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# Home Truths

Facing the Facts on  
Children, AIDS,  
and Poverty



Final Report of the Joint Learning Initiative on Children and HIV/AIDS



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This report summarizes the findings and recommendations of the Joint Learning Initiative on Children and HIV/AIDS (JLICA). The contents of the report emerge from the work of JLICA’s four Learning Groups and the contributions of all Learning Group members. Responsibility for all aspects of the report rests with JLICA. The views and recommendations expressed are not necessarily those of JLICA’s Founding Partner organizations and supporters.

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# A Message from the Co-Chairs



The global fight against HIV and AIDS has changed the nature of public health action and the world's expectations of what such action can achieve. But the AIDS fight has short-changed children. For more than a quarter-century, affected children have remained peripheral to the AIDS response by governments and their international partners.

This report makes the case for redirecting the response to HIV and AIDS to address children's needs more effectively. Drawing on the best body of evidence yet assembled on children affected by AIDS, it shows where existing approaches have gone off track and what should now be done, how, and by whom.

The report summarizes the evidence from two years of research and analysis by the Joint Learning Initiative on Children and HIV/AIDS (JLICA). JLICA is an independent, time-limited alliance of researchers, implementers, activists, policy-makers, and people living with HIV. Launched in October 2006, it includes some 50 core participants from a dozen countries, linked to many more stakeholders and reviewers around the world.

JLICA's report is addressed primarily to national policy-makers in heavily-burdened countries and to their advisors. It also speaks to international donors, agencies concerned with children and AIDS, international and national non-governmental organizations, and civil society groups. While many of JLICA's findings and recommendations have relevance across a range of contexts, including low-

prevalence countries, the main focus of our research and analysis has been on countries in sub-Saharan Africa where AIDS converges with widespread poverty and inequality.

This report is only one of JLICA's outputs. Behind it lie more than 50 systematic reviews and other research products that contain the core evidence on which our recommendations are based. These products will constitute a lasting resource for the field. Equally important, the report is backed by the joint learning process itself, which has borne fruit in ways that go far beyond the production of scientific papers. JLICA's learning model has engaged participants from a wide spectrum of disciplines and backgrounds, yielding insights that no single constituency on its own could have produced. The result is evidence-based guidance on how the global AIDS fight can respond better to children, as well as lessons on how putting children and families at the centre can open a new way forward for AIDS action as a whole.

The global AIDS response is now at a crossroads. A new context for action on AIDS is emerging and, with it, fresh opportunities for progress, but also new uncertainties for affected children. HIV prevalence rates are stabilizing and have even begun to fall in some hard-hit countries; yet we are sobered by the realization that the epidemic is not about to be conquered. More generations in sub-Saharan Africa will grow up with HIV and AIDS as part of the context of their daily lives. The sense of an acute crisis is yielding to the realization that

AIDS is a long-wave phenomenon that will test the resilience of communities and governments for decades more.

JLICA argues that facing “home truths” on children, AIDS, and poverty is critical to reframing the global response. Our report challenges business as usual in action on HIV and AIDS. But it does so by recognizing the AIDS movement’s achievements — and urging that they be extended. What is needed is not to curtail AIDS-specific programmes, but to harness the successes of the AIDS fight to energize broader forms of action to protect and empower the most vulnerable members of society, especially children.

To tackle the long-wave effects of the epidemic, Universal Access to HIV and AIDS services and support must be combined with a social protection agenda. This integrated approach is necessary to create conditions in which vulnerable people can take up and benefit from HIV and AIDS prevention, treatment, care, and support. JLICA’s report documents why this strategy is needed and shows how it can be achieved. It argues that placing children front and centre is the key to unlocking AIDS programmes’ full capacity to accelerate national development by strengthening families, supporting collaborative action within communities, and securing the human capital of rising generations.

JLICA completes its work amidst an unfolding global financial and economic crisis. Instability in the financial system will affect resource flows for

health and development in as yet undetermined ways and for a duration we cannot foresee. In parts of Africa, this new calamity threatens to compound the damage already inflicted by a protracted food crisis. These conditions make the implementation of JLICA’s recommendations even more urgent. In situations of crisis, the risks for vulnerable groups — including children affected by HIV and AIDS — increase. But so, too, may opportunities to promote bold change. This is the spirit in which JLICA delivers its messages. The recommendations put forth here are ambitious. They are also necessary, if we are at last to make decisive progress in improving children’s lives in the context of AIDS and to maximize the contribution of AIDS policy to development goals.

Throughout its lifespan, JLICA has worked closely with numerous partner organizations and has contributed scientific content to policy debates. Even before publishing this final report, we have begun to see our key findings examined in global and national policy forums. This momentum must now expand. We invite readers of this report to review the results of JLICA’s two years of effort, and we urge you to join us in ensuring that evidence-based solutions are translated into action.



Peter D. Bell



Agnès Binagwaho

# About JLICA and this Report

The Joint Learning Initiative on Children and HIV/AIDS (JLICA) is an independent, time-limited alliance of researchers, implementers, activists, policy-makers, and people living with HIV. Its goal is to improve the well-being of children, families, and communities affected by HIV and AIDS by producing actionable, evidence-based recommendations for policy and practice.

JLICA has worked to:

- generate and mobilize evidence to strengthen children's outcomes
- expand space for new thinking across disciplinary, sectoral, and geographical lines
- advance action through recommendations and advocacy
- facilitate linkages among bodies of knowledge, communities, and institutions engaged in children's well-being in the context of AIDS.

JLICA was created through an accord among six Founding Partner organizations: Association François-Xavier Bagnoud—FXB International; the Bernard van Leer Foundation; FXB Center for Health and Human Rights, Harvard University; the Global Equity Initiative, Harvard University; the Human Sciences Research Council; and the United Nations Children's Fund (UNICEF). The Initiative was formally launched in October 2006. It is led by two global co-chairs: Peter D. Bell, President Emeritus of CARE USA and Senior Research Fellow at the Kennedy School of Government, Harvard

University; and Agnès Binagwaho, Permanent Secretary, Ministry of Health, Rwanda. JLICA's research activities have been conducted by four thematic Learning Groups:

■ **Learning Group 1: Strengthening Families**, chaired by Linda Richter (Human Sciences Research Council, South Africa), Lorraine Sherr (University College London, United Kingdom), and Angela Wakhweya (Family Health International, United States of America)<sup>1</sup>

■ **Learning Group 2: Community Action**, chaired by Geoff Foster (Family AIDS Caring Trust, Zimbabwe) and Madhu Deshmukh (CARE USA, United States of America)

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

■ **Learning Group 4: Social and Economic Policies**, chaired by Alex de Waal (Social Science Research Council, United States of America) and Masuma Mamdani (Research on Poverty Alleviation, Tanzania).

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<sup>1</sup> Dr Wakhweya withdrew as co-chair in September 2007 because of a change in her work commitments.

A complete list of Learning Group members is included in Appendix 2 of this report. JLICA's Learning Groups have been supported by a secretariat based at the FXB Center for Health and Human Rights, Harvard School of Public Health, and at FXB International, Geneva.

JLICA Learning Groups have generated more than 50 systematic reviews and other research products. JLICA research outputs are freely available on the Initiative's website at <http://www.jlica.org>.

This final report summarizes JLICA's main results and recommendations. For reasons of economy and readability, references to non-JLICA sources have been kept to a strict minimum in the final report. The primary inputs to the report are the technical papers and synthesis papers produced by JLICA's Learning Groups. Non-JLICA publications are cited only when: (1) a piece of primary data or an important original argument from such a source is referred to directly; (2) the publication in question has itself been cited in a JLICA technical report as an especially pertinent contribution to the literature. Non-JLICA sources cited in the text are marked with an asterisk (\*). Readers interested in more extensive bibliographical documentation on any point discussed in this report are invited to consult the respective JLICA technical reports and Learning Group synthesis papers, which contain comprehensive reviews of the relevant literature.

## Abbreviations

<b>AIDS</b>	acquired immunodeficiency syndrome
<b>AMPATH</b>	Academic Model for Prevention and Treatment of HIV/AIDS (Kenya)
<b>ART</b>	antiretroviral therapy
<b>ARVS</b>	antiretroviral drugs
<b>BOTUSA</b>	Botswana-USA Partnership
<b>CBO</b>	community-based organization
<b>CDVC</b>	Care Delivery Value Chain
<b>CSG</b>	Child Support Grant (South Africa)
<b>CSO</b>	civil society organization
<b>DECT</b>	Dowa Emergency Cash Transfer (Malawi)
<b>ECD</b>	early childhood development
<b>FBO</b>	faith-based organization
<b>FPI</b>	Family Preservation Initiative (Kenya)
<b>G8</b>	Group of Eight nations
<b>HIV</b>	human immunodeficiency virus
<b>JLICA</b>	Joint Learning Initiative on Children and HIV/AIDS
<b>LAC</b>	Latin American countries
<b>MAMP</b>	World Bank Multi-Country AIDS Program
<b>M&amp;E</b>	monitoring and evaluation
<b>NGO</b>	non-governmental organization
<b>NPA</b>	national plan of action
<b>OECD</b>	Organisation for Economic Co-operation and Development
<b>PCR</b>	polymerase chain reaction
<b>PEPFAR</b>	United States President's Emergency Plan for AIDS Relief
<b>PMTCT</b>	prevention of mother-to-child transmission
<b>SCTS</b>	Social Cash Transfer Scheme (Zambia)
<b>TASO</b>	The AIDS Support Organisation (Uganda)
<b>TB</b>	tuberculosis
<b>UN</b>	United Nations
<b>UNAIDS</b>	Joint United Nations Programme on HIV/AIDS
<b>UNICEF</b>	United Nations Children's Fund
<b>WHO</b>	World Health Organization





# CHAPTER 1 The Global Response to Children Affected by AIDS: Where Have We Gone Wrong?

The first chapter of this report describes the impacts of HIV and AIDS on children and examines why the response from governments and their partners has fallen short. The chapter argues that these shortcomings will not be overcome by incremental advances in current forms of action. A bold change in approach is necessary that: (1) extends support and services to all children in need, including, but not limited to, children who have lost parents; (2) builds policies and programmes that support extended family and community networks in caring for children; and (3) tackles poverty and gender inequality, which strongly influence child outcomes and amplify the impact of HIV and AIDS on children.

## A Flawed Response

AIDS has devastated the lives and hopes of millions of children worldwide (Figures 1 and 2, Box 1). The response from governments and their partners has been hampered by flaws that weaken results where needs are greatest. Well-intentioned, but misdirected, efforts drain resources that could be invested in more effective approaches. As a result, despite growing concern and mobilization, the response to children affected by HIV and AIDS continues to fall short of what it should achieve. To date:

■ **Poor families are supporting affected children with minimal assistance, including from their**

**governments.** Families and communities continue to bear approximately 90% of the financial cost of responding to the impact of HIV and AIDS on children (Richter, 2008). Across sub-Saharan Africa, families have provided the bulk of care, support, and protection for children affected by AIDS with little or no formal assistance from outside agencies. Families' effectiveness in absorbing the shocks of HIV and AIDS and other afflictions points to a crucial lesson: strong, capable families must be the foundation of any long-term response to children affected by AIDS. But families in heavily burdened areas today face an erosion of their coping capacities through the combined impacts of AIDS, poverty, and food insecurity (Drimie & Casale, 2008). Governments have the responsibility to provide needed support and services.

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Strong, capable families must be the foundation of any long-term response to children affected by AIDS.

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■ **Community responses are poorly understood and supported.** In the areas hardest hit by HIV and AIDS, communities have mobilized to provide urgently needed support to affected families and children. The large majority of these efforts rely on mutual assistance among equally poor community members. Recently, growing numbers of international donors have sought opportunities to partner with communities, but lack understanding about how best to support community action. A 2007–2008 JLICA study in

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Asterisks indicate non-JLICA sources.

