



JLICA 

JOINT LEARNING INITIATIVE
ON CHILDREN AND HIV/AIDS



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The effect of HIV/AIDS on young people reaches far beyond the millions of children infected, orphaned or caring for sick parents. Widening circles of children - particularly in sub-Saharan Africa - face increased vulnerability as HIV/AIDS disrupts food security, undermines community capacity, saps local and national economies and decimates the health and education workforce.

For too long, children have lived at the margins of the response to HIV/AIDS. The Joint Learning Initiative on Children and HIV/AIDS (JLICA) was founded in October, 2006, to promote a new focus on children's wellbeing - not only as a humanitarian imperative, but also as a crucial step in efforts to reverse the larger HIV/AIDS epidemic worldwide.

JLICA is a cross-sectoral, multidisciplinary and independent collaborative that engages policymakers, practitioners, community leaders, activists and researchers from across the natural and social sciences. Our objective is to mobilize the evidence base, encourage fresh thinking and disseminate the practical operational knowledge that will lead to the most effective programs and policies to protect and support children. Our guiding vision is a world in which children affected by HIV/AIDS obtain the protection and support they need to survive and flourish.

JLICA produces reports and analyses designed to influence and improve programmatic responses in the field; sponsors workshops at which policymakers and practitioners can learn from one another and build foundations for sustained collaboration; and operates a communications platform supporting evidence-based action for affected children. JLICA does not seek to perpetuate itself or carve a permanent niche in the HIV/AIDS research landscape. Instead, it aims to get a specific job done by a defined target date.

In a world scarred by HIV/AIDS, JLICA seeks to make common cause with all people committed to helping children flourish. On behalf of the individuals and organizations involved in this vital work, and the tens of millions of children affected by the epidemic, we thank you for your work and interest in JLICA, and ask for your ongoing support of innovative, effective approaches to halt the spread and reduce the impact of HIV/AIDS worldwide.

Co-Chairs, Joint Learning Initiative on Children and HIV/AIDS



Agnes Binagwaho
Executive Secretary of Rwanda's
National Commission to Fight AIDS



Peter Bell
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HIV/AIDS has affected the lives of tens of millions of children and adolescents and is placing increasing numbers at risk.

Globally, about one in six AIDS deaths is a child. Yet, the impact of HIV/AIDS on children goes far beyond those living with HIV themselves. In sub-Saharan Africa and parts of South Asia, virtually every child has been affected as HIV/AIDS disrupts families, communities, schools, health services, livelihoods and economies – impacting children's lives today, and into the future.

Of the fifteen million children who have lost at least one parent to AIDS, many confront stigma, exploitation and abuse, along with reduced access to basic care, adequate food and schooling. And, in a cruel cycle, young people orphaned by AIDS or other causes, particularly girls, can become more vulnerable to HIV themselves due to harassment, family disruption and severe economic pressures stemming from the epidemic.

If we are to reverse the cycles that keep the AIDS epidemic growing, we must work together to reduce the vulnerability of children.

While the global response to AIDS accelerates, children are being left behind.

While increased efforts to address HIV in developing countries are having some positive impact, children, their families and caregivers continue to receive far too little attention:

- New resources to combat HIV are not being used to respond to the needs of children and families
- Simple, available technologies to prevent HIV among children are poorly implemented, and efforts to develop and provide AIDS treatment for children lag far behind those for adults
- Action to reduce the social and economic impacts of AIDS on young people languish at the bottom of government priorities

Today, 25 years into the epidemic, a second generation of young people is growing up with their life prospects dimmed by the impact of AIDS.



- **2.3 million children were living with HIV, and more than half a million children became newly infected with HIV in 2006¹**
- **Approximately 380,000 of the 2.9 million people who died of AIDS in 2006 were children. A thousand children die every day.² Most are under five years old³**
- **Child-survival rates are worsening in countries where remarkable improvements had only recently been reported. In Botswana, for example, child mortality rates have nearly doubled since 1990⁴**

Families and communities are at the heart of the AIDS response – but governments must provide the services and support that families and communities need to survive.

