

# The Joint Learning Initiative on Children and HIV/AIDS

JLIC 



# Responding to the Deepening Impact of HIV



# on Children and Young People

HIV/AIDS has affected the lives of tens of millions of children and adolescents and is placing millions more at risk. More than two million children were living with HIV in 2007, and over a thousand children are newly infected with HIV every day.<sup>1</sup> In the most severely affected regions of the world, the impact of the epidemic is measured not only in individual lives, but also in the disruption it causes to families, communities, schools, health services, livelihoods and economies — disruptions that have profound consequences for the life chances of children.

While the global fight against HIV has changed the world's expectations of what concerted public health efforts can achieve, the response has short-changed children.

Families, many living in extreme poverty, continue to care for children affected by HIV and AIDS with little or no external assistance.

**“The response to HIV/AIDS cannot be effective in the long-term if it does not respond squarely to the impact on children.**

—Peter Bell, Senior Research Fellow, Hauser Center for Nonprofit Organizations, Harvard University; President Emeritus, CARE USA; and JLICA Co-Chair

Community responses that backstop families are similarly overlooked. Together, families and communities bear 90% of the financial cost of caring for the affected children.

While political commitment and resources have increased, governments in most countries hard-hit by HIV and AIDS have yet to implement responses commensurate with the impact of the epidemic on children and families.

<sup>1</sup> UNAIDS, *Report on the Global AIDS Epidemic*, 2008.



### **The Joint Learning Initiative on Children and HIV/AIDS (JLICA)**

The Joint Learning Initiative on Children and HIV/AIDS (JLICA) is an independent, interdisciplinary, time-limited network of researchers, policy-makers, practitioners, community leaders, activists, and people living with HIV dedicated to improving the well-being of children, families and communities affected by HIV and AIDS.

Over its two-year programme of action, JLICA has mobilized evidence, encouraged fresh thinking, and disseminated practical knowledge on how to protect and support children affected by HIV and AIDS. In collaboration with the many

dedicated and effective organizations addressing the needs of children, JLICA provides an independent analysis of what is working, and what needs to change, in the global response to the impact of HIV and AIDS on young people.

Launched in October 2006, JLICA includes some 50 core participants from a dozen countries, linked to a stakeholder group of several thousand, most of whom live and work in developing countries.

JLICA is led by global Co-Chairs Agnès Binagwaho, former head of Rwanda's National AIDS Control Commission, and newly appointed Permanent Secretary of Health, and Peter Bell, President Emeritus of CARE USA.



**JLICA's programme of research and analysis is conducted by four thematic Learning Groups:**

**JLICA Learning Group 1, Strengthening Families,** is chaired by Linda Richter (Human Sciences Research Council, South Africa) and Lorraine Sherr (University College London).

**Learning Group 2, Community Action,** is chaired by Geoff Foster (Family AIDS Caring Trust, Zimbabwe) and Madhu Deshmukh (CARE USA).

**Learning Group 3, Expanding Access to Services and Protecting Human Rights,** is chaired by Jim Yong Kim (François-Xavier Bagnoud Center for Health and Human Rights, Harvard University) and Lydia Mungherera (Mama's Club and The AIDS Support Organization, Uganda).

**Learning Group 4, Social and Economic Policies,** is chaired by Alex de Waal (Social Science Research Council, New York City) and Masuma Mamdani (Research on Poverty Alleviation Organization, Tanzania).

JLICA is supported by Executive Co-Directors Alayne Adams and Alec Irwin, and Project Manager Kavitha Nallathambi.



# Directions for Action

JLICA research has identified the following priority directions for policies to support and protect children affected by HIV and AIDS:

## **1. Improve children's health and life chances by redirecting policies and programmes to support children affected by HIV and AIDS within the context of their families.**

In hard-hit countries, some 95% of affected children, including those identified as having lost one or both parents to the disease, continue to live within their extended family. Yet current responses have primarily targeted children in isolation from the families on whom they rely for care and support. JLICA research highlights effective strategies to improve outcomes for children while reinforcing the caring capacities of families. Directions for action include:

- Keeping children in families by promoting care within the extended family and community instead of orphanages, except as a last resort
- Keeping families intact by expanding access to AIDS treatment for children and adults through family treatment models
- Using family-centred approaches to strengthen the prevention of transmission of HIV from parents to children

## **2. Strengthen community action to support children and families affected by HIV and AIDS.**

Local networks and community organizations provide the first line of support to families and children affected by HIV and AIDS. Today, increasing opportunities for outside partnerships and resources are available to strengthen community-based efforts — but rigid application procedures and monitoring requirements impede local engagement in decision-making.

