is integrating the access-delivery infrastructure with the local external context within resource-poor environments. This step is vital for improving access to care since external conditions in such settings often constrain effective care delivery. This activity calls for creating communities of practice. Local practitioners, including doctors, nurses, and community health workers, are a rich source of information about what enables or impedes successful program design and implementation. Engaging practitioners helps to disseminate best practices by creating communities of practice around specific global health delivery challenges that will include professionals at all levels from around the world. Since local conditions will vary in important respects from country to country, the field of global health delivery science will need to develop a rich set of heuristics to tailor delivery choices to local circumstances.

Investing in health care systems can catalyze economic development in at least three ways:

- (1) by promoting employment;
- (2) through targeted procurement of goods, services, and equipment from local sources; and
- (3) by catalyzing an improved infrastructure in the communities that contribute to health and thus lead to increased productivity that results in wider economic benefits.

Such a vision for integrated global health care might effectively build on traditional values that define social health and meaning in terms of the broader community and family (see **Box 1**).

The effective implementation of change that addresses the access barriers and gaps requires both an integrated conceptual system, such as that briefly summarized in this section, as well as discrete activities that ensure success in meeting these goals. The following sections of this paper discuss and explore such discrete activities as they relate to lifestage-appropriate services for children affected by HIV/AIDS in resource-poor settings.

**Box 1. "I am because we are": A community-based vision for HIV/AIDS awareness**

Integrated global health delivery services are strengthened when they intentionally integrate with the local external context of the community. One such context is the view, common in many cultures, that individual, family, and community are inseparable parts of a whole. One ethicist from the University of Botswana puts it this way in a critique of faith-based support of HIV/AIDS intervention as it affects human rights:

"HIV & AIDS bring the relationship of the rights of the individual and the rights of the community into critical focus. That is, what does it mean to be faithful to the ethic, 'I am because we are, and we are because I am,' an ethic that must take both the individual and the community seriously? Given the socially driven face of HIV & AIDS, an exclusive focus on an individual's physical symptoms and treatment as a private secret of the infected and the affected aided the spread of the pandemic itself, rather than its prevention. Such an approach has not even protected the individual, let alone the community.... A community approach that looks at the existence and health of individuals as inseparably intertwined within all relationships is more suited to dealing with issues of poverty, gender inequality, child abuse, spousal and ethnic violence, racism, national corruption, international injustice, and ethnic, migrant, and sexual discrimination." (Dube, 2006)

## B. Increasing access to lifestage-appropriate services

### 1. Introduction

HIV/AIDS risk factors vary according to a child’s age and stage in development. Existing programs tend to target children by conceptualizing them within one of three developmental categories: prenatal through age five; school-aged children; and adolescents/young adults. While there is much overlap between the three groups, certain key issues, summarized below, have particular lifestage-appropriate relevance.

Services for children between the prenatal period and age five focus on a broad range of services, including access to pediatric care (primary and specialized, i.e. ART access), offering HIV tests and treatment (when indicated) routinely for all pregnant women, improving access to prenatal care and safe delivery services, nutrition supplementation (when indicated), PMTCT, ECD, as well as access to basic services such as clean water, sanitation, and adequate housing. As Drobac et al. demonstrate in their delivery care value chain model for PMTCT, an integrated family-centered approach that targets this initial age group faces the particular challenge of simultaneously serving two interdependent patients, the mother and the child (Drobac, Rodriguez, Khan, & Sullivan, 2008).

Services for school-aged children must be designed to address a slightly different set of risk factors relevant to this group (roughly ages 5–10 years). Key issues for this sector include ensuring that a child is able and equipped to attend school (e.g., providing free education, cash transfers to families to buy basic transport and supplies); particular gender-related risks of children denied basic schooling in order to care for younger siblings or ill family members; promoting physical and psychological health (including nutrition and clean water) that enhances a child’s ability to learn; and addressing the risks of sexual encounters, including the risk of abuse, or other risky behaviors even at this young age.

Table 2: Examples of Lifestage-Appropriate HIV/AIDS Services

Prenatal – Age 5	School Age	Adolescents/Young Adults
HIV testing and treatment for pregnant women	Services facilitating school attendance (e.g. free education)	Accurate and practical sexual health education
Prenatal Care	Physical health services (nutrition, clean water)	Psychological support
Safe delivery services	Psychological health services	Gender empowerment
Pediatric Care	Addressing gender inequality and risky sexual behaviors	Engagement in ECD programs
PMTCT		Counseling and testing services
ECD		Employment counseling and job training
Access to basic services		

Services for adolescents/young adults must include all of the components present for the first two groups, tailored to meet the particular circumstances of risk that challenge this group of individuals as they transition into adulthood. Such services include practical and accurate information on avoiding risky behaviors and preventing HIV/AIDS transmission. Adolescents may serve as primary caregivers, and thus be engaged in ECD programs for younger siblings or their own children. Health care to teens should include psychological support, and should empower girls to make safe sexual choices. Lack of sexual choice due to economic, social, or cultural issues is a key factor in HIV/AIDS transmission and teenage girls are particularly vulnerable, although evidence suggests that adolescent girls’ (and boys’) knowledge about HIV transmission is improving (UNICEF, 2008). Some communities are intentionally forming support groups for adolescent girls (see case description 2). There is also growing awareness of the need to be sure that HIV-positive adolescents are sensitively and clearly informed of their status rather than receiving only very broad counseling that addresses the issues in general terms. Teenage girls who become pregnant must be seamlessly enrolled into existing HIV-testing and, if positive, into PMTCT and

HIV treatment programs. Employment counseling and job training provide vital resources that, supported by cash transfer programs, further enhance HIV/AIDS prevention efforts by offering specific alternatives to high-risk behaviors and enable adolescents, who may already head households, to build and advance the economic stability and strength of their community and society.

## **2. PMTCT**

Despite the fact that technology exists to dramatically reduce the risk of mother-to-child transmission (MTCT) of HIV, the implementation has fallen far behind the scientific advancements in prevention of mother-to-child transmission (PMTCT) services; this is one of the starkest examples of the “knowledge-implementation (“know-do”) gap” for access to services for children affected by HIV/AIDS in the developing world. Since the initial regimen was developed for PMTCT in 1994 (Connor et al., 1994), millions of children have unnecessarily become HIV-infected and died due to lack of access to this intervention.

As of 2005, fewer than 10% of HIV-positive pregnant women had access to PMTCT services worldwide (UNAIDS, 2006). However, there have been some improvements since that time (UNICEF, 2008), with some countries developing policies and programs to significantly increase access to PMTCT. In addition, access to ART among adults, including pregnant women, is also increasing and WHO recommends offering ART for HIV-positive pregnant women who have CD4 cell count less than 350 cells/mm<sup>3</sup> (WHO, 2006).

Another element of the knowledge-implementation gap for PMTCT is the quality of care. There are a broad range of PMTCT regimens available, ranging in effectiveness from less than 2% to 8% transmission (without breastfeeding). Single-dose nevirapine reduces transmission to about 8% transmission (Jackson et al., 2003), whereas ART or a combination regimen developed by Lallemand et al. (2004) can result in less than 2% HIV transmission. Therefore, the rate of MTCT will vary based upon the regimen offered; this includes the ability to ensure that women present for prenatal care no later than 28 weeks of gestation to receive the regimen described by Lallemand et al. (2004).

Another factor that influences transmission rates is breastfeeding. To date, there are no ARV regimens that can completely prevent MTCT through breastfeeding. Kourtis et al. (2006) estimate that between one third and one half of all MTCT in resource limited settings occurs through breastfeeding. Data from South Africa indicate that HIV transmission through breastfeeding can be as low as 4% at 6 months of age among infants who are HIV-negative at 6 weeks of age and who are exclusively breastfed. It is important to note that mixed feeding (breastfeeding offered with any other food or liquid) has a higher risk of transmission compared with exclusive breastfeeding (Coovadia et al., 2007). However, the only way to prevent MTCT caused by breastfeeding is to provide an alternative infant feeding strategy. The most common strategy employed is formula feeding. While formula feeding has been advised for HIV-positive women residing in industrialized countries, given the poor water quality found in many developing countries, there has been considerable debate about the child mortality and morbidity risks involved with offering infant formula in those settings.

A study performed in Botswana (Thior et al., 2006) demonstrated that a combined outcome of HIV transmission and mortality risk was comparable at 18 months of age for children whose mothers were breastfeeding (and receiving ARVs) and those mothers who formula-fed. This evidence suggests that the risks of formula feeding do not outweigh the benefits. However, water quality in Botswana may have affected the findings of this study. In settings where water quality was addressed, the negative outcomes associated with formula feeding appear to be reduced. For example, in Cote D'Ivoire there were no differences in risks of diarrhea/ respiratory infection, malnutrition, hospitalization, or death in breastfed versus formula-fed infants of HIV-positive women (Becquet et al., 2006). These findings were sustained after a two year follow-up period (Becquet et al., 2007). Similarly, a program in Rwanda focuses on

educating mothers and ensuring that formula is mixed with clean/purified water. This study also demonstrated a relatively low mortality rate among infants (21/1,000 person-years) (Stulac et al., 2007). This program offers comprehensive, community-based support that engages community health workers.

Recently, WHO, which has recommended that formula feeding should be used among HIV-positive women when it is “acceptable, feasible, affordable, sustainable, and safe” (WHO, 2006), indicated that countries should review their policies to determine what infant feeding strategies may be viable in their settings (WHO, 2007). It is likely that the relative safety of offering infant formula depends on the context. Data from South Africa indicate a reduced risk of HIV transmission and death in settings where the population had access to piped water; however, when there was no access to piped water, formula feeding resulted in an increased risk of mortality (Doherty, 2006).

#### **Box 2. The mothers2mothers program**

The mothers2mothers (m2m) program in South Africa offers a strategy that addresses the contextual variability when considering infant feeding and HIV risk. For this program, “mentor mothers” who have prior experience with PMTCT programs offer support to new program mothers and are compensated for their efforts. Women in this program were counseled in both exclusive breastfeeding and exclusive formula feeding, and were more likely to adhere to exclusive (rather than mixed) feeding as well as more likely to choose 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).

Engaging community members and/or community health workers appears to be a key “ingredient” for success of PMTCT programs. In addition, involving networks of women infected with HIV may result in the development of creative strategies to address the conundrum of infant feeding where HIV is highly prevalent. In terms of promoting safety of infant feeding, a number of factors need to be considered, including: improving water quality; access to materials for infant feeding; infrastructure development; preventing stock-outs; increasing access to postnatal and pediatric care; ensuring availability of ORT; and providing ongoing education, counseling, and support of mothers (LG3 JLICA, 2008b).

Programs that offered strategies to improve access to PMTCT services included: decentralization of services; having a community-based approach; ensuring closer follow-up of mothers and infants; strong investment of the central government; integration of PMTCT services in maternal and child health care; availability of routine HIV-testing; provision of psychosocial support of women; involvement of civil society; and availability of ART for pregnant women (LG3 JLICA, 2008b; LG3 JLICA, 2008c). In Thailand, a nearly 70% PMTCT coverage was related to an integrated approach to PMTCT and reproductive health services with good access to antenatal care and care during delivery (Amornwichet et al., 2002; Teeraratkul et al., 2005).

In addition to integrating PMTCT services with other health care services, other strategies to increase uptake of PMTCT and enhance follow-up include:

- offering provider initiated HIV-testing and counseling (PITC) rather than standard voluntary testing and counseling (VCT) (Welty et al., 2005; Chandisarewa et al., 2007)
- addressing concerns regarding HIV-related stigma, disclosure, and gender-based violence (Medley, Garcia-Moreno, McGill & Maman, 2004; Semrau et al., 2005)
- expanding access to reproductive health services
- engaging community health workers and/or peer outreach educators (Khan et al., 2007)
- increasing local knowledge of PMTCT services (Kominami et al., 2007)
- trouble-shooting health systems failures and constraints (Nkonki et al., 2007)

Critics of PITC argue that providers who support such broad testing must be prepared to take on the responsibility of ensuring intervention, care and treatment to everyone who tests positive. A gap in services exists when the provider initiates testing but then fails to guarantee and deliver effective treatment.

### **3. HIV treatment**

While there have been achievements in pediatric HIV/AIDS treatment in recent years, a number of implementation gaps remain in issues surrounding HIV treatment. These include access to testing for HIV/AIDS in children, access to cotrimoxazole therapy in addition to other pediatric HIV treatment, and adherence promotion. Each of these is discussed briefly below.

#### ***a. HIV testing access***

##### *Testing: Infants*

WHO promotes early diagnosis of infants because the timely initiation of ART improves the survival chances of children infected with HIV (WHO, 2006). In older children and adults, HIV can be identified through antibody testing. In infants under the age of 18 months, however, transfer of maternal antibodies makes it difficult to determine if the child is HIV-positive. Thus, HIV in infants must be diagnosed in a different way: through assays to detect HIV DNA, HIV RNA, or the p24 antigen (WHO, 2006).