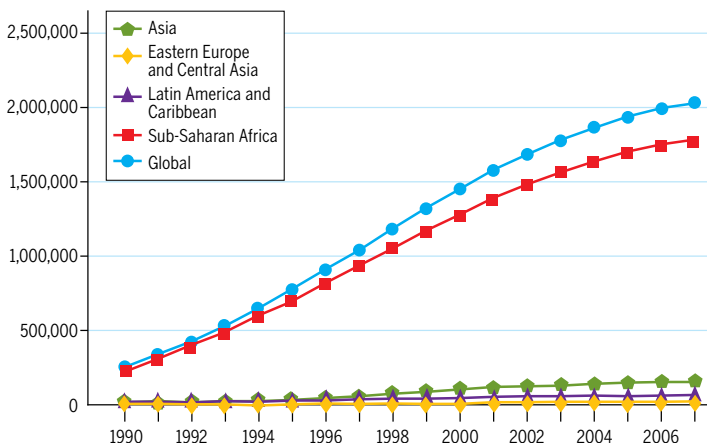
four Ugandan sub-counties, for example, found widespread dissatisfaction among community groups towards externally-funded projects that were characterized by disbursement delays, unrealistically tight timeframes, and inflexibility on the part of donors (Nshakira & Taylor, 2008).

**Implementation of key services falls short of needs.** To protect children and give them a better future, families must be able to draw on effective services in health care, education, and social welfare. Despite plans on paper and some progress on the ground, services are still far from reaching the scale required in hard-hit communities. Recent gains in coverage levels for some HIV- and AIDS-related services are a tribute to the dedication of governments, advocates, implementers, and communities. But modest advances should not blind us to enormous unmet needs. In 2007:

- Only a small portion of children living with HIV were receiving antiretrovirals, and in sub-Saharan Africa, children were significantly less likely to receive treatment than adults (Richter, 2008).
- Only 33% of pregnant women with HIV in low- and middle-income countries received antiretrovirals to prevent vertical transmission (Richter, 2008; WHO, UNAIDS & UNICEF, 2008\*).
- Fewer than 4% of the estimated 1.5 million children exposed to HIV during gestation and birth received co-trimoxazole prophylaxis by two months of age (Richter, 2008; WHO, UNAIDS & UNICEF, 2008\*).
- Only 30% of children in sub-Saharan Africa could expect to enrol in secondary school (Baingana et al., 2008).
- Sixty per cent of children in southern Africa were living in poverty (Richter, 2008).

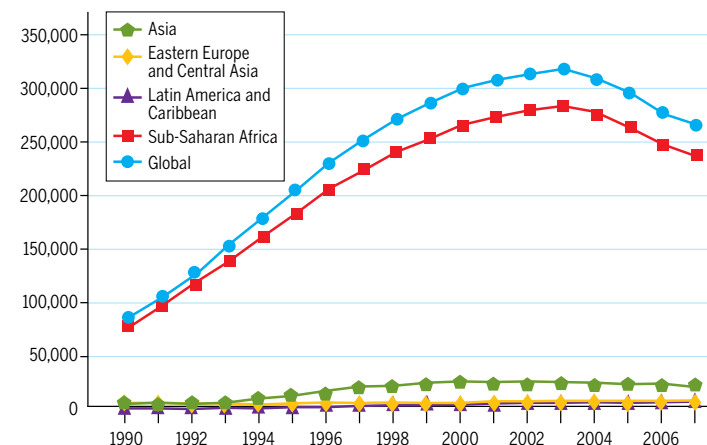
**Global political commitment and resources are insufficient.** Despite energetic advocacy by some groups, children affected by AIDS remain

**Figure 1: Children Living with HIV Globally, 1990–2007**



Source: Richter, 2008. Data from UNAIDS, 2008.

**Figure 2: Child Deaths Attributable to AIDS Globally, 1990–2007**



Source: Richter, 2008. Data from UNAIDS, 2008.

marginal in global debates on the AIDS response and in the allocations and programmes of many international funders and implementing agencies. Some major agencies’ spending earmarks for “orphans and vulnerable children” are beginning to spur real advances, but resource levels in the most severely affected countries still remain far below what is needed to build robust, comprehensive programmes for children and families affected by HIV and AIDS at national scale.

## Three Critical Challenges

These failures in the global response to children affected by HIV and AIDS cannot be overcome by simply doing “more of the same.” They point to deep flaws at the heart of the response to date. JLICA has identified three critical challenges that must be addressed to correct these distortions and deliver better outcomes for children.

### 1. Government-led support and services must reach *all* children who need them in poor communities affected by HIV and AIDS. This includes children who have lost parents, but also many others.

It is vital to come to the assistance of all children who experience grave forms of vulnerability and deprivation. To date, responses to children in the context of HIV and AIDS have been primarily focused on orphans. The number of children orphaned by AIDS has been adopted as a marker of the severity of national epidemics, and providing support to children who have lost parents has been seen as an overriding imperative. However, it is not only orphans who face difficult conditions in very poor communities.

JLICA’s comprehensive review of the evidence indicates that many studies on orphan outcomes are marked by significant flaws in design, such as failure to control for HIV status, which may lead researchers to attribute to children’s orphan status the negative impacts that arise from HIV infection. The quality of research in this area needs to be improved (Sherr, 2008). The best available evidence shows that, in settings of widespread destitution, when large, reliable data sets are used, differences between orphans and non-orphans do not emerge or are very small compared to the deprivation, suffering, and vulnerability that *all* children confront (Richter, 2008).

As expected, orphans do suffer some disadvantages, especially with respect to education, and more so if they come from the poorest families (Sherr,

2008). There is also some evidence that adolescents and young people who have lost parents may be somewhat more likely than their peers to begin sexual activity at an early age and to engage in risky sexual behaviours, although the reasons for this are not yet well understood (Cluver & Operario, 2008). These effects merit concern but should not obscure the more important message emerging from JLICA’s findings: in poor, heavily impacted communities, children who have lost parents to AIDS are part of a much larger group of children who face severe and urgent needs.

### Box 1. Direct Impacts of HIV and AIDS on Children

Recent statistics on children indicate that the epidemic’s impact continues to grow in scope and severity:

- The number of children living with HIV per year globally has increased eight-fold since 1990. An estimated 2 million children were living with HIV in 2007, 90% of them in sub-Saharan Africa (Richter, 2008; UNAIDS, 2008\*).
- 370,000 children were newly infected with HIV in 2007, representing 17% of all new HIV infections globally (Richter, 2008; UNAIDS, 2008\*).
- 270,000 children are believed to have died from AIDS in 2007 (Richter, 2008; UNAIDS, 2008\*).
- Adolescent girls are particularly vulnerable to HIV infection. In some populations in sub-Saharan Africa, a fifth of girls under 18 years of age are infected with HIV (de Waal & Mamdani, 2008).
- Millions of children witness the debilitating effects of HIV on parents and caregivers, some becoming the “caregivers of their caregivers.”
- In 2007, some 12 million children in sub-Saharan Africa were estimated to have lost one or both parents to AIDS, representing approximately 37% of parental loss from all causes (Richter, 2008; UNAIDS, 2008\*).

JLICA's research has also revealed that inconsistent definitions of the term "orphan" have created confusion among donors, distorted programmatic goals and methods, and undermined the value of much existing research (Sherr, 2008). The definition of "orphan" adopted by UN agencies and used in the production of global statistics is "a child who has lost one or both parents." This definition is at odds with everyday understandings in western and African cultures. Confusion is further fuelled by a routine failure to define "orphan" in the AIDS literature. The majority of published papers either do not define "orphan," or do so inconsistently (Sherr, 2008). These inconsistencies weaken

**Box 2. A Call to Revise the United Nations Definition of "Orphan"**

JLICA leaders have warned that the existing UN definition of an orphan, "a child who has lost one or both parents," distorts the global response to children affected by HIV and AIDS (Richter, Foster & Sherr, 2006\*; Richter, 2008). In a May 2008 article in *AIDS Care*, JLICA leaders urged that the definitional confusion "be remedied at an international level and as a matter of high priority" (Sherr et al., 2008:535).

JLICA's engagement has contributed to growing momentum on this issue. In an August 2008 press statement, UNICEF observed that use of the current UN definition of "orphan" might cause people to assume mistakenly that all children who fall under this definition are completely cut off from parental and family support and "in need of a new family, shelter, or care." This misunderstanding could encourage the use of narrow interventions that target children as isolated individuals and miss the chance to support families and communities to care for children. The agency acknowledged "growing consensus on the need to revisit the use of the term 'orphan' and how it is applied to help overcome this confusion" (UNICEF, 2008a\*). JLICA welcomes this statement and recommends that the existing definition be reviewed and amended rapidly.

findings, making it impossible to compare results meaningfully across studies. This limits the policy learning that can be derived from existing research. In light of this situation, JLICA leaders have called for the UN definition of "orphan" to be revised and welcome indications that a review of the definition may be imminent (see Box 2).

However defined, orphans are of concern. But children's needs, not their orphan status, must be the primary focus when designing and implementing policies (Richter, Sherr & Desmond, 2008). Governments bear responsibility for ensuring universal provision of support and services to all children based on need.

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The myth that most orphans and vulnerable children lack family and social networks has created a damaging legacy.

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**2. Policies and programmes supporting children must build on the strength of extended families and communities.**

The focus on orphans in the global response has encouraged the view that orphanage care and other forms of non-family care are a needed and appropriate remedy to Africa's "AIDS orphans crisis." Beyond the known negative impacts of non-family care, the myth that most orphans and vulnerable children lack family and social networks has created a damaging legacy. The focus on orphans has framed mitigation as an individual rather than a national social problem (Richter, 2008; Richter, Sherr & Desmond, 2008).

Research conducted for JLICA underscores facts that have critical significance for a more effective response to children's needs in the context of AIDS:

- Some 88% of children designated as "orphans" by international agencies actually have a surviving parent (Belsey, 2008; Sherr, 2008).
- Approximately 95% of all children directly affected by HIV and AIDS, including those who

have lost parents, continue to live with their extended family (Hosegood, 2008).

- Children of HIV-positive parents experience need long before their parents die; programmes focused only on orphans may disadvantage or exclude children during the disease trajectory.

These facts highlight the need and opportunity to support children in and through their families. In turn, to be sustainable, a family-centred response must build on the strengths of local social networks and community organizations, which provide the first line of support for affected families. Local responses aim to strengthen the capacity of caregivers by enhancing traditional care and support systems based on family, kinship, or community ties (Schenk, 2008).

Community initiatives for children affected by HIV and AIDS have multiplied in the past decade in response to urgent need. Community organizations, in particular faith-based organizations, have unparalleled reach in sub-Saharan Africa and enjoy high levels of approval and trust among the people they serve (Foster, Deshmukh & Adams, 2008).

Community and family networks are under increasing strain in many settings, as the pressures of AIDS, poverty, and food insecurity intensify. However, they remain vital for children (Schenk, 2008). Building up the resources of families and communities that are already providing for children, rather than creating artificial structures to replace families, is the logical direction for a more efficient, effective, and sustainable response.