In regions where HIV/AIDS has had the greatest impact, the burden of caring for millions of AIDS-affected children falls almost exclusively on families, including orphan-headed households, and communities. Today, some 90% of assistance to children affected by HIV/AIDS comes from extended family and near neighbors – governments and other institutions contribute almost nothing.

Families and communities care best for children; but governments and other institutions must do their part to help family members and local networks survive and support children in the long-term. States have an obligation to: (1) strengthen key services such as education, health care and social assistance to help children, their families and communities cope with vulnerability; and (2) strengthen supports to caregivers to meet children's daily economic, relational and developmental needs.

Today, families and communities bear virtually the entire burden of caring for affected children, with negligible help from governments and international agencies. The lack of support places increasing strains on communities, causes destitution for families, and jeopardizes the health, wellbeing and futures of tens of millions of children.

1. UNAIDS, 2006.

2. Ibid.

3. Newell M-L et al (2004, 2nd October), 'Mortality of infected and uninfected infants born to HIV-infected mothers in Africa: a pooled analysis', *The Lancet* 364 (9441).

4. UNICEF, 2004.

Close to half of all families in southern Africa have someone living with HIV or AIDS or a person who has died from AIDS-related illness.



The Joint Learning Initiative on Children and HIV/AIDS (JLICA) believes it is past time for new approaches that match the scale and gravity of the crisis.

JLICA is an action-oriented, global collaborative of researchers, practitioners, policymakers and people affected by AIDS that collects, analyzes and promotes the best evidence-based strategies to reduce the impact of HIV on children, families and communities. JLICA's interdisciplinary Learning Groups work to promote sound, evidence-based policies and to expose and overcome the barriers that impede action on the most important issues affecting children, their families and communities.

Today, effective responses to the impact of HIV on children and young people are hindered by:

- Uncertainty about what policies and interventions work best
- Major gaps in the capacity of governments and institutions to implement effective national programs to help children, their families and communities
- Disagreement about how to best build and sustain health systems, expand education and ensure social protection for children
- A concentration of funding in capital cities, which is often not where it is needed most
- Lack of coordination among governments, multilaterals, NGOs, foundations, donors, academic institutions, faith-based organizations, and community groups

JLICA emerged from an overwhelming consensus among experts and front line workers alike that the global response to AIDS is leaving children, their families and communities behind. Despite expanding responses to the epidemic, prevention and treatment efforts still largely overlook the needs of young people. The burdens of care and upbringing of affected children are left almost exclusively with affected families and communities.”

– Agnes Binagwaho, M.D., Rwandan pediatrician and JLICA co-chair

JLICA reviews existing research; conducts strategic studies in under-researched areas; organizes public forums and reports; and disseminates best practices to stimulate innovative thinking and problem-solving on behalf of children affected by HIV/AIDS. JLICA promotes effective, innovative policies and programs to:

- Strengthen government health, education and social services for children, and coordination between government and non-governmental organizations
- Improve the economic and social capacity of affected families and communities



- Increase access to maternal and pediatric HIV treatment and care
- Improve prevention efforts to reduce adolescent vulnerability to HIV
- Broaden the response to children’s needs beyond the narrow definition of “orphans and vulnerable children”
- Expose misinformation, lack of resources or bottlenecks that slow effective responses, and develop strategies to overcome them

JLICA envisions a world in which children affected by HIV can survive and flourish, and in which families and communities are supported to protect and care for children.

How JLICA works

JLICA is a time-limited, results-focused alliance of experts united in an intensive two-year effort to deliver the best evidence on what works to help children affected by HIV/AIDS. JLICA:

- **Mobilizes and generates evidence:** JLICA collects and assesses scientific evidence on operational and policy issues related to children and HIV/AIDS, and documents experiential knowledge emerging from communities of practice
- **Facilitates linkages:** JLICA connects people and ideas, facilitating collaboration and coordination across the many individuals, groups and communities of knowledge and practice working to mitigate the impact of HIV/AIDS on children
- **Expands space for new thinking:** JLICA stimulates innovative thinking and problem solving by promoting interaction between experts in a variety of fields
- **Advances action:** JLICA formulates clear recommendations on priority actions for governments and other stakeholders, and works with partners to accelerate their implementation



Learning Groups

Each of JLICA's four thematic Learning Groups (LGs) focuses on specific priority areas for action.