In infants less than 18 months, detection of HIV DNA and/or HIV RNA is dependent on access to polymerase chain reaction (PCR) and highly sensitive reverse transcriptase (Fischer et al., 2004; Nesheim et al., 2003; Rouet et al., 2001; Rouet et al., 2003; Orne-Gliemann et al., 2006). In areas with resource constraints, these methodologies have been limited to reference laboratories due to their costliness and sophistication (Rouet et al., 2005). One solution is dried blood spot (DBS) testing which enables blood specimens to be collected in remote areas and tested for HIV up to three months after collection (Brambilla et al., 2003). Use of DBS methods has been shown to be feasible in resource limited settings (Sherman, Jones, Coovadia, Urban & Bolton, 2004). Recently, DBS was successfully incorporated within Botswana's early infant diagnosis project within the national PMTCT program (Creek et al., 2008). In Botswana, health care professionals in Francistown's clinics and reference hospital were taught how to perform DBS on infants between the ages of six weeks and seventeen months. After health care professionals provided counseling to parents and performed the test, the DBS sample was sent via courier to Botswana's national reference laboratory in Gaborone, which is equipped with the ability to perform DNA PCR testing using the DBS method (Creek, 2008).

Other cost-effective technologies being developed include real time PCR and highly sensitive reverse transcriptase tests (Rouet et al., 2005). Swaminathan et al. (2007) has also provided initial evidence that the CD4/CD8 ratio can be used as a marker for HIV status in infants.

##### *HIV testing: Adolescents*

HIV/AIDS testing for adolescents is another important step to ensure that children and young adults gain access to ART in a timely manner. Several studies have demonstrated the importance of supportive relationships in an adolescent's decision to get tested. A recent qualitative study performed in Zambia with 16 to 19 year olds showed that supportive reactions from family members were important in youth's decisions to access VCT.

Additionally, adolescents typically did not attend VCT with a family member, but were more likely to attend with a friend or alone (Denison et al., 2008). In a study performed among adolescents in the United States, support from health care providers was an important facet of the decision to be tested,

with 53% of adolescents who were HIV infected and 66% of uninfected adolescents reporting provider influence (Murphy, Mitchell, Vermund, & Futterman, 2002). Factors related to HIV-related stigma may also influence the decision of adolescents to get tested. Focus groups in South Africa among 12 to 24 year olds suggested that youth were afraid of knowing their status and believed only symptomatic individuals needed to be tested (MacPhail et al., 2008).

In Zambia, the Ukani Support Group, the Centre for Infectious Disease Research in Zambia, and the Lusaka Health Management Team worked together to create an initiative that targeted HIV testing in adolescents through offering VCT in community-based basic schools. The initiative included a four week curriculum covering various topics related to HIV such as stigma, VCT, and the risks faced by adolescents of contracting the disease. Students were grouped by age to ensure that age-appropriate messages were delivered. Parents were also encouraged to attend, but they were grouped separately from the adolescents. In a four month time period, 2,127 children participated in the program, of which 83% consented to HIV testing (Banda et al., 2006).

### ***b. Cotrimoxazole***

A second gap in HIV treatment in children is lack of access to cotrimoxazole. Cotrimoxazole prophylaxis, an antibiotic, has been shown to effectively reduce HIV related morbidity and mortality in adults (Anglaret et al., 1999; Wiktor et al., 1999) and children (Chintu et al., 2004), specifically by reducing death and hospital admissions from respiratory conditions in children (Mulenga, 2007). Chintu et al. (2004) found a 43% relative risk reduction in mortality and a 23% reduction in hospital admissions among children ages 1–14 years in a double-blind cotrimoxazole prophylaxis trial.

The WHO, UNAIDS, and UNICEF recommend the use of cotrimoxazole in adults and children impacted by HIV internationally (WHO/UNAIDS/UNICEF, 2004). While cotrimoxazole is effective in preventing lower respiratory tract infections, Coutoudis et al. (2005) suggest the potential of increased risk of diarrhea among infants on cotrimoxazole, highlighting the importance of ensuring that an infant is HIV-positive before initiating cotrimoxazole therapy. Additionally, use of cotrimoxazole prophylaxis has been shown to be cost-effective through modeling techniques. One study of such modeling techniques in Zambia suggests that the treatment is associated with incremental cost effectiveness ratios (ICERs) of US \$72 per life year gained, US \$94 per quality adjusted life year, and US \$53 per disability life year (Ryan et al., 2008).

Despite its effectiveness in reducing opportunistic infections among individuals who are HIV-positive, there fails to be widespread access to cotrimoxazole. Of the 4 million children in need of cotrimoxazole, only 4% are currently receiving the intervention (Zachariah, 2007). Barriers in cotrimoxazole scale-up have included concerns regarding increased drug resistance, poor access to PMTCT and children's health programs in areas of high HIV prevalence, lack of policy guidance on the importance of joint administration of ART and cotrimoxazole, few national targets regarding use of cotrimoxazole, and supply shortages of the drug (Zachariah, 2007).

Zachariah (2007) makes several concrete recommendations on how to best scale-up cotrimoxazole use including decentralized, integrated care services for children's health (to address concerns that families must attend specialized HIV clinics to receive prescriptions for cotrimoxazole) and general expansion of PMTCT services, early diagnosis of HIV in children, and training on the benefits of cotrimoxazole use for health care providers and communities.

### ***c. Treatment access***

Along with difficulties in cotrimoxazole treatment access, many regions continue to face a lack of access to ART therapy for children. HAART treatment is the recommended first line treatment for HIV-positive children (Working Group on Antiretroviral Therapy and Medical Management of HIV-Infected Children,

2008). The regimen is known to reduce mortality among adults (Hammer et al., 1997) and children infected with HIV (de Martino et al., 2000). In a ten year follow-up study of children on ART in the US, Patel et al. (2008) found a 76% lower mortality rate for HAART regimens over non-HAART regimens. More recent findings by Violari et al. (2007) of reduced mortality among asymptomatic perinatally infected infants on HAART have prompted recommendations to initiate ART for infants under the age of 12 months, regardless of their clinical status, CD4 count, or viral load (Working Group on Antiretroviral Therapy and Medical Management of HIV-Infected Children, 2008; WHO, 2008a).

Gaps in ART treatment continue to exist, in part due to health care system failures. ART is often vertically implemented, causing failure of integration of ART services with care for other childhood diseases. In South Africa, health care professionals cited limited clinical space, lack of clinical capacity, and “fear of treating children” as major concerns with pediatric ART rollout (Michaels, Eley, Ndhlovu & Rutenberg, 2006). Limited human resources and capabilities of the health care system mean that some individuals within the population, such as those of higher socioeconomic status, those who have more information, or those who live closer to clinics, preferentially receive ART treatment over others (Meyers, 2007; Scott, 2005).

### **Box 3. The Elizabeth Glaser Pediatric AIDS Foundation**

The Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) has attempted to address the gap in HIV care and treatment. In 2004, with the support of PEPFAR and CDC funding, EGPAF started Project HEART in Côte d'Ivoire, Mozambique, South Africa, Tanzania, Zambia, the Democratic Republic of Congo, Kenya, Rwanda, and Swaziland. Project HEART provides ART through a family-based approach, with the goal of saving lives and preserving families. As of the end of 2007, Project HEART has provided care for 348,900 individuals, including over 28,000 children. Of these, ART has been provided for 190,000 people, including 15,000 children. Future goals of the organization include ensuring that 15 percent of the patients it provides services for are children (EGPAF, 2008; Marlink et al., 2006).

In terms of addressing human resource issues in sub-Saharan Africa, the African Network for the Care of Children Affected by HIV/AIDS (ANECCA) has worked towards scaling up human resource capacities by educating health care workers on how to provide appropriate care for a pediatric population. ANECCA has trained senior pediatric care clinicians from seven African countries who will become regional trainers in their respective countries. ANECCA also created and distributed a training curriculum for pediatric AIDS care to several African countries (Tumwesigye, Mbori-Ngacha & Kieffer, 2006).

Similarly addressing the lack of skilled health care workers capable of providing care and treatment to a pediatric HIV population, Chiang Rai Regional Hospital (CRH) in Thailand expanded pediatric HIV services by moving care to the community setting. At nine community hospitals pediatric care teams consisting of physicians, nurses, pharmacists, counselors, and individuals living with HIV were created. While children were still initiated on treatment at CRH, their follow-up appointments occurred at the community hospitals. Additionally, people living with HIV assisted with adherence education and home visits. In the first 9 months of the program, 278 children initiated ART at CRH, with 44 receiving follow-up care at community clinics. Forty-two individuals were reported to have good adherence, no adverse events, and no opportunistic infections (Hansudewchakul et al., 2006).

#### ***d. Adherence promotion***

For ART treatment to be effective in improving health outcomes in children and suppressing HIV, adherence to treatment is essential (Van Dyke et al., 2002). Studies in pediatric populations have shown that as the number of missed treatment doses increases among children, the risk of virologic failure also increases (Flynn et al., 2004; Watson & Farley, 1999). Additionally, poor adherence may lead to

increased drug resistance. Adherence is a significant issue within the pediatric population – several studies have shown that only 60% to 70% of children and/or caregivers report full adherence to ART regimens (Van Dyke et al., 2002; Katko, Johnson, Fowler & Turner, 2001; Watson & Farley, 1999).

Among children, difficulties with adherence to ART depend on several factors, including how the medication tastes and dependence on an older caregiver to provide treatment (who may limit provision of treatment due to social factors or fear of disclosure of status) (Gibb et al., 2003; Reddington et al., 2000). Children with poor caregiver relationships and those who have caregivers with a lower perceived quality of life are more likely to be non-adherent (Mellins, Brackis-Cott, Dolezal & Abrams, 2004). Additionally, some adults place too much responsibility on older children who are not yet able to maintain adherence to treatment on their own (Working Group on Antiretroviral Therapy and Medical Management of HIV-Infected Children, 2008). There are also adherence issues specific to adolescents infected with HIV, including denial or fear of HIV infection and daily lifestyle burden (Murphy et al., 2003). Adherence can be particularly difficult for HIV infected youth who want to fit in with their friends. For both younger and older children, HIV disclosure can be a main issue hindering adherence – one benefit of HIV disclosure to children is that adherence to therapy typically improves (Bikaako-Kajura et al., 2006). Additionally, adolescents who believe that HIV treatment will improve their quality of life are more likely to adhere (Belzer, Fuchs, Luftman & Tucker, 1999).

There are several interventions designed to improve adherence among children and adolescents. Within the United States, technical interventions which have shown some success include pill-swallowing training sessions with children (Garvie, Lensing & Rai, 2007) and medication alarms that remind children to take their medications (AIDS Institute New York State Department of Health, 2001). Family and peer support interventions have also shown to be effective in improving adherence outcomes (Lyon et al., 2003).

Internationally, MSF partnered with Provincial Hospital of Surin in Thailand, to provide an adherence intervention in which the majority of participants had over 80% adherence in short-term and long-term adherence. The intervention included a home visit before beginning ART treatment to identify a child's caregiver, nurse-led group education sessions with caregivers and children, and individualized daily treatment schedules. During follow-up visits, adherence to treatment was assessed by self report and individual analysis of barriers which led to adherence difficulty. Additionally, games and a hotline were used as tools to answer questions regarding treatment (Blasco et al., 2003).

Another pediatric adherence program reporting success involved using age-appropriate children's activities to help groups of HIV-positive children better understand how to take their treatment and create positive images of treatment for children. Children were divided into groups based on their age (1–5 years, 6–8 years, 9–11 years, and 12–16 years) and each group visited the hospital monthly, where nurses led them in various activities. While younger groups focused on learning how to take medication, older groups learned about the benefits of disclosure and having friends to help maintain adherence. Among this group of children, average adherence was 96% (Nuntasee, Yentang, Petdachai & Wilson, 2006).

#### **4. General pediatric care, nutrition, clean water, and sanitation**

According to UNICEF's 2008 report on the State of the World's Children, 2006 marked the first time in recent history when the number of deaths among children under the age of five fell below 10 million, to 9.7 million (UNICEF, 2008). This marks significant progress in reducing child mortality – however, the WHO indicates that a large majority of these deaths are due to preventable and treatable conditions (WHO, 2008b). Significant attention has been paid in recent years to the causes of neonatal, infant and child mortality (the literature is vast; see e.g., Black, 2003), as well as to cost-effective and relatively easy-to-implement interventions that can have major impacts on child survival.

In particular, key efforts have focused on preventive interventions (including breastfeeding, immunizations, nutritional programs, and micronutrient supplementation) and basic treatment for common diseases, including pneumonia, acute respiratory infections, diarrheal diseases, malaria and HIV. After the Alma Ata Declaration on Primary Health Care, a strategy of “selective primary health care” was proposed as an initial feasible step towards comprehensive primary care. This model targeted diseases identified as the most important contributors to high infant and child mortality rates. Based on this framework, UNICEF launched its “child survival revolution” in 1982, with emphasis on four low-cost interventions: growth monitoring, oral rehydration therapy, breastfeeding and immunization (GOBI). Eventually three additional components were added: food supplementation, family spacing and female education (GOBI FFF). Another longstanding model that places greater emphasis on integration of primary care services is the Integrated Management of Childhood Illness (IMCI), which was introduced in 1992 by UNICEF and WHO. IMCI comprises a broader approach to case management of childhood illness (UNICEF, 2008).