### **3. Family poverty and gender inequality must be tackled to improve outcomes for children affected by HIV and AIDS.**

Supporting children through their families requires making family poverty a central policy concern. Family poverty and gender inequality

multiply the impacts of HIV and AIDS on children. Until governments and their partners address these underlying issues, we will see only limited improvements in children's outcomes. Evidence assembled by JLICA highlights five essential facts about poverty, inequality, children, and AIDS:

- **Family poverty significantly limits households' capacity to protect children against the effects of HIV and AIDS.** Families that are economically vulnerable when HIV strikes are unable to compensate for lost income and are less able to meet the direct and hidden costs of health care, including additional food, medicines, and transport. As a consequence, both affected adults and children in these families are likely to experience greater debilitation from opportunistic infections, more rapid disease progression, and earlier death. The greater caloric needs of individuals living with HIV may also be difficult to meet in poor families, further compromising the health and well-being of children. Since poor households have few savings and assets to compensate for income lost due to adult illness, children may be withdrawn from school and enlisted as carers and earners in efforts to provide for the family. Increasingly, the convergence of AIDS, poverty, and food insecurity means that key long-term investments such as proper nutrition, education, and securing children's inheritance rights fall by the wayside as families grapple with how to ensure short-term survival (Drimie & Casale, 2008).
- **Once it enters households, HIV pushes affected families deeper into poverty, with severe consequences for children's well-being.** A substantial literature demonstrates the impoverishing effects of HIV and AIDS on individuals and families in all settings (Richter, Sherr & Desmond, 2008). In Botswana, households were found to spend 25% of their income on each person living with HIV (Richter, Sherr & Desmond, 2008). Deepening family poverty undermines children's well-being in a variety of ways. It is likely to reduce their access to food, even more so in families that have taken in orphans (Gillespie, 2008). In

a rural region of South Africa, the presence of a child orphaned by AIDS decreased the odds of the household being food secure by 12% (Jukes et al., 2008; Schroeder & Nichola, 2006\*). For children with HIV-positive parents, school attendance and performance are frequently compromised due to the caregiving and economic responsibilities that they must assume (Jukes et al., 2008).

- **The social and economic disempowerment of girls and women drives the spread of HIV and leads to new infections in children.** In high-burden countries, gender inequality shapes power relations, sexual relations, and thus HIV risk (Gillespie, 2008). Age differences (with the accompanying social power gradient) and economic asymmetries between female and male sexual partners place girls and women at a dangerous disadvantage. Women confronting destitution and hunger are often forced into increasingly risky behaviours (Drimie & Casale, 2008; Gillespie, 2008). In addition to the toll on women themselves, these social and economic drivers of women's vulnerability directly increase the risk that children will be exposed to HIV, because the vast majority of infections in children result from vertical transmission.
- **HIV prevention messages advocating individual behaviour change are of limited use to girls and young women, without structural interventions to reduce gender inequalities.** Behaviour change campaigns, and especially the famous ABC formula — abstain, be faithful, or use a condom — derive from belief in the power of information and individual agency. But JLICA's research shows that a focus on information and individual behaviour change is insufficient to allow young people, especially young women, to escape infection (de Waal & Mamdani, 2008). Even when risks are well-known, patriarchal social norms and economic pressures mean that many girls submit to the persistent sexual advances of men in positions of relative power, including bus drivers, teachers, sugar daddies,

employers, policemen, and neighbourhood vigilantes. To the extent that society considers their sexual predation to be normal, these men may enjoy near-total impunity, and girls' recourse to legal protection is rarely an option. Indeed, many girls enter into transactional relationships in the hopes of protecting themselves against the unwanted advances of others, even though it exposes them to the risk of HIV (Hallman, 2008; Mabala & Cooksey, 2008). Structural measures are critical to a more effective prevention approach. Such measures include ensuring girls' physical safety at school, at work, on public transport, and in places of recreation; tackling the culture of impunity that empowers men to prey on girls and young women; keeping girls in school; and improving their economic independence (de Waal & Mamdani, 2008; Jukes et al., 2008).

- **Poverty limits uptake and impact of HIV and AIDS prevention and treatment.** A fifth critical fact is that poverty weakens the results of AIDS control programmes. As AIDS treatment programmes roll out, implementers increasingly see that people's capacity to take up and benefit from services is limited by a lack of money to purchase food and medicines, cover transport costs, and compensate for income sacrificed in order to devote time to seeking health care. As a result, returns on large global investments in AIDS control programmes fall short of what could be achieved.



To progress, national action on children in the context of HIV and AIDS must tackle these entwined challenges: reshape programmes to respond equitably to children’s concrete needs, not to labels that may misrepresent the reality of their lives; bolster the families and communities that are already caring for children; and tackle family poverty and gender inequality, which critically constrain children’s outcomes in communities affected by AIDS.

These agendas have a shared prerequisite for success. They demand that decision-makers expand their view of what constitutes AIDS policy and whom such policy serves.

## **Broadening Our Reach to Serve Children Better**

To date, an individualistic focus has limited the results of action for children in the context of HIV and AIDS. Broadening that focus means supporting children in and through their families and communities. Doing so, in turn, requires addressing family poverty. But in the communities most affected by AIDS, destitution is pervasive. It makes neither ethical nor political sense to try and alleviate the poverty *only* of those households that have been directly affected by HIV and AIDS. While experiencing great distress, these families, even if they could always be identified, are often scarcely worse off than their neighbours who have not



been directly impacted by the epidemic, or whose HIV status has not been established.

This presents policymakers and programme implementers with a problem that is also an opportunity: identifying strategies to deliver support to children and families affected by AIDS through equitable social policies that will benefit broader segments of the population and hence be politically viable in a context of competing resource demands. How national policy-makers can meet this challenge is a core topic of JLICA’s research and a central theme of the rest of this report.

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Decision-makers must expand their view of what constitutes AIDS policy and whom such policy serves.

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## **Finding the Way Home**

The “home truths” described in this chapter are painful to confront. They show a global response to children affected by AIDS that has lost its way. These difficult truths, however, also carry a positive message. JLICA’s analysis has identified failures and challenges in order to move towards a more effective response.

The remainder of this report describes a set of positive strategies grounded in JLICA’s evidence. These strategies will enable governments and their partners to address the failures described above and deliver better outcomes for children. The approach encompasses four lines of action:

- Support children through families.
- Strengthen community action that backstops families.
- Address family poverty through national social protection.
- Deliver integrated, family-centred services to meet children’s needs.





# CHAPTER 2 Refocusing the Response: Putting Families at the Centre

The first step to delivering better outcomes for children affected by HIV and AIDS is to redirect policies and programmes to support children in and through their families. This chapter shows why a family-centred approach is vital and describes specific priority components that it must include. It begins by clarifying JLICA's definition of "family" and the rationale for placing families at the centre of efforts to support children. The chapter then summarizes the evidence on how family structures and coping capacities in sub-Saharan Africa are being affected by HIV and AIDS. It identifies five key areas of action for a family-centred approach and concludes by showing that family economic strengthening can be a critical catalyst needed to enable rapid progress across the five areas.

## **Families Care Best for Children**

To date, the response to children affected by HIV and AIDS has largely adopted policy and programming models that target individual children as the beneficiaries of interventions. Programmes attempt to "reach children" with food support or school uniforms, paying little attention to children's social context and relational networks, including their family ties. This approach mirrors the individualistic models on which early HIV and AIDS programming was based in northern countries, and which were

subsequently exported to the developing world (Sherr, 2008). Individualistic strategies are poorly adapted to the realities of African societies and are inappropriate for meeting the needs of children. By focusing policy and service provision predominantly on the individual child, we miss the opportunity to draw on and strengthen the structure that is most effective in responding to children's needs: the family.

The idea of a family-centred approach does not presuppose a particular model of family or family life. For JLICA, families are social groups connected by kinship, marriage, adoption, or choice. Family members have clearly defined relationships, long-term commitments, mutual obligations and responsibilities, and a shared sense of togetherness. Families, in their many forms, are everywhere the primary providers of protection, support, and socialization for children and youth (Richter, Sherr & Desmond, 2008). A large and well established body of research shows that nurturing family environments are associated with positive outcomes for children across a broad range of indicators. Families provide the context in which children develop, learn, and thrive (Richter, Foster & Sherr, 2006\*).

Of course, not all families care well for children, and in the worst cases, family members can be physically or emotionally abusive. Child protection measures are critical in these rare cases as a means of preventing and responding to harmful family circumstances. But child protection

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Asterisks indicate non-JLICA sources.

measures, too, should work as part of a continuum of family-centred services and support. No other social group or institution can replace functional families in promoting children’s well-being.

## Families and Human Capital

The term “human capital” designates people’s skills, knowledge, and capabilities for productive work. Their human capital forms the basis of people’s ability to contribute to economic processes and secure their livelihoods through work. All countries, especially those facing development challenges, must be concerned with building and enhancing human capital.

Adult health, cognitive capacities, and skills are fundamental constituents of workers’ human capital. Research has shown that these adult capacities are substantially determined by childhood conditions — including nutrition, health, stability, stimulation, and education. By providing a safe and healthy environment for children, the family acts as the motor of human capital creation in a society (Adato & Bassett, 2008).

During the first three years of life, the basic circuitry of a child’s brain is being “hard-wired” at a rapid pace (Kim et al., 2008a; Shonkoff & Phillips, 2000\*). Disease, nutritional deficiencies, or failures in appropriate stimulation during this critical time disrupt the healthy formation of brain circuitry. Such disruptions often signify a permanent reduction in the child’s learning ability, with negative consequences for later school performance and earning potential. Studies from around the world confirm how poverty and nutritional deficiencies lead to poor childhood health; compromised educational attainment; and reduced economic potential in adulthood. Poor, stunted children can expect to see their annual adult incomes reduced by more than 30% from the level they would otherwise have attained (Adato & Bassett, 2008; Grantham-McGregor et al., 2007\*). Conversely, there is evidence that good nutrition, good health care, and competent

parenting during the crucial early childhood period can build a sturdy foundation for physical growth, cognitive development, and later economic success (Chandan & Richter, 2008; Kim et al., 2008a).

Some of the most serious effects of the AIDS epidemic result from cumulative damage to human capital formation within affected families. Policy and programme approaches that engage families and work to strengthen family caring capacities are a critical means to safeguard children’s human capital—and with it, countries’ economic future.

## Families in the Context of AIDS

As a result of the epidemiology of HIV in Africa, the family has an even more central place in the HIV and AIDS epidemic than in other crises. In Africa, HIV is transmitted primarily through heterosexual sex and by vertical transmission from parents to their children. This means that HIV clusters in families. But AIDS is a “family disease” in a double sense. It is within the family that affected children are exposed to the risks, suffering, and loss associated with the disease; but it is also through their family connections that children receive the material and emotional support to manage risks, overcome suffering, and move on from loss to a productive and satisfying life (Richter, Sherr & Desmond, 2008). Professional psychosocial interventions are



necessary to support the very small number of children who develop clinical psychopathology as a result of distress and lack of support. However, such interventions are not necessary for the majority of affected children, nor can they replace the dedicated, long-term warmth and care that children experience in family environments. It is the presence and quality of everyday caring relationships that primarily determine children's ability to rebound from adversity.

## Are African Families Failing?

How are families' caring capacities and overall viability being affected by HIV and AIDS? Are families in the hardest hit areas breaking down under the epidemic's assault, as some researchers had predicted? Experts have published conflicting assessments, some highlighting the resilience of families, others reporting an erosion of family structures and cohesion in high-prevalence contexts.

JLICA's review of the data finds strong evidence of family resilience, but with limits that must concern us and motivate action. Overall, the effects of HIV and AIDS on African family structures have not been irreversibly destructive—yet. What longitudinal population-based survey data are available suggest a strong predisposition for the survival of households, including in high-prevalence settings.



One sign of this is that, since the 1970s, households in southern Africa have, on average, increased, rather than decreased, in size. This increase indicates that many households that have lost adult members to AIDS have subsequently been joined by other adults, and thus replenished their family capital. Popular media reports are dominated by images of child-headed households and “skip-generation” households composed only of children and elderly people. Though people in these difficult situations need special support, large population-based studies repeatedly show that these household forms remain extremely rare (Hosegood, 2008).