LG 1: Strengthening Families

Families and communities are the mainstay of children's protection in the face of the AIDS epidemic. LG 1 focuses on the challenge of how to strengthen the capacity of families to provide better care for children, examining questions such as:

- How can HIV/AIDS prevention, treatment, care and support programs help to strengthen families?
- Are cash transfers feasible social protection strategies for families in extremely resource-constrained societies?
- What are the likely economic and social costs if countries fail to support families?

LG 2: Strengthening Community and Civil Society Response

Community responses to the impacts of HIV/AIDS on children are proliferating, yet remain largely self-financed and undocumented. The need for technical and financial support for these responses has received too little attention from governments, international organizations and NGOs. LG 2 seeks to define how external organizations can best provide support for community responses, and asks:

- What initiatives are being undertaken by communities to support children, and which programs and policies work best to improve children's lives in specific settings?
- How important is child/youth participation in community-level efforts to support affected children?
- What data are collected by communities supporting vulnerable children, and how can community-based management information systems be improved?

LG 3: Expanding Access to Services and Protecting Human Rights

Effective delivery of health, education and social protection services is essential to improving survival and quality of life for children affected by HIV/AIDS, and should strengthen families and communities and nurture local autonomy. Yet, service delivery in heavily burdened settings faces numerous obstacles. LG 3 addresses these questions:

- What services are currently available to support children affected by HIV/AIDS, their families and communities; what obstacles slow the effective implementation of services; and how can they be overcome?
- How should prevention of mother-to-child transmission (PMTCT+) services be linked with early child development interventions?
- How can services be effectively integrated to address children's needs, while also strengthening the primary response role of families and communities?

LG 3 is also supporting a practitioner-focused Learning Collaborative on strengthening child survival at rural health centers in three districts in Rwanda, to test innovative service delivery strategies that may reduce HIV infections in children while improving other aspects of children's and families' health.

LG 4: Social and Economic Policies

LG4 documents the major policy revisions and substantial new resources that will be needed for governments and international institutions to adopt and implement effective social and economic policies for children on the scale necessary. LG4 also investigates HIV prevention among adolescents and older children, with a focus on gender issues, sexuality and the determinants of HIV exposure. Key questions being examined by LG4 include:

- What political factors influence the adoption of good policies?
- What are the resource implications of achieving social protection policies and programs for children, and how can policies be designed to maximize the opportunity for success?
- What role do gender and sexuality play in developing effective HIV prevention programs and policies for young people?



JLICA Timeline and Deliverables

JLICA was launched in October 2006. Draft versions of Learning Group research papers will begin to be posted on JLICA's website (jlica.org) for public review and comment in Fall, 2007. Learning Group synthesis reports will be completed in Spring, 2008, and the final comprehensive JLICA report will be released in December 2008.

JLICA will also advocate for a major focus on children at the XVI International AIDS Conference in Mexico City in August 2008, and JLICA evidence and recommendations will feed into the strategic directions for action on children affected by HIV/AIDS emerging from the international Inter-Agency Task Team (IATT) and the 2008 UNICEF-sponsored Global Partners Forum on Children and HIV/AIDS.



September 2007

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JLICA founding partners are the Bernard van Leer Foundation; François-Xavier Bagnoud International, the Human Sciences Research Council and UNICEF. Other JLICA contributors include the UK Department for International Development (DFID), the Government of the Netherlands, Irish AID, the FXB Center for Health and Human Rights at Harvard University, which hosts the JLICA Secretariat, and the Rockefeller Brothers Fund.

JLICA's institutional partners include CARE; the Coalition for Children Affected by HIV/AIDS (CCABA); Elizabeth Glaser Pediatric AIDS Foundation; the Inter-Agency Task Team on Children and HIV/AIDS (IATT); Family AIDS Caring Trust (FACT), Zimbabwe; Family Health International (FHI); the Human Sciences Research Council (HSRC), South Africa; Partners In Health; Protecting Families against AIDS (PREFA), Uganda; RENEWAL project of the International Food Policy Research Institute (IFPRI); Research On Poverty Alleviation (REPOA) Tanzania; the Social Science Research Council (SSRC), New York; The AIDS Service Organization (TASO), Uganda; and UNAIDS.