Relatively little attention has been paid to children’s access to health care across the globe. Some studies have demonstrated that differences among children within countries as well as among countries are related to nutritional status, care-seeking behavior, access to interventions, and mortality – and that all of these are related to both household and national poverty levels (Rosenberg, 2007). Examining children’s health outcomes in developing countries in parallel with statistics on human resources for health suggests not only a severe lack of access to primary health care in many developing countries but specifically a lack of access to pediatric care. For example, the WHO reports that although just over 50% of the world’s population resides in urban areas, more than 75% of the world’s doctors and more than 60% of the world’s nurses are located in urban areas.

In addition to pediatric care to comprehensively reduce gaps in health outcomes for children and communities affected by HIV/AIDS, one must also ensure that children’s access to basic needs is addressed, which includes adequate nutrition, safe drinking water, and sanitation. The importance of these basic needs in preventing childhood diseases and ensuring child survival has already been well established. Up to 50 percent of under-five child deaths worldwide are attributed to malnutrition (UNICEF, 2007). Nutritional deficiencies in vitamin A, iodine, iron and insufficient caloric and protein intake have been known to affect physical and cognitive development (Engle et al., 2007). An estimated 88% of deaths due to diarrheal disease, which account for 17% of under-five deaths globally, can be attributed to poor hygiene, unsafe drinking water and inadequate access to sanitation (UNICEF, 2006).

The importance of these essential human needs is heightened in the context of HIV/AIDS, where addressing these needs can reduce the incidence of opportunistic infections and help those affected by HIV/AIDS live longer and healthier lives. Sufficient nutritional status can aid in combating the depleting effects of diarrhea and upper respiratory infections, as well as offsetting the effects of malnutrition and physical weakness caused by AIDS. Clean water and adequate nutritional status are prerequisites for the optimal usage of HIV drugs. Decreasing the incidence of diarrhea can also have a substantial impact on children affected by HIV/AIDS, as morbidity and mortality due to diarrheal disease is more severe in children with HIV/AIDS. Studies have shown that HIV-positive infants are 11 times more likely to die from diarrhea compared to those who are HIV-negative (Thea et al., 1993), and HIV-negative infants born to HIV-positive mothers are at a 3.5 times greater risk of developing recurrent bouts of diarrhea compared to infants born to HIV-negative mothers (Keuch et al., 1992). It is clear that meeting these basic human needs can have a substantial impact on the lives of children affected by HIV/AIDS.

In spite of the known benefits and the provision of the right to essential health necessities outlined in Article 24 of the Convention on the Rights of the Child, there are still a large number of communities around the world whose basic needs are not met. In developing countries, 26% of under-fives are moderately-to-severely underweight, and 10% of under-fives are severely underweight (UNICEF, 2007). More than 30% of households in developing countries do not consume iodized salt and 28% of children lacked full coverage of vitamin A supplementation in 2005 (UNICEF, 2007). In developing countries, 20%

of people do not use safe drinking water sources and about 50% are without adequate sanitation, with countries in sub-Saharan Africa demonstrating higher estimates. Furthermore, there is a strong urban-rural disparity in accessing safe water sources and adequate sanitation facilities (UNICEF, 2007).

Although integrating water, nutrition and sanitation programs into HIV/AIDS services can mitigate the impact of HIV/AIDS, few programs for people living with HIV/AIDS include a focus on basic water, sanitation, and hygiene. Water, sanitation and hygiene services are affordable, sustainable, and relatively easy to deliver, provide benefits throughout the course of AIDS infection, and provide health benefits to an entire household (Tulenko, 2007). Some existing models of integrated sanitation and HIV/AIDS programs look promising (See Box 4).

#### **Box 4. Hygiene Improvement Project**

The USAID-funded Hygiene Improvement Project incorporated hygiene improvement activities to alleviate the impact of diarrhea and improve the lives of those infected and affected by HIV/AIDS (Hygiene Improvement Project, 2006). A case-control study by Lule et al. (2005) found that PLWHA who were randomized to use home chlorination of water, safe storage of household water and basic hygiene education had 25% fewer diarrhea episodes (95% CI: 0.59 – 0.94) and 33% fewer days with diarrhea (95% CI: 0.48 – 0.94) compared to those in the education arm of the study. These benefits were also conferred to other household members. As diarrhea is the most common opportunistic infection affecting those living with HIV/AIDS, clean water and sanitation can enable fewer sick-days, improvements in physical health and increased economic and educational opportunities.

## **5. Education and early childhood development interventions**

### ***a. ECD interventions***

The link between education and health (both child survival and development) has been well-established (Palfrey et al., 2005; Shonkoff & Phillips, 2000). This relationship is even more important in societies with a high burden of HIV/AIDS, as children are more likely to be exposed to factors that can detrimentally impact their cognitive development and future psychosocial and physical health. Such factors include chronic poverty, stress, parental illness, and parental death. Domestic violence may lead to a constant level of elevated stress hormones in children that can disrupt brain chemistry and lead to impaired learning, memory, social development, and susceptibility to physical illnesses as an adult (Center on the Developing Child at Harvard University, 2007). Furthermore, the importance of nutrition in children affected by HIV/AIDS is heightened due to the necessary dietary intake for effective medication administration and the detrimental effects of malnutrition and physical weakness caused by AIDS.

Early childhood development initiatives can play a major role in minimizing these risks and promoting a strong and safe family environment to nurture a child's development. The importance of early childhood development (ECD) interventions, which may include components such as nutritional supplementation, home visits, family education, and formal pre-school, have been well documented, and many studies have shown the importance of a child's early developmental years for child survival as well as future health status and educational attainment (Shonkoff & Phillips, 2000). It has been shown that interventions that enrich early childhood environments can contribute to improved health as well as social and economic outcomes in adulthood, especially for children in resource-poor settings (Hawkins, Kosterman, Catalano, Hill & Abbott, 2005). Some long-term benefits of experimental ECD programs have included improved school achievement, a reduced risk of emotional and behavioral problems, fewer high-

risk behaviors, and positive economic outcomes (Hawkins et al., 2005; Reynolds & Temple, 1998; Schweinhart, Barnes & Weikert, 1993).

While it is recognized that effective implementation of ECD depends on locally appropriate models, some lessons have been learned from model ECD programs that have been implemented in low-resource settings. Engle et al. (2007) identified several characteristics of successful ECD interventions, including integrating health, nutrition, education, social and economic development; focusing on disadvantaged children; including parents and families as partners; blending traditional child-rearing practices with evidence-based methods; and providing ECD staff with sufficient training and supportive supervision. Integrating nutrition and health care with ECD can improve the physical and cognitive growth and functioning of children (Engle et al., 2007), especially combined with the depleting effects of HIV/AIDS and the need for sufficient food and water to take medications. Nutritional supplementation as part of an ECD program in Jamaica (combined with a weekly home-based play session for cognitive stimulation) was found to benefit motor and cognitive development (Grantham-McGregor et al., 1991). Home-based ECD interventions, which are more likely to target the most vulnerable mothers and children, have also been shown to benefit mothers' psychological well-being and children's subsequent development. An ECD intervention based in Colombia found that home visiting to promote early cognitive development and environmental stimulation increased parental involvement with the child. An interactive effect between nutritional supplementation and the early childhood development intervention was also found to be significant in this study (Super, Herrera & Mora, 1990). For children affected by HIV/AIDS, a highly effective model would integrate ECD with PMTCT programs. Since both ECD and PMTCT share common features and resources (including the involvement of mothers, fathers and extended families; community support; and trained community health workers), integrating these services would offer a logical and sustainable approach to the provision of both services. It is vital that parents be engaged in a clear understanding of the benefits of ECD from the outset of such integration. In pilot trials of ECD that CARE initiated with UNICEF and Save the Children, for example, parents initially interpreted the ECD program as a "drop-off" center or babysitting option until the benefits were clearly described to them (William C. Philbrick, CARE, personal communication).

While implementing services is difficult in settings with limited human and material resources, there have been many examples illustrating the feasibility and success of programs integrating parenting skills development and nutritional support into primary health care (Engle et al., 2007). More broadly, accessibility, uptake and adherence to the program may be severely impacted by the impoverished conditions of a population, including transportation barriers, fatigue, and malnutrition. Some barriers to effective and sustainable ECD scale up include lack of awareness among mothers, health care providers, and communities about the need to support early childhood development; lack of legislative and financial support from governments, and difficulties in accessing vulnerable mothers and children.

### ***b. Access to education***

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, 31 countries, the majority of which are in sub-Saharan Africa, are in danger of failing to meet the 2015 deadline of universal completion of primary education (UNESCO, 2002). At the secondary 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 countries. In cases where gains in enrolment have been achieved, they risk being undermined by the poor quality of education and remaining school fees (Global Campaign for Education, 2008). Many of the highest HIV prevalence countries continue to struggle to provide primary and secondary school education to their populations (Jukes, Simmons et al., 2008) (**Table 3**).

Table 3.  
Illustrative HIV Prevalence and Primary and Secondary School Gross Enrolment Rates

	Adult HIV Prevalence (2005)	Gross Enrolment Rate (Male/Female) (2006 unless otherwise noted)	
		Primary	Secondary
<i>Zambia</i>	17.0	118/116	31/25 (2002)
<i>Mozambique</i>	16.1	113/97	18/13
<i>Tanzania</i>	6.5	112/109	7/5 (1999)
<i>Uganda</i>	6.4	116/117	21/17 (2002)
<i>Nigeria</i>	3.9	98/78 (1999)	24/22 (1999)
<i>India</i>	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](http://stats.uis.unesco.org/unesco/TableViewer/document.aspx?ReportId=198&IF_Language=eng)

In many countries, children affected by HIV/AIDS are even less likely to attend primary and secondary school than their non-affected peers. In addition to the challenges in accessing education that face all children, such as cost, distance and household responsibilities, children affected by HIV/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 higher priority places on continued education for orphans.

### ***c. 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 of which supports the connection between female education and increased use of maternal health 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 (Hargreaves et al., 2008), 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 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 indicate 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 similar 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 ( $p=0.01$ ) (de Walque et al., 2005).

Therefore, while evidence indicates a trend toward a relationship between higher education and lower HIV risk, this relationship does not hold in all settings and for all individuals. Vandemoortele and Delamonica (2002) explain these contextual differences by the stage of the HIV epidemic in each country, arguing that in countries with more developed epidemics, education becomes protective against HIV as more educated individuals adapt their behavior more quickly than illiterate and poor individuals.

The shortfall in educational attainment holds particularly serious consequences for girls and women. According to UNAIDS, in 2007 women comprised 61% 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 risk of contracting HIV due to both biological and social factors 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 lifetime. In all sites except Ethiopia women who reported experiencing violence from an intimate partner were significantly more likely to report that they knew that their partner had had sexual partnerships with other women during their relationship (WHO, 2005). Although education, particularly beyond the primary level, has been shown to be protective against both HIV and violence, gender gaps in enrolment 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 in enabling 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 the skills needed to address their risk of HIV.

## **6. Social stressors, mental health risks, and psychosocial support**

### ***a. Stressors and strategies for support and intervention***

Children affected by HIV, including those who are infected, are vulnerable to a wide range of stressors, including HIV-related stigma, caring for a parent who is ill, or death of a parent. School difficulties and dropout, diminished nutritional status, lack of shelter, and inadequate access to health care have all been documented among children affected by HIV (Lyons, 2005). Children whose parents have died or can no longer provide for and protect them are more vulnerable to exploitation and violence.

Aside from the physical stressors that they encounter, children infected with HIV have been found to have a high rate of mental health disorders, the most common of which is depression (Mialky et al., 2001; Battles et al., 2002). In a five-year longitudinal study of adolescents living with HIV, over 25% of participants reported episodes of clinical anxiety and depression, and a smaller but still substantial percentage reported suicidal ideation and/or attempts. Behavioral problems have also been observed in India as more prevalent among HIV-positive youth ages 6–11 compared to their uninfected peers (Grover et al., 2007); this finding has HIV prevention implications as these youth transition into adolescence. Battles and colleagues (2002) found that when the adolescents perceived social support from adults and when the HIV status of their parents/caregivers (when applicable) was disclosed to their friends, the risks of depression, drug and alcohol use, criminal activity, and sexual risk behaviors were lower. Despite the fact that greater disclosure has been found to decrease the prevalence of depression, due to stigma and discrimination around HIV many children are unaware of their own HIV status, and those who are aware are often advised not to share this information (Mialky et al., 2001; Oleske, 1994; Grubman et al., 1995). HIV-related stigma of HIV-positive children and young people has been shown to persist within the context of ART access (Ayres et al., 2006) and may result in feelings of isolation and exclusion that may affect their psychosocial health as well as their adherence to treatment.