Despite positive signs of family resilience, reports from many sources show that the pressures on family coping capacities are growing in areas where high AIDS burdens and food insecurity combine with chronic poverty (Drimie & Casale, 2008). Dual epidemics of HIV and TB multiply the health damage and economic burdens that families confront (Baingana et al., 2008). There is still time to strengthen vulnerable families in hard-hit areas. But for millions of children and families, the window of opportunity for supportive action is narrowing.

## Supporting Children in and Through Families

In 2004, the widely endorsed *Framework for the protection, care and support of orphans and vulnerable children living in a world with HIV and AIDS* highlighted family support as critical to children's well-being (UNICEF et al., 2004\*). Some organizations working on the front lines of the epidemic, for example, The AIDS Support Organisation (TASO) in Uganda, have long provided family-centred services. Major funding agencies, including the United States President's Emergency Plan for AIDS Relief (PEPFAR), have recommended the adoption of family-focused models in the provision of AIDS-related services. So far, however, large-scale implementation of family-centred

approaches has not occurred. This is partly due to persistent uncertainty about what family-centred policies and programmes require in practice (Wakhweya, Dirks & Yeboah, 2008). JLICA research has identified five key practical thrusts of a family-centred approach.

### 1. Keep Children and Parents Alive.

At the heart of a family-centred approach is the need to ensure the survival and health of children themselves and the adults that care for them. Prevention of parent-to-child transmission through family-based testing and prevention of mother-to-child transmission (PMTCT) programmes is critical, as are family-based treatment and support.

#### ■ Prevention of vertical transmission:

Prevention of HIV transmission from parent to child is an area where a family-centred approach holds special promise (Sherr, 2008). Despite recent progress in expanding PMTCT, coverage levels, uptake, and results of programmes to prevent vertical transmission in the hardest-hit areas remain disappointing. One contributor to this failure is the individualized approach of many PMTCT programmes, which focus on mothers in isolation from their relational context. A family-centred model emphasizes couples testing for HIV, treatment for mothers living with HIV, and referral to treatment within a family approach.

Testing only the mother may activate destructive gender and power dynamics within the family, since it is frequently assumed that the first family member who tests positive was also the first infected, and, thus, “responsible” for bringing the disease into the family. This dynamic changes when couples test together. Couples testing can also ensure that discordancy (difference in HIV status between the two partners) is picked up and so help avoid transmission within the couple during pregnancy, and afterwards. Couples testing is showing good results in Rwanda and Zambia (Sherr, 2008).

The imperative to keep children and parents alive has implications for the type of antiretroviral regimen given to mothers during pregnancy and delivery to prevent vertical transmission. Use of monotherapy in this context may compromise a mother’s ability to benefit from combination antiretroviral therapy (ART) later on. A family-centred approach mandates PMTCT strategies that safeguard women’s capacity to benefit from later ART (Sherr, 2008).

Additional distinctive features of a family-centred approach to HIV prevention come into play after the child is born. Current PMTCT programmes rarely incorporate infant testing, despite the existence of accurate but relatively expensive polymerase chain reaction (PCR) tests that can establish infant serostatus at six weeks. In family-centred HIV prevention and treatment roll out programmes, PCR tests should be included in the basic service package (Sherr, 2008; Kim et al., 2008a).

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Prevention of HIV transmission from parent to child is an area where a family-centred approach holds special promise.

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■ **Treatment for all family members:** Expansion of access to treatment for adults and children is also a critical component of a family-centred response, ensuring that HIV-positive adults in the family are healthy, productive, and able to support the material, social, emotional, and cognitive needs of children in their care.



Adult treatment brings numerous benefits for children, including reductions in labour demands on children and increased opportunity to attend school. A study in western Kenya found that, after 100 days of ARV treatment for an adult family member, the rate of children's participation in the labour market decreased significantly, especially for children in the age group 8 to 12 years. In the six months following parents' initiation of ART, children in the study spent 20–35% more time in school per week than before treatment began (Kimou, Kouakoa & Assi, 2008).

Family-centred treatment programmes may accelerate the expansion of paediatric treatment, improve children's adherence to therapy, and secure better outcomes for children living with HIV. A 2008 study from a South African clinic found that HIV-positive children who received care from an HIV-positive adult were less likely to die than positive children whose caregiver was HIV-negative or untested (Reddi et al., 2008\*). Results from this small study suggest a change in the way affected families are viewed, from passive patients to implementers actively engaged in the response. Far from being rendered powerless by the virus, families affected by AIDS who are able to access treatment may have unique reserves of skill that programmes can harness to deliver better results for children. Importantly, family approaches encourage the inclusion of fathers and other male family members, who are otherwise often sidelined and insufficiently provided for (Sherr, 2008).



Family-centred approaches to PMTCT and ART embody a fresh strategic direction critical for breaking the momentum of HIV and AIDS in high-burden settings in sub-Saharan Africa. Where its effects are most severe, the epidemic will not be contained by testing, counselling, treating, and supporting one individual at a time. After more than a decade, coverage and uptake of key interventions continue to lag where needs are greatest. A multiplier approach is needed that can expand the number of people that programmes reach. Models that engage family networks hold this promise.

## 2. Keep Children in Families.

Promoting family care for children who have lost parents is crucial to a family-centred approach. There is strong evidence that orphanage care, particularly in large residential settings, leads to worse outcomes for children (Sherr, 2008). It is also expensive, costing up to 10 times as much per child as community-based care (Richter, Sherr & Desmond, 2008; Desmond et al., 2002\*).

Alternatives to orphanage care through extended family structures exist for virtually all children affected by AIDS in sub-Saharan Africa. The tradition in many African societies of caring for children within the extended family opens numerous solutions, and they should be used. However, poor families cannot be expected to continue caring for additional children without support from the state and civil society organizations. Income assistance from the state will be especially critical.

Many children are placed in orphanage care because their families are too poor to provide for their material well-being. Families' unique advantages in nurturing children can operate only if families have a basic level of material resources. As AIDS mortality rates and the number of children requiring care rise in sub-Saharan Africa, more and more families find their capacity to meet

children's basic needs dangerously stretched (Richter, Sherr & Desmond, 2008; Gillespie, 2008). But the answer is not to build more orphanages or create more out-of-family care alternatives. Supporting families by furnishing them with additional resources will enable extended kin to give children the personal, responsive nurturance that families are uniquely suited to provide.

### 3. Build Family Caring Capacities.

A family-centred approach requires enhancing the capacities of parents and carers to support children through critical developmental stages. Two promising strategies are home health visiting and early childhood development interventions (Chandan & Richter, 2008).

Home health visiting involves community workers' making regular visits to pregnant and new mothers and families in their home environments. These programmes seek to improve outcomes for children by enhancing parenting knowledge and practices and providing social support and practical assistance to families. In high-HIV-burden settings, home visiting for pregnant mothers could serve as a platform not only for family-centred HIV-testing and PMTCT, but also for the promotion of child survival, maternal mental health, and family strengthening through connection to additional services. Bereavement and parental depression are sorely neglected in much current programming, although there are well-established links between parental mental health and child development (Sherr, 2008). Outreach to HIV-positive pregnant women and new mothers could provide psychosocial support and parenting information during a time of change and vulnerability. Such interventions may lighten the burden of care that poor, HIV-positive women must shoulder (see Box 3).

Home visiting can generate especially valuable results in rural areas, where travel to local clinics can be both time consuming and costly. In sub-

#### **Box 3: Supporting Mothers' Mental Health in the Context of HIV/AIDS**

Women in sub-Saharan Africa not only carry the disease burden of HIV, they also shoulder the care burden of the epidemic. This is not surprising, as cross-culturally, and especially in patriarchal societies, care work is largely women's work. The World Health Organization (2000\*) estimates that between 70–90% of illness care globally is provided in the home, predominantly by female family members.

While parenting and care-giving are challenging under normal conditions, they can be especially difficult within the context of poverty and HIV. Although the research evidence is still emerging, there are indications that one of the main indirect effects of maternal HIV on infants is compromised parenting, mediated, in part, by maternal depression (Stein et al., 2005\*). Home health visiting programmes could provide positive mothers with psychosocial support, in addition to enhanced parenting knowledge, thereby improving health outcomes for both mothers and children.

Source: Chandan & Richter, 2008.

Saharan Africa, home visiting programmes can build upon existing structures of community health worker and home-based care programmes, the latter having become an established intervention strategy for meeting the health-care needs of people living with HIV and AIDS.

Early childhood development (ECD) programmes constitute another promising strategy to increase family caring capacity while building children's human capital at a crucial life stage. In high-income countries, ECD programmes are generally targeted towards children and families living in poverty and are intended to counteract the factors that place low-income children at risk of poor outcomes. Although programme models vary, ECD programmes often comprise multiple components that include early childhood education; health

screenings and immunization; nutritional support; and parental support. ECD programmes adopt the principle that it is most cost-effective to invest in children's well-being during their early years. Well-designed early childhood interventions in the United States, for example, have been found to generate a return to society ranging from us\$1.80 to us\$17.07 for each programme dollar spent (Chandan & Richter, 2008; Karoly, Killburn & Cannon, 2005\*). These benefits stem from effects such as higher educational attainment, lifelong increases in earning potential and reduced rates of special needs among children who participate in ECD programmes.

Currently, fewer than 10% of young children in sub-Saharan Africa have access to early stimulation or pre-school programmes (Chandan & Richter, 2008; Kim et al., 2008a). Scaling up high-quality early childhood development



programmes in high-prevalence countries could strengthen families and positively impact the life trajectories of poor children. Programmes might also engage fathers and provide opportunities to better understand and meet the needs of other family members, including siblings and grandparents (Sherr, 2008).

#### 4. Empower Families to Educate Children.

If families are functional and supportive, children are more likely to go to school and to perform well. In addition to its other benefits, secondary education reduces girls' HIV risk (Jukes et al., 2008). Evidence suggests that for girls, simply being enrolled in school is protective against HIV. Girls who are attending school are less likely to begin having sex at an early age, which is a risk factor for infection. Girls' education is also associated with reductions in HIV risk through a variety of other mechanisms, from increased understanding of health issues, including HIV; to enhanced self-efficacy and sense of control in relationships; to more frequent condom use; to a greater capacity to benefit from the protective effects of social networks (Jukes et al., 2008). The extent to which education is valued and accessed by families influences HIV risk for children and adolescents. Moreover, given the powerful associations between maternal education and child health outcomes, expanding access to education for girls today is likely to have a beneficial intergenerational effect on family caring capacities and health outcomes into the future.

## 5. Backstop Families with Child Protection.

An approach that supports children in and through their families also recognizes that there are situations in which family care breaks down. For these cases, child protective services must be provided. Currently, such services exist in name only in many settings. JLICA urges building up community systems involving police, health and education services, traditional authorities, and others to identify and protect abused children. Community organizations can play a central role.

### **The Missing Key: Economic Strengthening**

Family-centred policies and programmes that address the five areas just described will improve children's well-being in the short term while reinforcing family structures and caring capacities for the long run. But for these strategies to yield their full benefit requires a crucial enabling condition: basic economic security for families. In many cases, lack of economic security will prevent families and children from reaping the benefits of interventions that could otherwise prove highly effective.

- To benefit from family-centred HIV and AIDS prevention, treatment, and support, families must have sufficient resources to meet the financial costs of care (including medicines and transport), as well as the opportunity costs of time spent on clinic visits and other activities related to accessing care.
- Keeping children in families depends on extended families' capacity to take in and care for needy children of kin. An enormous store of caring skills exists in families across Africa. But children's basic material needs must be met in order for family care and affection to bear fruit. Increasingly, the cumulative effects of HIV and AIDS, endemic poverty, and food insecurity are constraining the material capacities of family and community networks to continue providing children with family-based care (Drimie & Casale, 2008). Under these conditions, more and more children risk being pushed into orphanages and non-family settings that are known to give less adequate care than nurturing families.
- Quality home visiting and early childhood programmes enhance children's human capital, reinforce parenting skills, and bolster competent care in families. But again, these programmes must build on a foundation of economic security that enables families to cover the costs of food,





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To be able to benefit from HIV prevention, treatment and support, families need basic economic security.