- Based on innovative research that explores how external actors and resources affect communities, JLICA recommends the creation of government-led national frameworks for collaboration between outside agencies and community groups. These frameworks should be linked to district-level coordination mechanisms and improved strategies for resource tracking.

### **3. Use national social protection policies as a critical lever to help families affected by HIV and AIDS provide care and protection for children.**

JLICA research has demonstrated that poverty severely constrains families' capacity to protect children against the effects of HIV and AIDS.

- National social protection policies are the best tools to reduce poverty and improve living conditions and futures for very vulnerable families affected by HIV and AIDS.

### **4. In many settings, direct income transfers will be the most effective and efficient option to improve outcomes immediately for vulnerable families and children.**

There is a range of social protection policy options that can benefit children affected by HIV and AIDS. Choices among policies will depend on national contexts and national government priorities.

- A systematic review by JLICA concludes that government-led income transfers to the poorest families show efficacy as a 'leading-edge' intervention. Income transfers can rapidly improve the lives of very vulnerable children and families in the context of HIV and AIDS, while laying foundations for a more comprehensive national social protection agenda.

### **5. Health, education and social welfare services work best for children when provided through integrated, family-centred programmes using community-based delivery models.**

As income transfers and other social protection policies roll out, they will stimulate demand for services that benefit children, above all in health care, education and social welfare. Countries must be prepared to meet this rising demand with more effective service delivery.

- JLICA research shows that programmes yield the best results for children when they adopt integrated intervention strategies providing a range of services to the whole family.
- JLICA recommends that countries roll out family-centred HIV and AIDS services within a community-based, primary health care model. This model should integrate nutrition, education and social support and confront the dual epidemics of HIV and TB.
- Countries can accelerate the roll-out of integrated services by using community health workers and community workers from other sectors who are well trained, supervised and appropriately compensated.



“JLICA’s focused programme of investigation and advocacy provides the information and evidence needed to significantly improve the global response to HIV and young people.”

— Agnès Binagwaho, MD, Permanent Secretary of Health,  
Republic of Rwanda and JLICA Co-Chair



# Moving Forward with JLICA's Recommendations

JLICA's detailed policy recommendations will be formally released at the end of the Initiative's mandate in early 2009. Even before the publication of its final report, however, JLICA's key findings have been enthusiastically received in global and national policy circles.

While rates of HIV prevalence are stabilizing, the long-wave impacts of the epidemic will resonate for generations to come. JLICA's evidence-based recommendations provide promising new directions for global and national policies and programmes that address the needs of vulnerable children in the context of their families and communities.

We invite readers to consult the more than 50 research reports and reviews produced by the initiative over its two-year programme at <http://www.jlica.org>, and to join us in ensuring that evidence-based solutions are translated into action for children, their families and communities.

# Our Partners

JLICA founding partners include:

- Association François-Xavier Bagnoud — FXB International
- Bernard van Leer Foundation
- Global Equity Initiative, Harvard University
- UNICEF

Other JLICA contributors include:

- Bill & Melinda Gates Foundation
- François-Xavier Bagnoud Center for Health and Human Rights, Harvard University
- Irish Aid
- Netherlands Ministry of Foreign Affairs
- Rockefeller Brothers Fund
- UK Department for International Development

JLICA institutional partners include:

- CARE USA
- Christian Children's Fund
- Coalition for Children Affected by HIV/AIDS
- Elizabeth Glaser Pediatric AIDS Foundation
- Inter-Agency Task Team on Children and HIV/AIDS
- Family AIDS Caring Trust, Zimbabwe
- Family Health International
- Global AIDS Alliance
- Global Action for Children
- Human Sciences Research Council, South Africa
- Joint United Nations Programme on HIV/AIDS
- Partners In Health
- Protecting Families Against AIDS, Uganda
- RENEWAL project of the International Food Policy Research Institute
- Research On Poverty Alleviation, Tanzania
- Social Science Research Council, New York
- The AIDS Support Organisation, Uganda



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