Common problems faced by children whose parents/caregivers have HIV include: dealing with stigma from other family members or the community; caring for a parent who is increasingly ill; assuming parental responsibilities in the family; coping with the death of a parent; and feeling insecure due to economic difficulties. Studies examining the psychosocial adjustment of children living with HIV-positive caregivers have found that, compared with children who were not affected by HIV, HIV-affected children exhibited higher rates of internalized responses to stress, resulting in depression and anxiety (Stein et al., 1999; Rotheram-Borus et al., 2001; Forsyth et al., 1996; Roth et al., 1994; Forehand et al., 1998; Kotchick et al., 1997).

While most of the studies on the effects of HIV on children have been performed in the United States, a similarly worrisome picture emerges when we consider research among HIV-affected children in the most highly-burdened countries. In one study performed in Tanzania, higher rates of suicidal ideation and internalizing symptoms such as anxiety and depression were documented among 10–14 year old AIDS orphans as compared with peers from families not affected by HIV (Makame et al., 2002).

Reducing the psychological effects of HIV on children is not only important to reduce depression and anxiety, but may also lessen the child's HIV risk behaviors. When children externalize their responses to stress, they have been found to engage in high-risk sexual behavior, substance use, aggression, and criminal behavior. While externalized behaviors may not be more common in all HIV-affected children when compared with the norms of adolescent development (Rotheram-Borus et al., 2001; Rotheram-Borus et al., 1999), the severity of parental illness may be related to the degree to which children externalize the stress they face and engage in high-risk behaviors.

It has been estimated that approximately 36% of children with mothers who are HIV-infected demonstrated problems that required some degree of psychological intervention (Adnopoz et al., 1994). A number of such interventions have been implemented in various settings, however, most of the formally evaluated interventions have been conducted in the United States. One type of intervention that has been employed is an expanded case management strategy in which HIV case managers focus not only on the HIV-infected individual but also on the needs of family members, including children (Stuber et al., 1992). If a parent needs additional support in caring for his or her children, the case manager can assist the parent with finding immediate assistance and with planning for the future care of his or her children. The case manager may also assess the child's mental health status and HIV risk behavior and provide one-on-one counseling with a specific focus on these issues. This "family-focused" approach to mental health for HIV-affected children has demonstrated improvements in family functioning and a reduction in a sense of social isolation of family members (Mellins et al., 1994; Schneir et al., 1998; Tenner et al., 1998).

In addition to one-on-one support provided by a health professional or case manager, children affected by HIV also appear to benefit from support group interventions (see **Case Description 2**). Roth and colleagues described a support group intervention for adolescents affected by HIV. The weekly groups were conducted with children ages 12–17 years over a three-year period; each group included 4–8 members. The groups were facilitated by a mental health professional and discussed a broad range of topics, including the social isolation and discrimination that families affected by HIV experience, instability due to socioeconomic constraints and poverty, coping with anxiety, dealing with loss, confusion about HIV, and the promotion of "safe sex" and risk reduction practices (Klein et al., 1994). Other support group interventions for HIV-infected youth have also focused on enhancing coping skills and adaptation (Mellins et al., 1994; Klein et al., 1994; Halperin et al., 1993). In addition, social support groups have been formed for younger children (between the ages of 8 and 13 years) with HIV (Lewis et al., 1994). These groups provided a safe atmosphere for discussing feelings about HIV infection and obtaining support from other group members and co-leaders. Other developmentally appropriate activities such as arts and crafts, pretend play, and poetry writing were used with these younger children. There is evidence from randomized controlled trials that psychological treatments for symptoms of depression in adolescents can be successful in developing countries, with adolescent girls showing greater improvement in depressive symptoms than boys following group-based therapy (Bolton et al., 2007); however this study addressed adolescent survivors of war and displacement rather than HIV infection. Some psychosocial interventions with HIV-infected youth have also included HIV prevention components (Donenberg et al., 2005). Rotheram-Borus et al. (2001b) evaluated a program for HIV-infected youth that focused on supporting self-care and adherence as well as promoting safe-sex behaviors. This cognitive-behavioral intervention emphasized coping skills and self-efficacy (e.g. in negotiating condom use). Youths in the intervention reported fewer sex partners, enhanced coping, and fewer incidents of

unprotected sex compared to those enrolled in the control group (Rotheram-Borus et al., 2001b; Rotheram-Borus et al., 2001c).

***Case Description 2***

**Friends for Life Girls support group, Alexandra Township, Johannesburg, South Africa**

Adolescent girls, ages 13-19, in Alexandra Township, in Johannesburg, South Africa have the opportunity to participate in the “Friends for Life” Girls support group that focuses on prevention and peer counseling. The “Friends for Life” is a non-governmental (NGO) non-profit organization that offers care, support, and empowerment to the broad spectrum of people living and affected by HIV/AIDS. The vision is to help people living with issues related to HIV/AIDS by enhancing and maximizing the quality of their lives by offering emotional, practical, and moral support to people affected by and those living with HIV/AIDS. By working collaboratively with the girls enrolled in the “Friends for Life” support group, the LG3 representative in South Africa (Barbara Sematimba) offers a number of key issues that were raised as well as lessons learned from the girls’ input and experience:

- Access to formal education reduces girls’ vulnerability to HIV/AIDS in this context
- Attaining a higher level of education allows girls more choices and helps a girl make informed decisions about her own future and welfare
- When targeting “school aged” girls it is critical to address the fact that the most vulnerable girls will most likely not be attending school; therefore, community-based initiatives are essential for adequate outreach
- HIV-related stigma/discrimination, competing priorities (such as the need to work—within the home or outside the home), and concerns for girls’ safety may serve as barriers to access to education for girls
- Chronic hunger and depression can have a tremendous impact on capacity to learn and future prospects
- Psychological trauma, caused by rape, sudden death of a parent, and exposure to violence, can have a significant impact on capacity to learn and self-esteem
- Offering psychosocial support in the community may help to address the effects of trauma and depression in this population by focusing on social support and positive coping strategies
- Support should also be offered to parents as well to address their own distress, particularly for those who are HIV-positive, and to be able to offer stronger support and caregiving/supervision for girls
- Girl children may also be caring for their ill parent(s), an additional challenge and stressor for this population
- A girl without adequate food or shelter may engage in survival strategies that place her at risk for HIV infection (e.g. transactional sex, offering sex for food or money)
- Poverty in the household can limit the family’s ability to pay school fees or other associated costs; initiatives that target poverty reduction may have an effect on increasing girls’ access to education
- Initiatives that address gender inequality on all levels can allow girls and young women to assert their sexual and reproductive rights without endangering themselves
- Formal education can empower girls to assert these rights and protect themselves from unnecessary HIV risk
- Integration of services and a multi-sectoral approach are essential to address the comprehensive needs of girls in this South African setting (Sematimba, 2008).

Empirical data from the U.S. also support the importance of interventions that enhance coping, social support, and caregiving skills among parents of adolescents affected by HIV on long-term health and psychosocial outcomes in youth. Rotheram-Borus and colleagues implemented a randomized controlled trial to evaluate a group intervention for adolescents affected by HIV and their HIV-positive parents. The intervention was designed to address the psychosocial needs of HIV-positive parents and their adolescent children (ages 11 to 21 years) in New York City and was based on cognitive-behavioral principles that focused on improving coping skills. The intervention had a positive effect on the adolescents’ coping skills. Positive outcomes were evident after six years of follow-up: the adolescents in the intervention group were more likely to be in school or employed, had a greater capacity to resolve conflict and problem-solve, and were more likely to have positive expectations for future life goals than the HIV-affected adolescents in the control group (Rotheram-Borus et al., 2004). Social support was found to be an important protective factor with respect to levels of depression and problem behaviors among adolescents enrolled in this study cohort (Lee, Detels, Rotheram-Borus, & Duan, et al., 2007).

Interventions on behalf of children affected by HIV in developing country settings are beginning to demonstrate positive effects on psychosocial health outcomes. A home-focused program coordinated by the Tulane University School of Public Health, Rwanda School of Public Health, World Vision Rwanda, and the Horizons Program trained adult volunteers from the local community to act as mentors to youth-headed households. The mentors visit households at least once a month to monitor the well-being of children and youth living without an adult caregiver; during their visits they provide support, guidance and informal life skills (Brown, Thurman & Snider 2005). The mentorship program was shown to significantly increase adult support for these youth and decrease their feelings of marginalization and isolation from the community; youth reported significantly less maltreatment and symptoms of depression compared to baseline levels before the intervention (Brown et al., 2007). Other locally developed programs have been shown to be appropriate, feasible and effective in resource-poor settings (See Box 5).

The idea of such community-based efforts, sustained primarily by community resources, has been promoted by some as the appropriate mechanism for developing culturally appropriate psychosocial interventions for children affected by AIDS (UNAIDS, UNICEF, & USAID, 2004). However, many poor communities cannot provide for the growing number of children affected by HIV without external financial and technical support. In a study performed in Lesotho and Malawi most of the youth interviewed lived with extended family members, and neither the child nor the family received any external assistance. Many of the orphans interviewed were neglected or abused. Poverty in the extended family's home was often the basis for neglect of the orphaned child. The authors of the study argued for reducing the financial burden on families who take in orphans by providing assistance in accessing outside resources, offering free primary education, and promoting income-generating projects for the guardians of these children (Ansell et al., 2004). The need for external support for communities assisting children affected by HIV was also raised by Sewpaul (2001) when describing the needs in South Africa. Given the pervasive poverty in countries most burdened by HIV, external support of programs for HIV-affected children and the families that care for them may be critical in ensuring that these vulnerable populations receive adequate access to needed resources.

### ***b. Psychosocial factors and HIV risk***

One key aspect of psychosocial support for children and youth affected by HIV/AIDS is preventing various types of exploitation. Exploitation often occurs because of a lack of protection (either through the loss or reduced efficacy of parents or as a result of stigma associated with HIV/AIDS) or as a result of struggling to survive on a day-to-day basis, which can result in children engaging in dangerous behaviors. The absence of adequate psychological, social and economic protection and support of children can result, for example, in sexual or physical abuse, engagement in sex work or other kinds of work in unsafe environments, living on the streets, failure to attend school or trading sex for passing grades.

One particular issue that requires additional research is that of children who live completely without adult protection or supervision. While there is limited published evidence that the number of child-headed households in heavily AIDS-affected communities is dramatically increasing, there are ample anecdotal reports from organizations working in these communities that these types of households are proliferating. Children may live in households headed by their siblings or other young people for a number of reasons. For example, adults in the family or community may be unwilling to take responsibility for additional orphans; children may be unable to trace their relatives when parents die (this is a particular problem for the children of migrants); children may receive support from adults but choose to stay in their childhood homes to retain their claim to property and maintain independence; or, they may seek to avoid abusive foster or adoptive families.

#### **Box 5. REPSSI and The Salvation Army**

An organization that has played a large role in advocating for psychosocial support services is the Regional Psychosocial Support Initiative for Children affected by AIDS, Poverty and Conflict (REPSSI), a non-profit coalition based in East and Southern Africa. REPSSI works with local community organizations to train course leaders and develop appropriate courses and manuals to mainstream psychosocial support into existing education, ARV, early childhood development, children's empowerment and nutrition programs. Key elements of their programming include the use of workshops to mobilize communities, 'Hero Books' which use autobiographical storytelling, art exercises to help children solve personal challenges, and body mapping as a tool to aid people in telling their life stories and sharing their feelings (REPSSI, 2008).

One of REPSSI's main partners is The Salvation Army (Zimbabwe), who started its Masiye Camp for children affected by AIDS in 1998. The Masiye Camp uses challenging experiential and adventure-based learning to encourage interpersonal and life skills development, particularly for children living in child-headed households or with ill parents (Fox, 2001). At Masiye Camps, children have the opportunity to share their personal experiences, learn coping skills from each other, and participate in group therapy with peers (Salvation Army, 2007). The utilization of youth as camp counselors facilitates psychosocial support. In addition, by giving young people meaningful work, it also serves as an effective means of youth HIV/AIDS prevention (Germann & Kaseke, 2002). In a 2001 evaluation of this program, approximately 45% of children indicated that their attitudes or behavior (including improved coping skills) had changed as a result of attending the camp (Foster & Jiwli, 2001). The Salvation Army also operates an innovative youth-organized Kids Club program in Bulawayo, Zimbabwe, which trains youth volunteer camp counselors from the Masiye Camp to meet weekly with children for group recreation and socialization, sustaining psychosocial support. A four-arm study (comparing youth exposed to community psychosocial programs, youth exposed to the Masiye Camp program, youth who attended Masiye Camp and went on to become youth peer leaders for Masiye Camp or Kids' Clubs, and youth not exposed to any psychosocial support programs) found that those who became peer leaders were the most likely to report feelings of self-confidence and the ability to cope with difficulties in life. Among all the interventions, participation as a youth leader was found to be strongly associated with psychosocial well-being outcomes for females. Despite this, leaders were also more likely to report outcomes related to psychosocial distress (including feeling overwhelmed and hopeless) (Gilborn et al., 2006). This highlights the importance of focusing not just on psychosocial support for individuals but also for those in caregiving roles.