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clothing, and shelter. All the parenting skills in the world cannot make children thrive if they do not have enough to eat.

- Even when families are strongly committed to sending children to school, their capacity to do so depends on economic factors. If families have no money to cover school-related costs, or if they cannot get by without children's labour contribution, families are forced to withhold children from school. These constraints particularly affect girls. The direct connection between family finances and girls' education was shown in a recent experimental study in Kenya. When the cost burden of girls' education on families was reduced through free provision of uniforms, girls' school attendance increased, and rates of teenage pregnancy fell (Jukes et al., 2008; Duflo et al., 2006\*).

Across all these areas, the evidence presents a consistent lesson. Other measures to address the impacts of AIDS and improve children's life chances will not succeed unless underlying family poverty and gender inequality are tackled. Direct

economic support to very poor families is a key missing piece that can break the bottleneck and improve results for children.

The need for economic support to poor families calls clearly for state action. Currently, the bulk of all assistance to vulnerable children and families comes to them from kin and their immediate community. Governments have unmet responsibilities in supporting families, which they must now shoulder. The adoption of the October 2008 Windhoek Declaration on Social Development by African Ministers in charge of Social Development signals growing momentum for systematic government action to support and protect families (African Union Commission, 2008\*). Government commitment backed by strong new evidence provides an historic opportunity to increase the effectiveness of family-centred policy.

In acting to strengthen families, governments and their institutional partners must work with local communities. Respecting and supporting locally-led responses is critical for any approach to children and families affected by AIDS that hopes for sustainability. The next chapter summarizes the evidence that JLICA has assembled on the nature of community response and how the efforts of external actors are affecting it.



# CHAPTER 3 Aligning Support for Community Action

In many settings, communities have provided the first — often the only — line of support for families affected by HIV and AIDS. Until recently, community groups rarely received assistance from donors, national and international NGOs, or government. This picture is beginning to change as international actors increasingly seek to partner with community organizations. However, opportunities to respond to local needs and to reinforce effective community action are being missed. The specific contributions of community action remain poorly understood. This chapter begins by describing the main forms of community response to children affected by HIV and AIDS. It then considers difficulties that community organizations often encounter in their relationships with external actors. It analyzes the promise, but also the risks, in potential new inflows of international resources to community level. The final section argues for more effective coordination, under government authority, between external agencies and community groups. Three specific strategies are recommended to improve coordination and strengthen support for community efforts.

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Asterisks indicate non-JLICA sources.

## **Local Social Networks — The First Line of Response**

In countries with weak social protection services and high HIV prevalence, informal networks of kin, friends, and neighbours have been and remain the primary source of support to affected children and their families. JLICA-supported analysis of data from a nationally representative household survey in Malawi found that over 75% of children lived in households that had received private transfers of cash or in-kind gifts from relatives, friends, and neighbours in the previous year. However, the value of such support tended to be small, and those in greatest need were least likely to benefit. Poor households with uneducated heads— in other words, those already least able to meet the essential needs of children in their care— received transfers of lesser value than other groups (Heymann & Kidman, 2008).

## **Organized Community Responses as a Backstop**

Organized community responses to the epidemic have multiplied in high-prevalence settings. Here, local communities — groups of people living in the same neighbourhood or sharing similar interests — have mobilized to act as backstops, or “safety nets,” to children and families in need. In Africa, organized community responses to HIV and AIDS preceded programmes for affected children

established by NGOs, international agencies, and governments (Foster, 2006\*). As early as 1987, community-based organizations in Tanzania were providing educational assistance, food, and clothing to children orphaned by AIDS (World Bank & University of Dar es Salaam, 1993\*). In Malawi, JLICA researchers found that some 40% of children lived in communities with local support groups for the chronically ill, offering counselling (31%), support for vulnerable children (25%), food or other in-kind gifts (24%), and medical care (20%) (Heymann & Kidman, 2008).

Community action for affected children is typically channelled through local organizations, such as churches or schools (Box 4). While community initiatives vary widely in capacity and scope, their proximity to the people they serve allows them to know and to adapt and respond quickly to changing needs and priorities. The proliferation of local initiatives for children affected by HIV and AIDS in recent years is an example of this ability to quickly mobilize around important community concerns. In a six-country study of 651 faith-based organizations supporting children, one half had been established in the preceding four years (Foster, 2004\*). Substantial “organized” local action on behalf of children was also noted in a JLICA survey of four sub-counties in Uganda. In each sub-country, between 15 to 25 active initiatives were identified, approximately 60% of which were locally-based (Nshakira & Taylor, 2008).

Locally-raised resources are the most common source of funding for many community initiatives. In a study of 109 religious congregations, coordinating bodies, and faith-based NGOs in Namibia, 80% reported that they received no external HIV/AIDS funding whatsoever (Yates, 2003\*). The overwhelming bulk of support came from member contributions, private donations, and local fund-raising. While many community initiatives recognize the urgent need for external technical and financial support to help expand and improve their services to children affected by HIV and AIDS, support is difficult to obtain even after

#### **Box 4: The Role of Faith-Based Organizations**

Faith-based organizations (FBOs) represent a majority of community-level HIV/AIDS responses in many African countries. In a recent study in Zambia, 63% of community-level organizations involved in health-related activities were congregations or religious support groups, and 25% had a response focused on orphans and vulnerable children (ARHAP, 2006\*). Harnessing the full capacity of faith-based groups to support affected children and families is crucial, but, to date, few community-level FBO efforts have been integrated within formal national AIDS responses or have received external funding (Mathai, 2008; Foster, 2004\*).

Surveys indicate that people value the compassion and commitment of FBO workers and their capacity to deliver spiritual and psychosocial support, in addition to medical care (ARHAP, 2006\*). When asked to identify the most valued attribute of religious health services, 358 workshop participants in Zambia and Lesotho ranked the intangible contributions of spiritual encouragement and compassionate care over visible, “tangible” factors, such as material support and curative interventions (ARHAP, 2006\*).

Among 25 FBO-supported orphan programmes in Zimbabwe, only one of 800 volunteers dropped out over several years of programme history, an indication of the level of commitment among FBO personnel (Phiri, Foster & Nzima, 2001\*). The fiscal contribution of the army of faith-based volunteers throughout Africa is enormous — their labour was conservatively estimated to be worth US\$5 billion per annum in 2006, an amount similar in magnitude to the total funding provided for HIV and AIDS by all bilateral and multilateral agencies (Tearfund, 2006\*).

significant effort (Foster, Deshmukh & Adams, 2008). All but one of 94 faith-based organizations (FBOs) surveyed in Namibia identified a need for training in HIV- and AIDS-related technical skills, yet only 20% belonged to a network or affiliation that actively supported their HIV and AIDS work (Yates, 2003\*).

While community responses to children affected by HIV and AIDS have expanded rapidly, there is growing evidence from high-burden settings that the cumulative burden of HIV and AIDS, coupled with poverty and food insecurity, is stretching community capacities as never before. Enormous goodwill may exist in communities, but local safety nets are fragile in the face of compounded stresses and unprecedented levels of demand. Neither are community-led initiatives a panacea for the most vulnerable. At times, these initiatives can contribute to stigma: marginalizing single women, disempowering girls, and overlooking young children. Although well-endowed in personal dedication, most community volunteers providing care and support lack resources, skills, and connections to networks of best practice. All efforts on behalf of children, whether community or externally led, should apply best practice principles that uphold equity, accountability, and the rights of the child (Zaveri, 2008).

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The cumulative burden of HIV and AIDS, coupled with poverty and food insecurity, is stretching community capacities as never before.

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## Help from the Outside

While large numbers of community-led initiatives remain isolated from external support, there is evidence that the pattern is beginning to shift. Increasingly, local organizations involved in supporting children affected by AIDS and their families are interacting with external agencies, including donors; national and international NGOs; and government. In Uganda, for example, three externally-funded multi-year programmes (World Bank, Global Fund, and PEPFAR) alone provide over US\$100 million to reach vulnerable children at community level. While new inflows of resources are vital, the growing involvement of outside actors in communities raises concerns. Inevitably, external agencies alter the way in which local community organizations function: in best cases, increasing community effectiveness in addressing the needs of HIV-affected children and their families, and in worst cases, introducing unintended distortions that may cause harm (Foster, Deshmukh & Adams, 2008).



## Making Aid Work Better for Children and Communities

JLICA's research confirms the critical importance of increased support from outside sources to strengthen community action for children affected by HIV and AIDS. However, JLICA's findings also indicate that much more effort is needed to evaluate the impacts of new programmes and funding streams on community action; ensure meaningful community participation in decision-making as programmes roll out; document effective models of collaboration; and ensure that good models are widely adopted.

To date, it is not clear how effective increased donor funding for community organizations has been, given the lack of impact assessments and systems for tracking resource flows to communities. A JLICA review of the published and grey literature revealed only 21 evaluations, reviews, or assessments of community-level initiatives in high-prevalence settings in Africa that possessed at least one round of post-intervention data focusing on health and welfare outcomes (Schenk, 2008). Commenting on the variable quality and rigour of evaluation design and data collected, the author concludes: "the evidence base guiding resource allocation is disappointingly limited."

JLICA research in Mozambique, Nigeria, and Uganda also identifies several shortcomings in the ways in which external support is delivered to community-level programmes for vulnerable children (Aniyom et al., 2008; Blackett-Dibinga & Sussman, 2008; Loewenson et al., 2008; Nshakira & Taylor, 2008):

■ **External support favours externally-led initiatives due to the inability of locally-led groups to navigate complex grant application procedures** that disadvantage those without connections, writing skills, and the ability to adapt to donor requirements (Box 5).

■ **Assistance is frequently targeted at individual children orphaned by AIDS rather than to affected households containing vulnerable children**, sometimes resulting in inequitable benefits as non-targeted children living in the same household are overlooked.

■ **Support inadvertently misses younger children** because of the focus on schooling in programmes for children affected by HIV and AIDS. This pattern persists despite strong evidence that investments made in early childhood have a critical long-term impact on human health and potential (Adato & Bassett, 2008; Chandan & Richter, 2008).

### Box 5: Provision of Resources to Community Initiatives in Uganda

In 2007, JLICA researchers conducted an evaluation of the effectiveness of external resource provision to support children affected by HIV and AIDS in four sub-counties in Uganda (pop. 141,811). The study identified 108 community-level initiatives that were responding to vulnerable children, a prevalence of one community-level initiative per 1,300 people. Most initiatives were independent groups or linked to local churches, schools, or clinics; around one quarter were linked to national NGOs or FBOs; and 14% were linked to international NGOs. Nearly two thirds of the initiatives had received external support, although locally-based groups were less likely to receive such support and were more likely to receive it in the form of material support rather than money. Among initiatives receiving external support, 85% received cash, 59% received material support, and 41% received technical support in the form of capacity building, training, or mentoring.

Source: Nshakira & Taylor, 2008.

■ **External agencies do not have the full trust of communities** due to delays in the provision of promised resources, limitations in how resources can be used, lack of consultation with community leaders, and reliance on agents who do not have the confidence of community members.

■ **Monitoring and reporting requirements imposed by external agencies lack local utility and relevance to community concerns** and are therefore often seen by community initiatives as diverting energies away from programme activities for vulnerable children and families (Box 6).