Children who live in abusive situations or who engage in potentially dangerous activities as a strategy to avoid abusive situations are at risk of both immediate and long-term psychological and physical trauma and disability. It is vital that these issues be addressed. At the most fundamental level, such situations violate legal rights—and legal obligations on the part of adult society to promote these rights—that have been promised to children through the Convention on the Rights of the Child, ratified by over 190 countries since it was initially adopted by the United Nations General Assembly in 1989.

Exploitation has devastating effects on the well-being of individual children as well as their communities. It also puts them at increased risk of future challenges, including HIV infection. The available literature on intersections between HIV and violence in both developing and developed countries provides evidence of multiple linkages (Maman, 2000, Jacobs, 2003). These linkages are cyclical: association with HIV increased risk of violence; and violence generates increased risk of HIV. A 2006 study in South Africa revealed that intimate partner violence (IPV) was strongly associated with other key risk factors associated with HIV infection (multiple sexual partners in the past year, recent sexual experience, and sex with older or more educated partners). Further, the investigators reported that "adverse experiences in childhood, including sexual abuse, increased the likelihood of having more past year partners" (Jewkes et al., 2006).

These results may in part be related to a higher burden of psychological symptoms among those who experience abuse, which may in turn increase the likelihood of HIV-risk behaviors. Among African American adolescents, those with elevated depressive symptoms at baseline were four times more likely to report inconsistent condom use at six months of follow-up (Brown et al., 2006). In addition to psychological distress, drug use was also found to be a significant mediating factor between abuse and

HIV risk among Latina adolescents (Newcomb et al., 2003). Substance use and conduct problems were also associated with HIV-risk behaviors in younger adolescent girls (ages 12–15) (Bachanas et al., 2002). Substance use, particularly alcohol abuse, may be an important factor to consider with respect to HIV risk among adolescents in sub-Saharan Africa (see **Case Description 3**).

Physical and sexual abuse are not restricted to a small sub-section of the population in most places. A 2003 household survey in eastern Uganda revealed a lifetime prevalence of intimate partner violence among women of 54%, including 14% reporting physical violence in the past year. A strong association was revealed between sexual coercion and lifetime physical violence (OR 3.8, 95% CI 2.5–5.7). This study was conducted to delineate reasons for low uptake of Voluntary Counseling and Testing for HIV. In focus group discussions conducted in conjunction with the survey, women reported that fear of subsequent intimate partner violence resulted in fearing HIV testing, disclosure of HIV results, and negotiating condom use (Karamagi, 2006). A study conducted in Kenya reported that the odds of HIV-positive women reporting domestic violence after notifying partners of results were 4.8 times those of HIV-negative women (Kiarie, 2006).

These results are mirrored in poor communities in countries in the Global North as well. A study in Baltimore, Maryland, showed HIV-positive women were more likely than HIV-negative women to report having experienced both physical and sexual abuse as a child (15% vs. 9%, respectively). HIV-positive women were also nearly three times more likely to report sexual abuse on more than one occasion by a non-partner compared with HIV-negative women (36% vs. 18%; OR 2.90) (McDonnell, 2003).

In summary, these findings suggest that addressing psychosocial issues, such as history of abuse (physical and sexual), substance use, psychological distress (e.g. depressive symptoms), and conduct problems may be an important aspect of HIV prevention interventions among HIV-affected youth. Self-efficacy is related to depression and can affect one's capacity to negotiate "safe sex." Greater understanding of the level of psychosocial risk in a given context can allow for more locally appropriate HIV prevention interventions that may address some of the root causes of HIV risk behaviors in high HIV burden settings. Primary prevention of psychological distress through supportive early childhood development interventions may have a long-term impact on HIV risk in adolescence and young adulthood.

**Case Description 3**

**Psychosocial issues that have an impact on HIV/AIDS risk among adolescents in sub-Saharan Africa**

Based on field experience and literature review, Dr. Florence Baingana, LG3 member and psychiatrist from Kampala Uganda describes key factors that increase adolescents' risk of HIV/AIDS (Baingana et al., 2008):

- Talking about sex is often a “taboo” topic in Uganda and other sub-Saharan African countries. There are remaining concerns that talking about sex may promote promiscuity among young people. This may prevent youth from obtaining necessary information on protecting themselves from HIV/AIDS
- Breakdown of culture and traditions has also resulted in more challenges in communication between older and younger generations. In many families, young people are educated by the older adults in the family or through *sengas* in the community (those who teach youth about coming of age issues). Due to the breakdown in this cultural tradition, there are commercial *sengas* offering unsupervised information to young people (Wadda et al., 2006)
- As a result of inconsistency of families and communities educating young people about sexual and reproductive health, there is a need for structured school-based interventions that incorporate education on HIV, as well as sexual and reproductive health (including family planning) more broadly. In addition, strategies to target youth not in school should remain an important priority
- HIV prevention education should also be tailored for youth who are HIV-positive (“young positives”) since there are a growing number of young people who were infected perinatally and are surviving longer due to increased access to ART (Baingana, 2008)
- Migration and urbanization has also resulted in dispersion of family and community networks, leaving education on sexuality to parents or other sources such as media, schools, and peers (Kyoheirwe Muhanguzi, 2005)
- Alcohol abuse is a concern in many sub-Saharan African settings and is the most common form of substance abuse in the region. It can impair decision making, result in nonuse or misuse of condoms, promote transactional sex, increase number of sexual partners, and allow girls to be more vulnerable to rape or sexual abuse (Simbayi, 2004; Theall, 2007; Tho, 2007)
- Stigma and discrimination hinders access to HIV testing and treatment in adolescents as it does among adults
- Young people often do not know where to obtain VCT or other health services, such as treatment for sexually transmitted infections
- Condoms are not made widely available to young people due to concerns by providers (e.g. concern that offering a condom is condoning sex at an early age)
- Girls in Uganda often become married at younger ages compared with men, increasing their HIV risk. Median age of first marriage is 18 for females and 22 for males. By the time that young people reach the age of 20 years, 66% of females are married compared with 20% of males (UBOS 2007)
- Adolescent girls with no education are more likely to be a co-wife compared to those with more education
- In addition, girls with no or limited education are more likely to be younger at first sexual intercourse
- Orphans and vulnerable children are more likely to be younger at first sexual intercourse, particularly for girls (MOH Uganda, 2006)
- Sexual violence is common among preadolescents and adolescents in Uganda—54% of those girls and women reporting sexual violence reported their first encounter occurring between the ages of 10 to 19 (UBOS, 2007)

**7. HIV prevention: youth/young adults**

As indicated above, one of the key mechanisms for reducing the burden of HIV among children and young people in high prevalence countries is by expanding access to and increasing the quality of

prevention of mother-to-child transmission (PMTCT) interventions. However, a second opportunity that has been relatively neglected is HIV prevention in youth and young adults.

As indicated above, greater than half of all new HIV infections worldwide occur among people under the age of 25 (UNAIDS, 2006). Their vulnerability suggests that greater emphasis needs to be placed on HIV prevention activities in these younger populations. Yet despite the critical importance of attention to promoting prevention among young people, there is only limited evidence about what types of interventions work (Paul-Ebhohimhen, 2008). While a comprehensive review is beyond the scope of this paper, we would like to highlight a few models of evidence-based interventions that offer potential for broad-based adaptation and scale-up in high HIV burden settings.

A 2006 WHO report offers a systematic review of evidence-based interventions focusing on HIV prevention in youth in the developing world (WHO, 2006). Organized in a “Steady, Ready, Go” framework, the report prioritizes interventions based on the quality of evidence of success. “Steady” indicates that the evidence threshold is not met, “ready” suggests that the evidence threshold is partially met, and “go” indicates that the evidence threshold is met and the intervention can be recommended for replication. This framework allows practitioners to select intervention designs to implement, and points researchers towards interventions that need to be evaluated further.

WHO noted, as the 2006 report was under development, that “There is no magic bullet for the prevention of HIV among young people. Many things need to be done through a range of sectors and organizations.” Key elements of successful prevention interventions include education, skills development, provision of services, risk reduction strategies and mitigating underlying vulnerability – without some combination of all of these elements, no single intervention will ensure protection against new HIV infection. Perhaps because many prior interventions have focused primarily on education, the majority of evaluations revealed mixed results on the effectiveness of HIV prevention interventions, which largely depend upon the context, broader aspects of the HIV epidemic (i.e. if the incidence is declining or increasing in a given country), as well as the structure and content of the intervention itself. One key limitation of many HIV prevention intervention studies is that most rely on behavioral outcomes that are self-reported (Auerbach et al., 2006). Therefore, there is increasing interest in using biomedical endpoints, such as the incidence of HIV or other STIs, as indicators of success.

However, the mixed evidence does not allow one to infer that all HIV prevention efforts have limited impact. Some HIV prevention strategies have been demonstrated to work, including some located in health care services, others based in education systems and still others through public information and media.

In particular, access to HIV testing and knowledge of one’s HIV status provides young people with a foundation to prevent further transmission of the disease (Maria, 2007). In addition, another health care intervention that has been shown to decrease HIV incidence is increasing access to services for family planning and treatment of sexually transmitted infections among youth (Denison et al., 2008).

A number of school-based HIV prevention education interventions have demonstrated effectiveness in developing countries. Kirby et al. (2006) reviewed school-based interventions and found that curriculum-based interventions comprised a significant majority of those that fell under the “go” category of the WHO classification described above. Many HIV prevention curricula are available online and from information clearinghouses. One limitation is that an intervention is more difficult to replicate in other settings without a structured curriculum. Although curricula generally cannot be directly “transplanted” from one setting to another, availability of a basic curriculum can allow for adaptation to the new context while retaining the primary educational and behavioral goals of the intervention. The limitations of these programs, of course, is that they rely on the presence of young people in schools or in other structured activities where systematic provision of information is possible.

Some interventions without formal curricula have also demonstrated effectiveness. For example, an intervention to prevent STIs and improve treatment-seeking behavior among youths in Nigeria demonstrated a reduction in the burden of STIs (Okonofua et al., 2003). This intervention targeted youths aged 12–21 years and relied on peer educators and health clubs to offer support. It is interesting to note that no other school-based intervention reviewed by Kirby et al. (2006) demonstrated a reduction in the burden of STIs, even when this outcome was assessed. The only other study reviewed by Kirby et al. (2006) that demonstrated an improvement in a “biomedical” outcome was an intervention study performed in Chile that demonstrated a reduction in occurrence of births/spontaneous abortion in the intervention group (Cabezón et al., 2005). This intervention targeted urban youth, aged 15–16 years and involved 10.5 hours of curriculum-based group discussion and brainstorming, addressing issues such as gender, self-assurance, emotions, prejudice, family planning, marriage and family, pregnancy and birth, among other topics. The primary goal of the intervention was prevention of teenage pregnancy (Cabezón et al., 2005).

However, many of the school-based studies reviewed did not show any evidence for effectiveness or demonstrated variations in effectiveness by gender (Kirby et al., 2006). Therefore, school-based interventions need to be carefully planned, evaluated, and complemented by other strategies, such as mass media (Bertrand et al., 2006), to maximize prevention of HIV transmission among youth. This is particularly evident with respect to youth who are not attending school and who are often at higher risk due to socioeconomic vulnerability and lack of awareness.

Strategies that may access these higher risk youth include mass media and community-based initiatives. In terms of mass media, while radio intervention alone reflected mixed or non-significant results, radio with other media, including television, demonstrated protective effects with respect to HIV risk (Bertrand et al., 2006). For example, greater discussion of condoms occurred among youth exposed to media campaigns in both Guinea (Fonseca-Becker et al., 2003) and Ghana (Tweedie et al., 2002). Some studies of media-driven initiatives have also demonstrated a reduction in the number of sexual partners (Xiaoming et al., 2000; Van Rossem et al., 1999; Kim et al., 2001). Only one media study conclusively demonstrated a reduction in HIV prevalence. This study was conducted in South Africa and involved radio as well as television media (Pettifor et al., 2004).

Although there are no community-based interventions in the developing world that have documented reductions in HIV prevalence, significant changes in sexual activity as well as condom use were observed for a number of interventions at the community level (Esu-Williams et al., 2004; Erulkar et al., 2004). Given the limited evidence, however, Bertrand et al. (2006) did not categorize any community-based interventions at the “Go” level according to the WHO criteria described above. Rather than concluding that community-based interventions do not work, however, we suggest that this reveals a critical need for researchers to partner with community organizations to systematically review and evaluate the effects of their programming.

The authors of the WHO report ultimately suggested a number of strategies needed for community-based interventions to succeed, including a screening procedure for selection of peer leaders; offering training and refresher sessions; assigning peer leaders specific tasks and objectives; supervising peer leaders and offering feedback; focusing on participatory learning activities; building links between components of interventions (such as linking outreach and education to referral for services); among other strategies (Bertrand et al., 2006).

Other programmatic options for HIV prevention to consider include encouraging delay or avoidance of sexual activity; supporting reduction in the number of partners; encouraging girls to avoid sexual relationships with older men; increasing awareness of the protective effects of male circumcision among men and age-appropriate access to it; offering treatment for drug addiction and promoting harm reduction strategies in appropriate contexts; reducing the occurrence of rape/sexual abuse; and

increasing access to post-exposure prophylaxis for cases of rape/sexual abuse (Maria, 2007; Pronyk et al., 2006).

**C. Cross-cutting themes for advancing access and quality of services for HIV-affected children and their families**

**1. Policy, the legal framework, and political will**

It is evident from a number of other successful initiatives that political will is an essential ingredient for success. However, what is often missing in discussions of political will is how it is defined and characterized in different contexts. For example, in Rwanda, given the transparency of the process with regard to OVC policy and program implementation, political will to a significant extent is coming from the populace. If the population, who is aware of progress via radio and television broadcast, is unsatisfied with program results, they will in turn elect a new mayor, the official responsible for program effectiveness (Binagwaho et al., 2008). This scenario is close to being an “ideal” source of political will, since the population benefiting from the programs has a say in the progress and evolution of implementation. However, in many settings this form of political will is not effectively “heard” and it is important to engage powerful stakeholders at various levels in order to foster program success.

Political will, although perhaps necessary, is not sufficient to ensure successful outcomes. Despite desirable outcomes from the population and/or policy-makers, the infusion of scientific knowledge is equally essential for program success. For example, does scientific knowledge support the idea that “abstinence” is a viable approach for HIV prevention? Although this approach has significant political support from U.S.-based resources, the scientific data do not necessarily reflect this priority strategy for HIV prevention. Similarly, while there can be political support easily generated for OVC, empirical data suggest focusing on families and communities and investing in capacity building at the local level may have a greater impact on child survival and well-being.

The gap between the scientific knowledge available and the current political climate or will needs to be addressed by a third necessary component of program success: social strategy. A tripartite model of scientific knowledge, political will, and social strategy (Fig. 1) was developed by Julius Richmond (Richmond et al., 1991) and reflects a process that has facilitated prior successes in public health programming, such as in the broad implementation of Head Start programming in the United States. (Richmond et al., 1991). Although political will might generate appropriate policies and legal frameworks, implementation without social strategy will lag far behind the initial vision set forth to expand access or improve quality of a given program.

**Development of Public Policy**

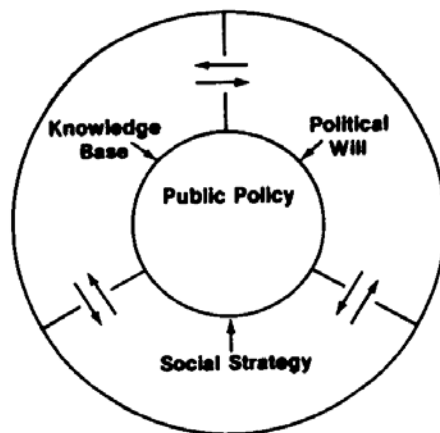


Figure 1. Julius Richmond's three-factor approach to health policy (Richmond et al., 1991)

## 2. Overcoming economic gaps and barriers: Strategies for funding

There has been increasing evidence that demonstrates an association between poverty, inequality, and HIV risk. As indicated by Adato and Bassett (2008), poverty can be related to limited access to information regarding HIV risk as well as constraints in following recommendations for reducing risk behavior. For example, a young woman who is illiterate will not have access to written prevention materials and may have limited economic opportunities. In settings of gender inequality, she may need to rely on her male partner to a large extent for her welfare and the well-being of her children. In some contexts it is the implicit power dynamic whereas in other situations a more explicit transactional sex may occur (Sa et al., 2007). While there are some contexts in which the direct link with poverty and HIV risk remains unclear, it is evident that pervasive economic inequality, which is often coupled by severe poverty, can promote HIV risk (Tladi, 2006).

There have been a few studies that have directly examined the impact of economic interventions on HIV risk or proximal risk factors (e.g. intimate partner violence). Among women enrolled in a community randomized controlled trial of a micro-finance intervention in South Africa, there was a 55% decrease in risk of physical or sexual violence by an intimate partner (Kim J.C. et al., 2007). However, this study did not demonstrate a direct affect on HIV incidence (Pronyk et al., 2006). In an intervention study among women who traded sex for money or drugs in the U.S., a combined HIV prevention-economic intervention (jewelry making) program resulted in a significant reduction in trading sex for money or drugs post-intervention (100% to 71%,  $p < 0.0005$ ). Similar results were observed for the median number of sexual contacts in the past month (10 vs. 3,  $p = 0.01$ ) and consistent condom use among those who continued to have sex trade partners (53% to 75%,  $p < 0.0005$ ). Mean job self-efficacy score also increased ( $p = 0.004$ ). In linear regression models, higher income from jewelry sales was associated with a greater reduction in the number of sex trade partners, comparing baseline to post-intervention ( $p = 0.013$ ) (Sherman et al., 2006). Although the design of this study offers pre- versus post-intervention estimates, the magnitude of the changes suggests a potentially positive impact of an HIV prevention-economic intervention on HIV risk behaviors in a high-risk population. A recent randomized study performed in Uganda found that an economic intervention with adolescents orphaned by HIV resulted in improvements in HIV prevention attitudes and an increase in education plans. In addition, since the intervention involved setting up Child/Youth Development Accounts to ensure savings for secondary school education, the average adolescent saved enough funds to cover the first two years of post-primary education (Ssewamala et al., 2008).

Indirect evidence of the association between poverty reduction and HIV risk also exists with regard to the link between cash transfer programs and improvements in education outcomes, in terms of enrollment and continuation (Adato et al., 2008). Higher level of education, in turn, have shown a protective effect with respect to HIV risk. Although there are some contexts in which there is not an observed link between lower level of education and HIV risk, this trend has been more evident in the past decade or so as the impact of the HIV pandemic has evolved (Hargreaves et al., 2008). This argument also relies on the assumption that on average, those who attain higher levels of education are less likely to suffer from poverty.

One element of “social strategy” is the need for a funding strategy. It is imperative to have a short-term (start-up costs) and long-term (recurrent costs) view of funding improvements in access to care and quality of service provision for children affected by HIV/AIDS.

### *a. Macro-level funding*

The level of funding over the last decade has been unprecedented in global health. From 2003 to 2007, an estimated \$38 billion has been made available for AIDS programs (Joint United Nations Programme on HIV/AIDS, 2007). In that time, the Global Fund to Fight AIDS, Tuberculosis, and Malaria (GFATM) and

the President's Emergency Plan for AIDS Relief (PEPFAR) have made the largest contributions in funding for HIV prevention and treatment. Since 2002, the Global Fund has provided \$8.6 billion and in its first five years, 2004 to 2008, PEPFAR's commitment was \$15 billion (UNICEF, 2008). Through UNITAID, which is an international drug purchase facility (IDPF), Brazil, Chile, France, Norway, and the UK, have made a commitment to pediatric treatment of HIV. In 2007, UNITAID's budget exceeded \$320 million and it is estimated that its budget may be as high as \$500 million in 2009 (UNICEF, 2008). United Nations programs, such as UNICEF and UNAIDS, also provide financial contributions in support of national programs (UNICEF, 2007). For example, UNICEF plans to raise \$1 billion by 2010 (which will include financing of PMTCT) and contribute this amount to HIV programs.

In terms of bilateral funding, a large number of countries have responded by making significant contributions; these include Austria, Denmark, Finland, Germany, Ireland, the Netherlands, Norway, Sweden, and the United Kingdom. Also worth noting is that the United States, as well as the United Kingdom and Irish governments, have earmarked 10% of funding for HIV to be allocated towards programs that serve children and adolescents.

Private donors have also emerged to support global funding efforts. The Clinton Foundation, for instance, has facilitated fundraising efforts, in addition to negotiating a reduction in the cost of pediatric ARVs to \$60 per year (William J. Clinton Foundation HIV/AIDS Initiative, 2006). In addition, other private organizations and foundations may offer funds for HIV prevention and treatment programs (e.g. The Bill and Melinda Gates Foundation, Pediatric AIDS Treatment for Africa [PATA] and the One-to-One Children's Fund in the UK).

Overall, the impact that these initiatives can make in funding HIV programming has increased dramatically in a relatively short time. However, sustaining these programs and initiatives and increasing availability of resources will require political advocacy and lobbying efforts. Diversification of funding sources as well as a broader health systems approach will facilitate improvements in the future and offer a more secure long-term strategy. Finally, as children and communities improve in terms of their health status, the associated economic gains at the local/ national level may constitute a multiplier effect, whereby initial "up front" investment leads to returns for future investment. This is an important piece of the funding puzzle that is often not considered. Children and other members of communities receiving support can become part of the "human infrastructure" to improve health outcomes in the long-term. For example, many HIV-positive patients receiving ART at Partners In Health's programs often become advocates, community health workers, or begin contributing in other ways to the community's well-being once they have recovered from the acute impact of opportunistic infections and their viral load becomes suppressed (Mukherjee et al., 2007).

Nevertheless, support from the international community, including multilateral organizations and bilateral agencies, will continue to serve as a cornerstone for supporting these initiatives. It is unrealistic to think that volunteer, community-based initiatives can adequately address the challenge of HIV and reduce the burden on children without external assistance. With adequate investment up front from the international community, there is the potential to stem the tide of the HIV pandemic, potentially resulting in lower expenditures in the long-term. However, without that investment, the HIV pandemic threatens to have a tremendous impact on children and their affected communities for many generations to come.

To complement the various macro-level funding efforts and maximize its impact, the international community should emphasize increasing transparency in fund allocation, distributing funding more equally across the various stakeholders, and optimizing the utilization of current resources. Allocating more funds for community-based initiatives in high HIV burden countries and less for international consulting efforts, may also improve efficiency of the funds available. In order to create a more equitable system, it is also critical to ensure that funds reach the peripheral rural areas rather than concentrating funds in large urban centers.

*Innovative methods in macro-level funding*

In addition to the traditional, public and private methods of macro-level funding discussed above, competition and cooperation among national governments, private industry actors, international institutions, NGOs, and non-profit institutions has resulted in new and innovative funding mechanisms (See Box 6).

**Box 6. France Diplomatie and UNTAID**

In 2006 France introduced a levy on the purchase of international airline tickets, known as the Airline Solidarity Contribution, to benefit the IDPF, UNTAID. 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 (France Diplomatie, 2007). Other countries including Chile, Brazil, Germany, and Spain have also expressed interest in enacting similar programs, especially those identified as equally promising by The Landau Report in September 2004 (i.e., 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) (France Diplomatie, 2004).

The recipient of the Airline Solidarity Contribution, UNTAID, is delivering another innovative method of financial support. At the nexus of private industry, governmental, and non-profit coordination, UNTAID 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; 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 includes 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 \$1 billion. It is estimated that this and similar financing efforts may generate \$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).

***b. Micro-level funding***

*Role of micro-credit*

Funding schemes on the household level can also have a substantial impact on the ability of a household to mitigate the burden of HIV/AIDS. As household incomes erode due to the consequences of parental illnesses or the need to act as caregivers for sick and orphaned children, strategies that stabilize incomes, increase savings, and foster the development of income-generating skills can strengthen social and financial safety nets, making it easier for households to cope (Pronyk et al., 2005). One effective means of financial support are microenterprise programs that improve access to credit and savings services to the poor, as well as provide training in income generating activities and facilitate linkages to markets and

raw materials. While there are many variations on size, target users, utilization and terms and conditions, micro-credit models share the basic premise of small loans being granted to the poor for self-employment projects that generate income, often with very low interest rates. Often, micro-credit programs have linked credit with skills building and education and take the form of a group-lending model, where a community shares responsibility for loan repayment. The focus on community and group methodology is useful for programs that include the distribution of health services and education. Reported loan repayment rates often exceed 96%, and most microfinancing institutions have been shown to recover their administrative costs through interest rates and user fees (Auwal, 1996).

Micro-credit programs around the world 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). Furthermore, participation in microfinance programs may help in reducing the economic and social vulnerability of its clients, acting as a structural intervention for preventing future HIV infections. Women's participation in credit program participation in Bangladesh impacted women's decision-making roles, access to financial and economic resources, led to greater social networks, greater household bargaining power compared with their husbands, and greater freedom of mobility (Pitt et al., 2003). Ashburn et al. (2008) showed that women's empowerment, as measured by the ability to control earnings from a micro-credit program in the Dominican Republic was significantly associated with HIV-related negotiation in women, including the ability to demand safer sexual practices. Increasing women's autonomy by granting greater access to public spaces and social interaction could impact HIV-related risk. Studies have shown that female participants in micro-credit programs have a lower risk of physical violence and sexual abuse (Hadi, 2000; Schuler et al., 1996). The Intervention with Microfinance for AIDS and Gender Equity (IMAGE) study, which integrates gender awareness and HIV education into a microfinance program, is currently under way in South Africa (Pronyk et al., 2005). Thus far, the intervention has been shown to reduce intimate partner violence, with no effect on the rate of unprotected sexual intercourse with a non-spousal partner or HIV incidence (Pronyk et al., 2006). Additionally, micro-credit programs may also be used to stimulate economic growth in young women to prevent entry into sex work for survival (Chase, 2004) and have been incorporated into community-level HIV prevention programs for sex workers (Rotheram-Borus et al., 2003).