■ **Chances to help more children are being missed** due to the imposition of rigid conditions and criteria for external funding that are out of step with community needs. Counterproductive, limiting conditions include: (1) strict adherence to age specifications for children to access benefits; (2) focusing only on specific groups, such as orphans; (3) limiting assistance to specific types of support, such as school fees; and (4) targeting responses to children in isolation from their families.

## Impact of External Funding on Communities

Funding for externally-administered activities for children affected by AIDS in sub-Saharan Africa has increased substantially in recent years. Further increases are projected — for instance, the United States government has earmarked 10% of its HIV and AIDS funding towards programmes for orphans and vulnerable children, amounting to some us\$4 billion over five years.

If this funding is used wisely, it could do immeasurable good for millions of vulnerable children. But used inappropriately, such massive amounts of external funding have the potential to undermine community responses. A proverb from the Congo warns: *“When you call for rain, remember to protect the banana trees.”* In other words, new resource inflows must be managed

carefully to avoid overwhelming existing local action. Some negative consequences of external programming are already being observed, including:

- The emergence of “briefcase community-based organizations (CBOs)” that take advantage of community-level funding opportunities. External organizations may wrongly view these CBOs as representing and benefiting the community and overlook more legitimate community-led responses needing support (Taylor, 2008\*).

### Box 6: Community Perspectives on Monitoring an Externally-Funded Programme for Orphans and Vulnerable Children in Mozambique

As part of the Scale Up Hope Program, Save the Children/US mobilized 50 committees in 5 districts to provide support to vulnerable children. Community “ovc Committees” meet frequently and monitor the number and types of services provided to children as required by the donor. Data are reported on a quarterly basis. Focus group discussions were conducted in 10 villages in Gaza Province, with community groups involved in monitoring. The research found that:

- No community committee was involved in development of the data collection instruments.
- Frequent changes of reporting formats were a major cause of confusion, as was the use of different forms for different donors.
- Data collection focused more on counting children and activities than assessing the impact of services on child well-being.
- Data collection was more difficult for “softer” support services (e.g. psychosocial support) than for concrete distribution activities.
- No committee reported systematic analysis or use of data for their own decision-making, planning, and advocacy purposes due to lack of time and perceived relevance.
- There was no linkage of community-level data to government structures at any level.

Source: Blackett-Dibinga & Sussman, 2008.

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A proverb from the Congo warns: *“When you call for rain, remember to protect the banana trees.”*

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- Some community groups are redirecting their accountability to external sources of funding and away from the communities that they serve.
- With the influx of external funding, community contributions are being withdrawn, thus increasing the risk that support efforts may collapse if external funding flows are reduced, interrupted, or discontinued (Heymann & Kidman, 2008).
- Community initiatives are being “mobilized” by external organizations to undertake their work. While taking advantage of the goodwill and availability of unpaid community volunteers, mostly women, these organizations provide few opportunities for community members to engage in decision-making around programme design, delivery, or monitoring (Blackett-Dibinga & Sussman, 2008; Heymann & Kidman, 2008; Nshakira & Taylor, 2008).

The solution is not to reduce urgently needed external support for programming at community level. The answer is for governments and international partners to take deliberate steps to ensure that programme models and resource flows match community needs and support the effective community-led responses already taking place. Critical to this outcome is more effective coordination among different stakeholders, informed by substantive community participation.

## The Need for Coordination

In many countries, the proliferation of external initiatives operating at community level without meaningful oversight has led to duplication, confusion, and undermining of local efforts. Each external agency sets its own rules for engaging with community groups, almost always with good intentions, but too often neglecting community voice and priorities. The results include inequitable distribution of services and support; reduced impacts from programming; and missed opportunities to build trust and nurture capacity within local organizations. As the number of external agencies seeking to operate and establish partnerships at grassroots level multiplies, and as the financial stakes grow, the need for effective coordination among actors becomes more acute.

Coordination cannot be achieved by piecemeal negotiations among individual actors. It requires a systematic approach at national level. National government is the appropriate authority to lead this process and establish ground rules for the interaction of international institutions with communities. Coordinating shared action between external agencies and communities is part of a broader process of stakeholder alignment critical to deliver better outcomes for children (Foster, 2008).





## Principles for Collaboration with Communities

Coordination between external actors and communities will take different forms in different country contexts, but certain core principles apply in all settings:

- **Community action must be strengthened: community initiatives are primary; external agencies must support and facilitate.** Community support for AIDS-affected children and families has been critical to protecting children from the worst effects of the epidemic. External resources and technical assistance from external agencies are key but should complement, not replace, community action.

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Communities should have a determining voice in how resources for affected children are allocated and used in their local settings.

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- **Communities must be centrally involved in decision-making.** Communities should have a determining voice in how resources for affected children are allocated and used in their local settings. Donors and implementing agencies



must create mechanisms for regular, substantive community consultation and involvement in the design, implementation, monitoring, and evaluation of externally-funded programmes that support children affected by AIDS.

- **Resources must be channelled to communities in appropriate ways.** Outside resources must be distributed using mechanisms and timelines that respect community processes and enable community groups to increase their effectiveness and expand the scale of their response. There is no single model for effective resource delivery at a national and local level. Context, needs, and capacities of communities must be taken into account. Communities should be enabled to access and monitor external resources to sustain their activities, expand their scale and scope, and establish or develop economic strengthening activities that maintain community safety nets.
- **Children must participate.** Affected children and youth should take part in defining the goals and methods of programmes that are conducted for their benefit. Their voices should be clearly heard in evaluating programme success (Fleming, Vatsia & Brakarsh, 2008). The international Convention on the Rights of the Child and the African Charter on the Rights and Welfare of the Child set the ethical and legal foundation of children's participation.
- **Community efforts and donor action must both be aligned with evidence-informed national policy.** Successful coordination depends on external agencies and civil society groups aligning their activities with national plans. The broader alignment process involves donor harmonization, national coordination of activities, and unified reporting systems (OECD, 2008\*). Grassroots community groups often lack information on national policies, but more established NGOs may play a mentoring role in helping smaller groups align their efforts.

## Three Strategies to Strengthen Coordination

JLICA recommends the adoption of three specific strategies to reinforce alignment and ensure that community action is appropriately supported (Foster, Deshmukh & Adams, 2008):

**1. District committees:** Where these do not exist, district committees should be established to maintain an active register of community-level activities supporting children and families affected by HIV and AIDS. This is a critical basic step to enabling more effective coordination and technical support.

**2. Resource tracking and aid effectiveness:** Working groups involving both government and civil society should be established to make recommendations on how to track and monitor external resources intended for children affected by HIV and AIDS. Crucial in these discussions is the need for systems of accountability that are understood by and useful to communities.

**3. Best practice frameworks for partnership and accountability:** National authorities coordinating

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Community efforts and donor action must both be aligned with evidence-informed national policy.

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the response to children affected by HIV and AIDS should develop frameworks of best practice to guide all actors (international development partners, government, civil society, and communities) in supporting children and families affected by AIDS. Some areas of focus include:

- Implementing partnerships among actors at different levels, which clearly spell out mutual rights, responsibilities, and expectations;
- Building community capacities around best practices and national policies;
- Mapping and regularly updating information on: (a) the needs of children and families; (b) initiatives in place to meet these needs at all levels (community, district, and national); and (c) the flow of resources to support these initiatives;
- Periodic participatory monitoring, review, and learning as integral elements of community-based interventions.



Together, these strategies provide concrete ways to more effectively align the action of community groups, donors, and national authorities. Implementing these measures will help ensure that the resources brought into communities by outside agencies yield maximum benefit for local people. It will also create frameworks within which community-based groups that best understand the needs of affected children and families can articulate these perspectives and press for changes to make policy and programming more responsive.

In the absence of adequate government response, local social networks and community groups across sub-Saharan Africa have organized to provide support to children and families affected by HIV and AIDS. Community action has addressed a broad range of needs, from supplying basic material necessities to caring for families' psychosocial and

spiritual well-being. On many fronts, communities have irreplaceable competencies that must remain central to an effective response. Urgent, unmet needs, however, have forced community groups to provide other forms of support that they are less well suited to deliver. Financial support to affected families is a clear example. Community action in this area has generally been a case of the extremely poor giving to the destitute. Such generosity has relieved suffering and saved numerous lives. But this model is neither morally acceptable nor sustainable. Government-led economic strengthening policies for families, if appropriately designed and delivered, could free communities from responsibilities that they are not well placed to shoulder and, therefore, reinforce community action in other areas where it adds unique value. The next chapter describes how states can best deliver the economic support to families that remains a critical missing piece in the response to children affected by HIV and AIDS.



# CHAPTER 4 The Critical Lever: Investing in Social Protection

Economic strengthening for families affected by AIDS is crucial to improving outcomes for children. This chapter presents evidence on the most effective actions that countries can take to provide vulnerable families with basic economic security. It argues that national social protection policies are the best tools for this task and shows that income transfers can be an especially effective approach. The chapter identifies six key advantages of income transfer programmes, and details how they benefit children. It looks at the pros and cons of different transfer models and addresses the question of their affordability. It emphasizes, however, that income transfers are not a “magic bullet.” They should and can work as the leading edge of a broader social protection agenda.

## **Tackling Vulnerability Through Social Protection**

The vulnerability of poor people can be addressed in different ways, including by encouraging private charity or stimulating economic growth. But national social protection policies have proved best at responding to the urgent needs of families and children living in extreme destitution. Many of today’s high-income countries adopted such policies during their phases of rapid economic expansion, and these measures played a key role in reducing poverty, overcoming social exclusion, and building human capital.

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Asterisks indicate non-JLICA sources.

Social protection is an umbrella term for measures that aim to reduce the vulnerability and risks faced by poor people and other disadvantaged social groups. A key facet of social protection involves supporting people who are temporarily or permanently unable to earn their own livelihoods as a result of age, illness, disability, discrimination, or other constraints (Adato & Bassett, 2008). Social protection encompasses both economic and non-economic approaches. Typical measures include:

- food distribution programmes for people facing emergencies or chronic food insecurity
- social security income transfers for people experiencing unemployment, poverty, disability, or other forms of vulnerability
- child and adult education and skills-strengthening, especially universal primary education
- early child development interventions
- school feeding programmes
- public works projects (cash for work or food for work schemes)
- health or asset insurance
- livelihoods programmes
- microcredit programmes.

Social protection for developing countries has moved firmly onto the development agenda recently as political support for its role in social development grows and evidence of its benefits mounts (African Union Commission, 2008\*; Adato & Bassett, 2008).

## How Should Governments Choose?

Many social protection measures could benefit children and families affected by HIV and AIDS. How should governments choose among these options? Along with proven effectiveness, political viability is a critical consideration. To understand the factors that increase viability, JLICA has linked empirical study of national policy processes in sub-Saharan Africa to a political science analysis of what generally makes good policy. The results pinpoint four essential characteristics shared by social policies relevant to children affected by AIDS that have been successfully implemented in the region. Successful policies:

■ **Are simple in basic conception.** The aims of successful policies can be stated in plain language—“a decent education for all,” or “provide resources to very poor families.” They have a simple, direct mechanism that is easily understood by all concerned. Once a programme is well established, it may evolve to become more complex.

■ **Make modest demands on institutions.** Many of the most effective social protection programmes involve one single line ministry—for example, Universal Primary Education in Tanzania or the Child Support Grant in South Africa. Implementation is straightforward for existing national institutions and mechanisms, without imposing major additional burdens on governments already facing capacity constraints (de Waal & Mamdani, 2008).

■ **Tap into broadly shared public concerns.** Populist policies are not always desirable, but policies are more likely to be sustainable if many people stand to benefit. African public opinion surveys regularly find that employment, education, and general health are major concerns, while people express less concern about HIV and AIDS. The support of national civil society organizations is also important. A policy that allows space for popular engagement and monitoring—for example, district-level scrutiny of budgets and spending—makes for stronger outcomes.