Despite the beneficial outcomes of micro-credit programs, there are many limitations to this funding model, especially in the context of high HIV/AIDS burden. Firstly, HIV/AIDS has been shown to have a negative impact on microentrepreneurs, resulting in poorer loan performance and higher staff costs (Parker, 2000). Because of this, and concerns about stigma, it may not be particularly beneficial to target micro-credit programs to those already seriously burdened by HIV/AIDS. Micro-credit programs have also not been successful in reaching the extremely poor in communities who have no asset base and are not able to repay their loans in full and on time, although targeted interventions are now in place to address this issue (Ahmed et al., 2006). Although micro-credit programs are cost-effective, sustainable and easy to scale up, they can be extremely challenging to implement due to difficulties in assessing default risk, preventing moral hazard, and establishing effective regulatory frameworks and enforcement mechanisms (Donahue, 1998).

### *Cash transfers*

In developing countries with a high burden of HIV, there has been an increased focus on social protection for the poor in the form of cash transfers in the hopes of protecting the human capital of children and families. The interactions between HIV/AIDS and poverty have been devastating to families in poor countries – destabilizing their safety nets and making it difficult for them to provide the basic necessities for children in education, health, and nutrition. While many wealthy countries provide basic social assistance for the poorest individuals in their populations, developing countries 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).

Social protection programs in the form of cash transfers can be designed in many ways. The cash transfers may be unconditional (given to the recipient without any obligations) or conditional (requiring individuals who receive the transfer to participate in various services). Eligibility for cash transfers may be based on poverty level of a household, may rely on vulnerability criteria of specific individuals, or may depend on whether families consist of elderly individuals or children (Adato & Bassett, 2008). The evidence for cash transfer programs suggests that both conditional and unconditional cash transfer programs have been effective in reducing poverty and in improving children's access to education, nutrition, and health.

#### **Box 7. Oportunidades and Red de Proteccion Social**

Conditional cash transfer programs, popular in Latin and South America, have shown success. One example is Mexico's Oportunidades program (formerly known as Progresa). The cash transfer in Oportunidades comes in two ways: first, families receive a fixed amount of money, provided they access medical care; the funds are intended to be spent on food (increased amounts and better food for improved nutrition). Second, children receive educational scholarships beginning in the third grade, as long as the child attends school at least 85% of the time. Estimates of the impact of Oportunidades over a two-year period from 1997 to 1999 show a headcount poverty reduction of 17% and a reduction in the severity of poverty by about 46% (Skoufias, 2005). A recent evaluation in 2003 found that the cash transfer component of Oportunidades is associated with better outcomes in child health, growth, and development and a doubling of cash transfers was associated with a higher height-for-age among children, less obesity, less stunting, and improved cognitive development (Fernald, Gertler, & Neufeld, 2008).

The Red de Proteccion Social (RPS) (or "Social Safety Net"), was created based on the Oportunidades model and targets poor families in rural Nicaragua. RPS also allows for cash transfers provided families access educational workshops and bring their children who are under five years of age for medical check-ups. Additionally, the model includes a "school attendance transfer" every other month, provided that children ages 7-13 maintain consistent school attendance. The program supplemented per capita annual household expenditures by 18%, allowing for an increase in food expenditures and an improvement in diet. School enrollment increased by a net 17.7 percentage points and average attendance in the target population improved by 23 percentage points. RPS also helped to improve nutritional status of children under age 5 by contributing to a 5 percentage point decline in the number of children who were stunted (a decline 1.5 times the rate observed nationally between 1998 and 2001) (Maluccio & Flores, 2004).

A recent review of cash transfer programs by Lagarde, Haines, and Palmer (2007) suggests that, as Oportunidades and RPS demonstrated, monetary transfers and mandatory educational workshops have been some of the best strategies to address financial barriers for families. The review questions how effective cash transfers would be in resource-poor settings with low access to interventions and other issues such as poor quality of services. In Malawi, preliminary qualitative analysis of Concern Worldwide's Dowa Emergency Cash Transfer project, which provides direct cash transfers for poor individuals in the Dowa district, 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. Beneficiaries spent a bulk of their money on food, allowing for rates of malnourishment among children to decrease (Devereux et al., 2007).

### **3. Decentralizing services**

Decentralization of services is the key to improving access to care (Bedelu et al., 2007). This has been demonstrated in a number of contexts (Kim, 2007) and does not only pertain to HIV/AIDS. Decentralization brings much-needed services to more remote areas and in most cases improves access. Unfortunately, efforts to decentralize have not always been successful, since efforts have not always been sustained and issues such as drug and supply stock-outs, lack of supervision and ongoing training, as well as deteriorating physical infrastructure impede success unless support is maintained. However, it is clear that many populations, particularly those living in remote rural areas, will not receive essential services without decentralization. For example, the literature on PMTCT programming suggests that success would be enhanced with decentralization of services (Bedelu et al., 2007). In particular, the argument has been made that PMTCT services in rural areas should not be restricted to the district hospital and should be accessible at the clinic level (Perez et al., 2004; Manzi et al., 2005).

One issue to consider when decentralizing services is how to ensure high quality of care. As one moves out to peripheral areas in most countries, health professionals are often less available. If responsibilities that are typically assumed by health professionals are being transferred to lay health workers, it is important to consider what is technically feasible in a given context, by taking into account local levels of education, literacy, and the need for ongoing training and supervision. In addition, strategies that worked in urban centers may not be as effective in rural or other remote areas. Therefore, local health workers need to be engaged in troubleshooting any problems that arise. Such an approach is used in the Institute for Healthcare Improvement (IHI) model for quality improvement and the learning collaborative approach would be a useful tool as one decentralizes services so that personnel can develop strategies for problems encountered and share those strategies with other health care staff members who serve similar populations. This is less of a “top-down” strategy and may yield faster solutions to problems or bottlenecks occurring at the local or regional level. (Bedelu, 2007; ‘Microfinance’, 2006; ‘Task shifting’, 2008).

### **4. Community-based support and the community health worker model**

Community health workers (CHWs) are active in addressing health concerns throughout the world in both developing and developed countries. While CHW programs are often introduced in order to address a lack of trained health professionals, CHWs have also proven more effective than professionals in supporting people and communities to respond to certain health challenges, particularly those that, like HIV/AIDS, require sustained and constant efforts or disproportionately affect poor or vulnerable communities that have limited experience with health systems (Haines et al. 2007).

Haines et al.’s examination of the possible roles of CHWs in promoting child survival notes that, “Although community health workers are not a panacea for weak health systems, the evidence base, despite limitations, does suggest that they can have an important role in increasing coverage of essential interventions for child survival and other health priorities” (Haines et al. 2007). With respect to HIV/AIDS, a recent review of CHW programs in South Africa noted, “CHWs in South Africa represent the most formalized end of a continuum of community participation around HIV/AIDS, from treatment literacy training programs for people living with HIV, to members of their social networks volunteering to be TB or ART “treatment buddies”, and participation in rights-based activist networks” (Schneider, 2008).

The current and potential role for CHWs in enabling communities to provide effective care and support, for children affected by AIDS in particular, reflects this desire among communities in high burden areas to be actively engaged in the response to the AIDS epidemic.

Concern remains that CHWs are merely substandard care providers for poor and vulnerable communities. However, in recent years, a limited number of observational case-management and randomized controlled trials have been conducted to document the effectiveness of the CHW-based approach to

provision of health education and care. However, most of this research has been conducted by formal health institutions, either public or private, that have affiliated CHW programs. Research by community organizations is even more limited and would be an important topic for future academic investigation. The findings of the studies nonetheless shed light on the strengths of CHW programs as well as some of the potential pitfalls and weaknesses.

Properly trained and adequately supported CHWs can be as effective as health professionals in providing basic care for endemic diseases with straightforward treatment, as well as for providing prevention services and maintenance care for people with chronic illnesses. None of the studies we examined showed the CHWs to provide substandard 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 with clients compared with clinic clients. Further, 95% of the CHWs' clients reported themselves satisfied or highly satisfied with the services provided (Stanback, 2007). In another study, in Zaire, malaria prevalence and incidence fell 50% in the CHW intervention area compared with the control area (Delacollette, 1996).

The presence of CHWs in the communities they serve is one of their key advantages. CHW strategies have been suggested for use in rural areas or other 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, 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 to malaria drugs (Onwujekwe, 2007).

CHWs can also take the time to visit people in their homes, a strategy that has been shown to be effective in both identifying, and supporting care for, people with various health issues. For example, a program in Bangladesh engaged CHWs in active home-visit surveillance for pregnancy and illness among neonates – evaluations of the program showed marked improvements in knowledge among families on danger signs and increased care-seeking from qualified providers upon referral from the CHWs (Bari, 2006).

Recent technological developments have also expanded the potential capacity of CHWs. Mobile phones, PDA's and community access to internet enable CHWs to receive updated information, regularly communicate with program monitors and summon medical or legal support when their skills are not sufficient to address a health or social problem they encounter.

In situations where CHWs are programmatically effective, cost-effectiveness is often another proven benefit. In Bangladesh and Pakistan, studies have compared Directly Observed Therapy (DOT) for TB supported by health professionals and CHWs. In Bangladesh the cure rates were essentially equal between the CHW and government groups, but the CHW program was significantly less expensive. The researchers concluded: "With the same budget, the [CHW] program could cure three TB patients for every two in the government program" (Islam, 2002). In Ecuador, a study was conducted to compare a CHW strategy to a district hospital-based strategy to promote coverage of immunization and concluded "in order to maximize the cost-effectiveness of immunization, it is important to involve community participation in both planning and implementation" (San Sebastián, 2001).

The role of CHWs can extend beyond specific disease treatment as well; researchers in Australia studied an intervention to address postpartum depression among women in rural areas, and concluded that therapeutic group work could effectively be conducted by community health workers (Craig, 2005). In their study on group-based interpersonal psychotherapy (IPT) for depression among adults in 30 villages in an impoverished area of Uganda that had been severely affected by the HIV epidemic, Bolton et al (2003) demonstrated the efficacy of psychotherapy using local persons trained in IPT. While this study—the first published controlled clinical trial of a psychological intervention in resource-poor sub-Saharan Africa—did not specifically target HIV-related depression, the findings suggest that it is feasible to

effectively integrate trained community health workers in providing psychosocial support to families and communities broadly affected by HIV-related social stressors.

There are of course potential caveats in using CHW strategies, and these pitfalls need to be addressed in the design of new interventions and carefully monitored for in ongoing follow up. Among the weaknesses identified in studies and evaluations are issues inherent in clients' preferences for health professionals and distrust of lay CHWs. Further, CHWs' specialization—to address only particular diseases or issues—and their need to earn an income as well as provide services, can undermine their potential effectiveness. In El Salvador, in communities where physical and financial access to health care is generally good, researchers found that the community placed "limited value" on community health workers, instead preferring higher cost private care because they perceived a higher probability of successful treatment and considered health facilities to provide "one stop shopping." (Lewis, 2004)

CHW training usually addresses particular diseases or health issues, enabling them to carry out their work with limited support but creates challenges if communities do not recognize them either as addressing important concerns or as efficient providers of an array of health care services. The study that documented the effectiveness of CHWs in addressing malaria in Zaire in the early 1990s nevertheless noted that "non-comprehensiveness of CHWs care and their ambiguous position in the health care system created problems that compromise the sustainability of the situation" (Delacollette, 1996). In a dengue control and prevention program in Brazil, the vector control prevention teams were not considered by the community to be important. The researchers concluded that "the program's vertical structure" limited its usefulness (Chiaravallotti, 2007).

Finally, all of these studies have an assumed level of quality among the CHWs. While rarely documented, adequate and constantly updated training is also key to successful implementation of health interventions by community health workers. Elements of a successful CHW strategy include the following:

- High-quality training and regular refresher or additional training
- Specialization in a few areas but the ability to address and refer for key health concerns of the community
- Awareness within the community of the services CHWs provide
- Strong linkages and referral system between CHWs and formal health care institutions
- Provision of payment or meaningful incentives to ensure CHWs prioritize the needs of their patients and make a long-term commitment to the program.

In conclusion, CHW-based health care and disease prevention strategies have proven potential to provide high-quality, acceptable, and cost-effective health services.

## **5. Family-centered services**

Children affected with HIV/AIDS cannot be treated as if they are independent of the context of the family and community surrounding them. Stable family environments are crucial to the healthy psychological development of children (Adam, 2004). The role of the mother has long been identified as crucial for child health, nutrition and survival, and there is a growing acknowledgement about the roles of fathers and addressing their needs and concerns (Taha et al., 1996). A model of family-centered services recognizes the essential role of the family unit, builds upon their strengths, helps families to cope with the challenges of living with HIV/AIDS and seeks to fully involve them in all aspects of their child's health, learning and development. This model for implementation has been shown to be associated with positive outcomes in child health and education (Concepcion, 2007). In the context of HIV/AIDS, families may offer irreplaceable strengths, but may also face unique challenges as they care for children affected by HIV/AIDS. This may be especially true for families who have to deal with problems of stigma, discrimination, disclosure, grief, and bereavement, which influence family functioning and the well-being of the child (Lewis, Wesley & Haiken, 1996). Furthermore, the impact of HIV/AIDS on the family unit in

terms of caring for ill family members, dealing with the devastating social and economic effects associated with the inability to work or attend school, and costs of health care and treatment make the need for family-centered services imperative. An effective model for family centered care can integrate programs in HIV prevention, education and nutrition, which may help ensure better access and retention of services as well as act as a gateway to family-based HIV care and treatment (Abrams, Myer, Rosenfield and El-Sadr, 2007).