JLICA case studies suggest that, when African governments have adopted policies on popular issues, such as universal primary education, they have proved politically sustainable despite prior scepticism from international experts (Mamdani et al., 2008).

■ **Are AIDS-sensitive, not AIDS-targeted.** AIDS-sensitive policies explicitly pursue wider social goals (e.g. education, poverty alleviation), while addressing problems associated with HIV and AIDS as an additional benefit. Social protection measures that are universal or else targeted using a familiar social criterion, such as extreme poverty, are generally the most progressive and cost-effective. Aside from the practical problems posed, explicitly targeting “AIDS orphans” or restricting benefits only to children affected by AIDS is likely to undermine the political viability of any proposal (de Waal & Mamdani, 2008).

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Successful social policies relevant to children affected by AIDS are simple in basic conception, make modest demands on institutions, tap into broadly shared public concerns, and are AIDS-sensitive, not AIDS-targeted.

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## Getting the Basics Right

JLICA's policy analysis found that, while elaborate, multisectoral strategies may appear desirable as countries grapple with complex problems, the most fruitful approach is to “get the basics right”—focus first on doing a few relatively simple things well and bringing them to scale.

The core question is what measures can be put in place to promote the well-being of all children in a sustainable manner. In many sub-Saharan African countries, where poverty is pervasive, children under 18 account for half the population, and many children live below the food poverty line. The challenge is therefore fundamentally one of meeting needs and realizing rights equitably. Policy responses must ensure that economic growth translates into development at the grassroots level; protect those who are not in a position to benefit immediately from growth-oriented policies; and build human capabilities fairly. Successful approaches should address children affected by AIDS by ensuring that all children's basic needs are met (de Waal & Mamdani, 2008).



## The Fundamentals of Income Transfer Programmes

Choices among social protection options must reflect national contexts, priorities, and political opportunities; no single solution can be applied in all countries. In the short term, many countries will prioritize measures that show promise to deliver rapid results for the most vulnerable families and children, while working as the leading edge of a broader social protection agenda. A strong argument can be made that income transfer programmes will be especially effective in this role.

Income transfers are cash disbursements to individuals or households identified as highly vulnerable, with the objective of alleviating poverty or reducing vulnerability. A milestone study carried out for JLICA (Adato & Bassett, 2008) reviewed over 300 documents describing and evaluating income transfer programmes in middle- and low-income countries. Such programmes have demonstrated benefits to children's nutrition, growth, education, health status, and use of health services in the past decade. Based on this evidence, JLICA recommends that income transfer programmes be rapidly implemented in countries severely affected by HIV and AIDS, using models tailored to national contexts.

The basic principle of income transfers is simple: put money in the hands of poor people. Transfers may be directed to households that meet poverty or vulnerability criteria; elderly or disabled individuals; families with children or, specifically, with girls; or families that have taken in orphans. Transfers may be unconditional or linked to participation in work, training, education, or other services. Mexico's rigorously evaluated *Oportunidades* programme sets three conditions for receiving income transfers: children's regular school attendance; routine visits by family members to health clinics; and participation in an improved nutrition programme.

Forms of income transfer programmes especially relevant to African policy contexts include:

- Unconditional income transfers to households living in extreme poverty (and/or meeting other selection criteria);
- Child poverty support grants (the South African Child Support Grant is a widely discussed model of this type);
- Old age pensions.

Evidence suggests that all of these types of transfers are likely to bring significant benefits to vulnerable children. It may appear surprising that old age pensions help children, but results from several countries confirm that households that include pension recipients increase spending related to children's welfare, for example on food. Studies have documented positive impacts of the South African old age pension on children's growth in recipient households, particularly for girls (Adato & Bassett, 2008). In addition, old age pensions are politically popular and can compete successfully for scarce budget resources. Both Botswana and Lesotho have recently introduced national old age pension schemes, joining a growing number of sub-Saharan African countries that have such programmes in place, or are considering them (Adato & Bassett, 2008).

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JLICA recommends that income transfer programmes be rapidly implemented in countries severely affected by HIV and AIDS, using models tailored to national contexts.

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## Six Advantages of Income Transfer Programmes

Income transfer programmes score well relative to other social protection policy options in terms of their cost, the level of implementation capacities that they require, and the ease and speed with which they can be scaled up. For families affected by HIV and AIDS living in extreme poverty, income transfer programmes have six major strengths.

### Income Transfers:

**1. Are efficient and direct:** Transfers put resources straight into the hands of people in great need. This approach contrasts with many forms of poverty relief, which involve money passing through numerous intermediary agencies, reducing the amount ultimately available to households. Transfers make it relatively easy to track flows of money, improving accountability and reducing the scope for waste and diversion of funds. For beneficiaries, income transfers deliver tangible benefits rapidly. Even a small amount of cash can make a difference in the living conditions of a poor family. And, in contrast to in-kind transfers (of food, for example), income transfers give families the dignity of choosing which areas of their lives require most immediate investment. Cash also gives families flexibility to change and adapt their strategies as conditions evolve.

**2. Do not require families to have pre-existing capacities:** Income transfers are apt for helping the most fragile families — those weakened by multiple stresses that may include hunger, chronic illness, and the death of family members. Destitute families debilitated by HIV and AIDS often lack even the relatively low levels of pre-existing capacities that are necessary to benefit from some other social protection strategies, such as food for work or cash for work programmes or microcredit schemes. In contrast, even the most disadvantaged families can immediately use cash in ways that benefit children.



### 3. Empower women and reduce gender

**inequalities:** Income transfers delivered to female members of households have been shown to improve women’s economic status; contribute to more equitable decision-making processes within families; and improve outcomes for children. Designating women to receive and manage family income transfers has been a very successful design feature in Latin American programmes (and elsewhere). Income transfers delivered to women constitute a structural intervention to reduce gender inequalities and, thus, women’s vulnerability in the context of HIV and AIDS.

### 4. Serve as a springboard to other services:

As income transfers enable them to escape from crisis management, very vulnerable families are in a position to benefit from additional social protection measures that demand greater capacities. For example, a family that has achieved an initial level of stability as a result of an income transfer might subsequently “graduate” to a microcredit programme.

**5. Are relatively simple to administer:** While middle-income countries such as Brazil, Mexico, and South Africa have developed more administratively sophisticated versions, basic income transfer programmes are comparatively simple to administer and have operated successfully in low-income countries with much weaker infrastructure, such as Bangladesh, Lesotho, Mozambique, and Nicaragua. Basic schemes require only adequate funds and a simple delivery and management structure.

**6. Are AIDS-sensitive:** In Malawi and Zambia, pilot income transfer programmes have been implemented in areas of high HIV prevalence but have targeted families based on poverty, not HIV status. A UNICEF-sponsored evaluation of the programmes found them to be highly AIDS-sensitive. It was estimated that about 70% of beneficiary families were affected by HIV and AIDS (Adato & Bassett, 2008; UNICEF, 2007\*).

## How Children Benefit

The following examples illustrate the benefits that income transfer programmes achieve for children. These data are just a small sample of a robust body of evidence (Adato & Bassett, 2008).

### Education

- In South Africa, children living in households with a female pensioner who receives the Old Age Pension show significantly improved school attendance. These households experience a one-third reduction in the school non-attendance gap that affects the children of poor families (Adato & Bassett, 2008; Samson et al., 2004\*).
- Evaluation of the scale-up of Malawi’s Mchinji Cash Transfer programme found that, after one year, the percentage of children newly enrolled in school was more than twice as high in intervention households (8.3%) relative to comparison households (3.4%). Over this period, a total of 96% of children from intervention households were enrolled in school compared to 84% of children in comparison households (Adato & Bassett, 2008; Miller, Tsoka & Reichert, 2008\*).
- Nicaragua’s Red de Protección Social conditional income transfer programme contributed to increasing school attendance rates by 20 percentage points on average (17% for girls, 23% for boys) and 33 percentage points for



the extremely poor. This was a combined effect of income transfers and interventions simultaneously undertaken to increase school capacity, such as employing more teachers (Adato & Bassett, 2008; Maluccio & Flores, 2005\*).

## Health

- Zambia’s Social Cash Transfer Scheme (SCTS) began a pilot phase in May 2004, and a comprehensive evaluation of the programme was published in October 2006. The incidence of illness among beneficiaries declined substantially between baseline and evaluation. The percentage of programme beneficiaries reporting some illness dropped from 43 to 35%. Children under 5 experienced a 12 percentage point reduction in the incidence of illness (Adato & Bassett, 2008; MCDSS/GTZ, 2006\*).
- A qualitative evaluation of Concern Worldwide’s Dowa Emergency Cash Transfer (DECT) project in Malawi found that recipients reported improved access to healthcare through greater purchasing power for expenses such as transportation, hospital bills, and medicines, leading to overall improvements in health and well-being. These improvements were important for groups with the weakest resistance to disease, such as malnourished individuals and those affected by HIV and AIDS (Adato & Bassett, 2008; Devereux et al., 2007\*).

Figure 3 shows improvements in uptake of health services associated with conditional income transfer programmes in Latin America.

## Food Consumption and Nutrition

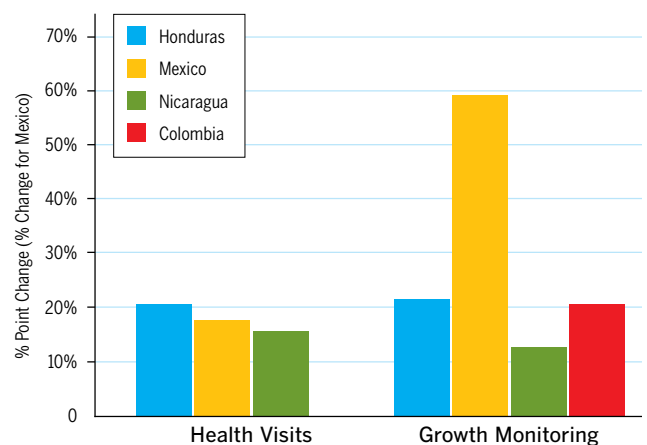
- Zambia’s Social Cash Transfer Scheme reduced the proportion of beneficiary households having only one meal a day from 19 to 13% and increased by 6 percentage points those eating 3 meals per day. Evaluators found a reduction from 56 to 34% in the number of

beneficiaries reporting hunger pangs after a meal, likely indicating an increase in the quantity of food consumed (Adato & Bassett, 2008; MCDSS/GTZ, 2006\*).

- Children who receive South Africa’s Child Support Grant (CSG) transfer before age two and continue to receive benefits during their first three years of life show significant improvement in height attainment. This gain in height is associated with increased future earnings in adulthood, which are estimated to be 60 to 130% higher than the cost of CSG support (Adato & Bassett, 2008; Agüero, Carter & Woolard, 2007\*).

Research shows that the largest portion of the transfer in most programmes is used to purchase food (Figure 4). The positive impact of income transfers on nutrition is noteworthy, given the critical importance of nutrition during the first three years of life for children’s physical health, cognitive development, and adult economic productivity.

**Figure 3: Impacts of Conditional Cash Transfers on Health Service Usage by Programme Beneficiaries**



Source: Adato & Bassett, 2008. Data from: Attanasio et al., 2005; Gertler, 2000; Gertler & Boyce, 2001; IFPRI, 2003; Maluccio & Flores, 2005.

NB: Upper estimates plotted in the graph for Mexico and Honduras. Data cited for Mexico represent percent change, while figures from other countries show percentage point increase.

## Targeting and Conditioning: Key Choices for Governments

Two important questions arise for governments and other agencies that are interested in implementing income transfer programmes to respond to the needs of children affected by HIV and AIDS: how to define the target beneficiary group, and whether and how to condition benefits.