HIV prevention in pregnancy and family approaches to child care have been identified as key areas in which strengthening family-centered approaches can be beneficial for the needs of children affected by HIV/AIDS (Sherr, 2008). HIV prevention in pregnancy has inherent benefits for children, and the use of PMTCT-services as a gateway for testing and treatment of mothers can act as a way to sustain families. Current limitations to achieving a family-focus in this area include the low uptake in HIV-testing and provision of ART to HIV-infected mothers in many high prevalence countries, as well as the narrow focus on mothers and the lack of HIV testing and treatment services offered to fathers (Sherr, 2008). Integrating HIV-testing services for couples and families could offer a better chance of ensuring social acceptability and reducing stigma, and addressing fathers' HIV-status may balance out gender biases within couples and achieve improvements in access to health care, HIV prevention, family planning and condom use (Weinhardt et al., 1999; Arthur et al., 2007).

While the engagement of male partners in PMTCT services has been recognized as a significant way to support and influence women to be tested for HIV, return for results, take ARTs, and practice safe infant feeding methods, males' knowledge of MTCT tends to be low (Asiimwe, Tumwesigye and Bajunirwe, 2004) and PMTCT programs have done little to involve men (Rutenberg et al., 2002). A study by Brou et al. (2007) found that more than half of HIV-positive women participating in a PMTCT study in Côte d'Ivoire did not disclose their test result with their partner and approximately 18% of those who disclosed their positive results experienced negative consequences, including blame, ending of relationships, and in one case, violence. Only about 20% of partners were tested for HIV, potentially due to the lack of couple HIV counseling and testing, the need for males to personally and actively request HIV testing, and the belief that couples cannot be serodiscordant. These divergent results may be addressed with more integrated PMTCT services that involve men in the process. That said, however, there is a lack of sufficient or adequate PMTCT information targeted towards men (Munene and Gathenya 2004), and there should be efforts to make such information more accessible to males, for example by directly providing the information outside antenatal clinic settings (Horizons, 2003), including men as active leaders in implementing PMTCT programs, and using older males or gender-specific groups to impart information (Burke et al., 2004). Recognizing that male partners tend not to accompany women to prenatal visits and are often unwilling to take time off work for clinic visits, The AIDS Support Organization (TASO) in Uganda initiated special sessions on Saturdays devoted to testing men. Another method TASO suggests to ensure that men undergo testing is to perform testing on male partners at the time when they accompany their wives to the clinic at the time of delivery (Andrew Kiboneka, TASO, personal communication).

Strengthening family-centered approaches in child care can also impact the cognitive, physical, emotional and mental development of children. Many factors affecting the stability and integrity of the family, including treatment of HIV-infected children, parental/caregiver death, institutionalized care, mobility and separation, schooling, nutrition, bereavement, cognitive development and parental mental states can all be addressed using a family-centered approach (Sherr, 2008). For example, early childhood development programs that included training of mothers in childrearing practices and stimulation exercises generally show significant positive effects on the cognitive and nutritional outcomes of children (Grantham-McGregor et al., 1991; Powell et al., 2004; Hamadani et al., 2006; Eickmann et al., 2003). Implementing family-centered approaches can also address barriers to school attendance within families (such as the need to contribute economically to household or take care of ill family members), and help ensure the mental well-being of parents, especially those suffering from postpartum depression, which has been shown to exert a negative influence on child development (Murray et al., 1996). Despite the knowledge

that the family unit can be a significant resource to help children cope with the HIV epidemic, there have been very few policy initiatives or international strategies in the global response to HIV/AIDS (Heymann et al., 2008). More evidence on families, children, and family-centered models needs to be done in order to implement appropriate and effective interventions for children affected with HIV/AIDS.

## **6. Strengthening the human resources infrastructure**

At the 1978 Alma Ata Conference WHO and UNICEF launched the primary health care movement, which has since become known as the “horizontal approach” to interventions, focusing on improving provision and access to primary health services as part of an overall strategy of health promotion. At the same time many health promotion interventions, such as National Immunization Days (NIDs) have taken a “vertical” or disease-specific approach to implementation, often focusing funding and human resources exclusively on addressing one health issue in order to expedite results. In the case of HIV/AIDS prevention, treatment and care, both a functioning health system and more broadly strong education and sanitation infrastructures are essential to effective interventions. The 2000 World Health Report defined health systems as *“all the activities whose primary purpose is to promote, restore or maintain health”* (World Health Report, 2000). Health systems include professional health workers, as well as traditional healers and home-based caregivers. Other resources, such as sanitation and schools are not considered part of a health system, but rather systems that feed into its effectiveness.

As suggested throughout this paper as well as papers from other JLICA learning groups, both education and primary health care play potentially important roles in preventing future cases of HIV and maintaining the health of people living with HIV and their families. However, many countries still lack the necessary education and primary health care infrastructure, including schools, community health clinics, and human resources. One of the most serious constraints to health systems in high HIV prevalence countries is the lack of trained health workers. According to the WHO, while sub-Saharan Africa has 11 percent of the world’s population and 24 percent of the global burden of disease, it has only 3 percent of the world’s health workers (The world health report 2006c – Working together for health. Geneva, World Health Organization.) The WHO has issued a series of recommendations to increase the number of health workers in developing countries, including more direct investment in the training and support of health workers, access to effective HIV prevention and treatment strategies for health workers, and approaches to encourage more women to enter the health services field (WHO, 2006c).

## **IV. Conclusions and guidelines for action to advance access to services and improve health outcomes among children affected by HIV/AIDS**

In conclusion, the available evidence suggests that key implementation gaps and access barriers are known. The challenge is to define and prioritize specific activities that will effect prompt and effective long-term change to improve children’s lives and health. In addition to the “cases” highlighted in this paper, the members of LG3 also identified several other discrete local activities that may enhance practical applications:

1. First, it is vital to build evaluation into each activity from the outset. The evaluation plan must be clear and deliberate, and engage all participants on the team.
2. Second, provider-initiated testing and counseling (PITC) may be even more effective when practiced in a context that acknowledges both rights and responsibilities, including the responsibilities of health care providers to ensure and deliver effective HIV treatment (ART) to everyone who agrees to be tested. Promotion of universal access to ART coupled with PITC may have a significant impact on the HIV epidemic.
3. Third, plan innovative and practical ways to test male partners within a setting that addresses cultural and work expectations for men’s health-related behaviors and also provides family support as needed. This might include weekend clinics designed for men or testing of male partners when they come with their wives at delivery.

4. Fourth, ECD educators can use the public space of PMTCT clinics, when children accompany mothers to the clinics, as one part of integrating ECD with PMTCT services; in such settings their role as educators can be directly observed, using the natural interests of children to draw parents into participation in more extensive formal ECD activities.

As broad guidelines for action, LG3 offers a summary of specific “next-steps,” outlined below. These are organized here by short-term, medium-term, and long-term strategies:

***Short-term strategies:***

1. Existing funding must be more effectively targeted to meet the needs of those for whom it is intended. The greatest immediate short-term need is to support existing effective community initiatives that reflect the successful practices outlined here, building on their strengths and enabling long-term continuity and promoting successful scale-up. Funding may be most effective when recipients have full agency to determine how it is used and there is full transparency about disbursement in ongoing open dialogue between funders and local community service providers.
2. Equally important is the application of innovative funding strategies at both the macro- and the micro-level. Although current financing must be used more efficiently and effectively, available funds remain insufficient to meet the needs of all children affected by HIV/AIDS. Innovative strategies exist that offer specific models for change. Successful economic strategies depend on political will for investment and management of macro-level financing to increase and sustain support for children affected by HIV. National and local governments as well as community and family leaders must have agency in planning such strategies and their application to a specific local situation.
3. Existing programs can benefit by recognizing the existing gap between scientific knowledge and their specific implementation (the “know-do gap”) and using this knowledge as an opportunity to design change that can directly inform policy and program development.

***Medium-term strategies:***

1. Innovative and adaptable strategies need to be further developed and employed to bridge these gaps in services and address persistent bottlenecks. Local community health workers (CHWs) and other community representatives, including youth, must be part of the development and leadership of successful strategies.
2. Delivery of services and funding needs to focus on an enriched understanding of “value” that is defined by positive health outcomes per dollar spent. Local evaluation is necessary to identify the value of a program as well as the remaining gaps. Local health workers and community representatives, including youth, can play a critical and collaborative role in establishing this perspective at each site and in each program.
3. Apply new models for integrated service delivery that can ensure continuity of care and maximize quality, with a focus on overall health outcomes of children and families, rather than the impact on a specific disease.
4. Investment in the health care infrastructure is essential at all levels, including the physical infrastructure, addressing such questions as: Does the plumbing work? Is electricity reliable? How many computers are needed, what database is most effective, and how will data sharing happen? How will patients move between clinics without loss to follow-up? Similarly, there must be investment in the availability of health care personnel and advancements in laboratory capacity. The infrastructure must also include practical investment in making decentralized care

beyond district hospitals into remote rural areas as an essential element of increasing access to care; this will include building or refurbishing clinics in rural areas, offering more mobile clinics, funding transport vehicles (for supplies and emergency care), training drivers, and ensuring that vehicles contain adequate space for all materials needed in such delivery of rural services.

5. Programs must address science-based issues that promote gender equity. For example, increasing educational access for girls in both primary and secondary schooling may equip children and adolescents with both self-confidence and knowledge to make informed choices about health and potentially high risk behaviors. Increasing access to education for girls requires comprehensive community and health-based support that might include cash transfers to female heads of households who will promote education, provision of school transport and supplies, strengthening adolescent health care programs, supporting teachers, and addressing issues of sexual risk and health/discrimination issues that might occur in the educational setting.
6. Enhance the capacity of health workers through ongoing training, re-training, supervision, and support (e.g. training in supply chain management to prevent stock-outs)

***Long-term strategies:***

1. Inadequate human resources for health (i.e. doctors (including pediatricians), nurses, pharmacists, laboratory technicians, and other health care workers) is a key bottleneck, and strategies to address this are critical for advancing access to care; one strategy that can address this involves expanding access to peer-outreach educators and CHWs. Incentives and/or remuneration may draw from innovative funding sources. Such incentives and/or remuneration should be easy to process, reliable and consistent, and adequate to motivate health workers by ensuring that their own basic needs are met.
2. Evaluate existing follow-up plans, identify what works or does not work, and invest in improving follow-up care and longitudinal observation of patients, since this is known to improve outcomes. Innovative and aggressive attention to issues that contribute to loss to follow-up are vital if the goal of long-term health outcome (“value”) is to be met.
3. Offer integrated family-centered and community-based services. Involve family and community members in discussing HIV-related stigma and planning practical ways to reduce discrimination. Build in educational programs that maximize access to care by discussing stigma and discrimination by and with health care workers; build relevant support into employee groups and retraining initiatives.
4. There is a persistent need for access to the most basic services necessary for human survival—eg. clean water, sanitation, food—as well as education, including early childhood development interventions. These are essential elements of maximizing children’s health and psychosocial outcomes. Involve communities in improving these services and integrate them into maternal, neonatal, PMTCT, and pediatric medical care. Providing food as part of the health care delivery system for HIV-affected families and children should never be considered a luxury; including such elements in programmatic planning can also improve adherence and minimize loss to follow-up.
5. Engage families, communities and governments in defining specific location-appropriate methods for increasing access to HIV prevention efforts, including PMTCT, HIV prevention education, routine HIV testing, and instituting broader structural changes (e.g. increased access to education, social protection, economic opportunities, and addressing gender inequalities).
6. Psychosocial interventions and community-based support may promote treatment adherence, self-care, HIV prevention, and psychosocial well-being among HIV-infected and affected youth

and their families. Establish psychosocial support groups to address issues such as HIV-related stigma, depression, isolation, and HIV-related social crises, such as domestic violence. Investment in child protection services would address situations of child abuse, which in turn could have a long-term impact on HIV prevention. Such care should be strengthened and integrated within the community health system as well as educational opportunities; Community health workers should be trained to recognize the need for such interventions and how to address them. Promote local networking of HIV-positive mothers.

7. A focus on “value” and health outcomes, not simply the “process” of providing services, will be an important feature of advancing access to care and quality of services for children affected by HIV/AIDS, their families, and their communities.

In conclusion, this paper argues that change is possible. Increasing access to health care and related services that overcomes implementation gaps and barriers is a realistic goal for global and community resources, working together. A dedicated, integrated action plan that sensitively applies all three of these approach strategies can promote an effective response to the HIV/AIDS crisis for the world’s poorest children and their families.

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