JLICA strongly cautions against targeting benefits specifically to children or families affected by AIDS. A substantial body of evaluation literature suggests that doing so is likely to spur resentment among equally poor and needy households, intensify stigma against people living with HIV and their families, and create perverse incentives that undermine programme credibility and effectiveness. It is better to reach children and families affected by HIV and AIDS by using extreme poverty as the primary inclusion criterion. In high-burden settings, this form of targeting has been found to be highly AIDS-sensitive and can be made even more so if a poverty measure is connected with at least one additional criterion, such as the household dependency ratio (the number of economic dependents per able-bodied working adult) or the degree to which households are labour-constrained (lacking able-bodied adults).

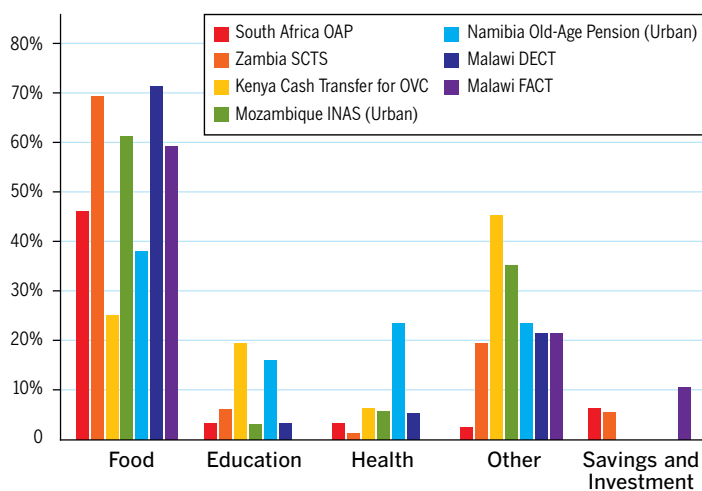
On the question of conditioning benefits, neither evidence nor expert opinion is conclusive. Concerns relate to African countries' administrative capacity to support conditional programmes and the availability of the services on which benefits would be contingent. Poor countries in Latin America and Asia have, however, used conditional income transfer programmes as an impetus to improve services, bringing in NGOs for implementation support where needed. This has resulted in substantial human capital impacts, and African countries could potentially obtain similar results (Adato & Bassett, 2008).

## Modest Investment, Strong Returns

A growing body of authoritative analysis asserts that any developing country, no matter how poor, can afford a social protection package for children affected by HIV and AIDS and extreme poverty. The International Labour Organization has costed a social protection package for low-income African countries—consisting of a small universal old age pension, universal primary education, free primary health, and a child benefit of US\$0.25 per day—at between 1.5 and 4.5% of Gross Domestic Product (Richter, 2008; Pal et al., 2005\*).

Income transfer programmes, in particular, are an affordable option, even for the poorest countries. A 2007 UNICEF evaluation of Malawi's pilot transfer scheme calculated that the programme could be scaled up to cover the poorest 10% of all households in Malawi for an annual cost of US\$42 million. The scheme would then be benefiting approximately 1 million people, including 650,000 defined as orphans and vulnerable children (Adato & Bassett, 2008; UNICEF, 2007\*). A recent Zambian

Figure 4: How Beneficiaries Use Income Transfers



Source: Adato & Bassett, 2008. Data from: Acacia Consultants, 2007; Devereux, 2002; Devereux, Mvula & Solomon, 2006; Devereux et al., 2007; MCDSS/GTZ, 2006; Moller & Ferreira, 2003.

NB: In the case of Zambia scrs, the figure represents the proportion of overall spending by beneficiaries on health. In the case of Malawi DECT, figures reflect 3 months of the 5-month programme period: January–March 2007.

pilot provided us\$15 per month to each of the poorest 10% of households. If such a transfer were implemented in all low-income countries in sub-Saharan Africa, it would cost only 3% of the aid to Africa agreed at the Gleneagles meeting of the G8 (Richter, 2008; DFID, 2005\*).

Arguably, the most compelling evidence for affordability of income transfers is the fact that some of the poorest countries in the world are already implementing transfer schemes using their own domestic resources. This is the case in Lesotho and Mozambique, for example. Botswana, Lesotho, Mauritius, and Nepal all have domestically financed universal old age pensions, which cost no more than 2% of GDP (Adato & Bassett, 2008; HelpAge International, 2006\*).

Redefining the target group for a social protection intervention from “orphans” to “the poorest 10 or 20 per cent of households,” as JLICA recommends, will significantly increase the number of beneficiaries. This decision has implications for programme costs. However, cost increases may be lower than they initially appear, because a family-centred approach allows benefit packages to be designed more rationally. Previously, economists costing benefits for affected children have often designed packages as if children had no resources at all and had to be given everything. In contrast, a family-centred approach recognizes that children and families already have some resources at their disposal (albeit inadequate). Benefit packages can therefore be adjusted accordingly, bringing per-child costs down. Moreover, programmes will not always require new money. The reorganization of existing expenditure can improve outcomes without demanding additional resources. Countries can shift from generally less-efficient to generally more-efficient solutions:

- From in-kind transfers to cash transfers
- From individualized to family-based services
- From high-overhead to low-overhead interventions.

With income transfers, as with most social programmes, there is an important sense in which “you get what you pay for.” Programmes with more resources, which are able to provide larger payments to families and connect cash with more robust complementary services, generally obtain better results. But in the case of income transfers, in contrast to some other interventions, even a modest investment has the capacity to change very poor families’ lives for the better in ways that benefit children. It is almost always possible to do more; ambitious and effective programmes have continued to evolve and expand over time. But without having to wait for ideal conditions, funds invested in transfers can do good immediately.

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Any developing country, no matter how poor, can afford a social protection package for children affected by HIV and AIDS and extreme poverty.

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## Using Income Transfers to Drive a Broader Social Protection Agenda

Income transfers are not a “magic bullet.” To work effectively, they must be linked to a wider array of social services for vulnerable families, as well as to systems that can deliver quality health care and education. High-performing Latin American conditional cash transfer programmes — for example in Brazil, Chile, and Mexico — owe much of their success to the close integration of transfers



with other services. Some programmes in more resource-constrained settings are also beginning to integrate income transfers with additional social protection services and complementary measures in health, education, and nutrition. For example, El Salvador's Red Solidaria transfer scheme is rolling out microcredit lending opportunities for beneficiary families, while an income transfer programme in Mozambique provides support for income-generating projects (Adato & Bassett, 2008). Malawi's Social Cash Transfer Scheme is linking with community-based organizations to provide access to early child development, psychosocial support, and home-based care services for transfer beneficiaries (Adato & Bassett, 2008). Such examples show how effective programme design can enable income transfers to work as the leading edge of a broader agenda of protection and support.

## **Social Protection: The Next Frontier in the AIDS Fight**

To date, many income transfers in Africa have been pilots led by NGOs and international organizations. Additional small-scale pilot projects are no longer required. The positive effects of income transfers are established. The critical factor now is national government leadership to take successful models to scale.



Governments will lead, but other actors are central to the effort. International agencies must support national policy and implementation processes, putting appropriate resources and technical cooperation at countries' disposal. Donors must be prepared to fund social protection for vulnerable children and families on its own merits, but also as a core component of the AIDS response. Equally critical, the social protection agenda needs the commitment of the civil society movements that have won historic victories in the AIDS fight.

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**The positive effects of income transfers are established. The critical factor now is national government leadership to take successful models to scale.**

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At many points in the epidemic, HIV and AIDS have brought human rights challenges into sharp focus. Fighting AIDS has demanded efforts to tackle stigma and discrimination, exclusion from school and work, gender power imbalances, and inequities in treatment access. The response has provided an impetus to challenge abuse and stand up for human rights and dignity (Richter, 2008). Today, AIDS civil society continues the struggle for Universal Access to prevention, treatment, care, and support, while widening its scope to encompass issues like health systems strengthening.

Social protection for the poorest and most vulnerable families is the next logical step in this progression. Without the economic strengthening that national social protection programmes can provide, Universal Access will remain an empty promise for many of those in need, even if coverage of HIV and AIDS services continues to expand. Fighting for access to services is not enough, if poverty, inequality, and social exclusion continue to prevent people from reaping the benefits of services. The same determination that spurs the ongoing fight for treatment should now be brought to bear on realizing the right of the poorest families in the poorest countries to social protection (Richter, 2008).



# CHAPTER 5 Making Services Work for Children

As income transfers roll out, national systems must be prepared to meet a rising demand for services.

Responding will challenge health systems capacities in many high-burden countries, where services for children affected by HIV and AIDS face substantial implementation failures. This chapter recommends strategies to strengthen key services for children and families in the context of AIDS.

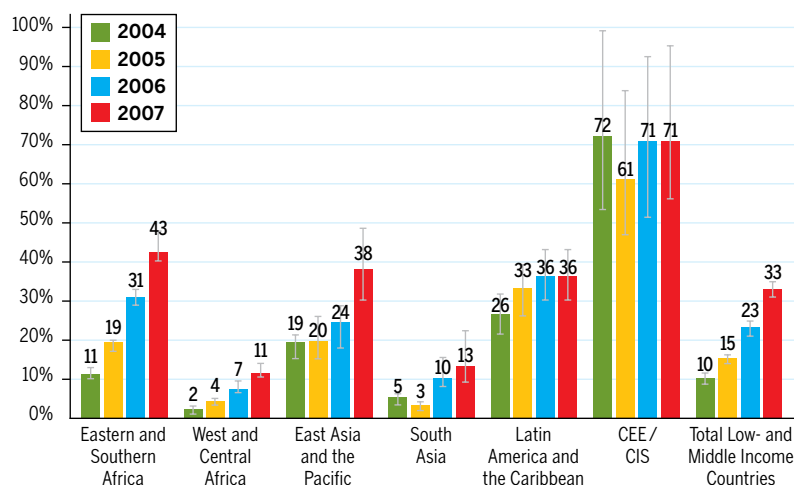
It argues that services work best for children when they are provided through integrated, family-centred delivery models, and it identifies four features that characterize especially successful models. Then it describes two practical tools that programme planners and implementers can use to reconfigure programmes and improve results. Finally, it identifies factors that have facilitated some countries' efforts to begin taking promising integrated programme models to national scale.

## The Implementation Challenge

Today, the well-being and life-chances of children affected by HIV and AIDS are undermined by implementation failures in many essential health services (Baingana et al., 2008) (Figure 5). Tackling

Asterisks indicate non-JLICA sources.

**Figure 5: Percentage of HIV-Infected Pregnant Women Who Received Antiretrovirals for PMTCT, 2004 – 2007**



Source: UNICEF, 2008d. The lines on the bars show the uncertainty bounds for the estimates.

these failures will require both substantial new investments in national health systems and fresh implementation strategies to deliver services more effectively at the local level. What causes implementation gaps, and how can they be overcome? What delivery strategies have generated the best results for children, and how can they be expanded? JLICA has shed fresh light on these pragmatic questions — through analysis of the published evidence and programme documentation, but also by conducting field-based implementation projects that have generated new evidence (JLICA Learning Group 3, 2008).

## Integrated Family-Centred Services Work Best for Children

JLICA's analysis of service delivery models found that programmes obtain the best results for children when they adopt integrated intervention strategies providing a range of services to the whole family. The most effective delivery systems integrate HIV and AIDS services with family-centred primary health care and social services provided through community-based models. Service integration becomes still more critical in light of the growing health and social impacts that communities face from entwined epidemics of HIV and TB (Baingana et al., 2008).

To understand how implementers are tackling the challenges of integrated services, JLICA has reviewed existing programmes for children and families affected by AIDS that are achieving strong results. It is important to acknowledge that evidence on programme performance in many heavily-burdened

countries is thin; significant additional investment in programme evaluation will be required as services for vulnerable children and families expand. Meanwhile, drawing on the currently available data, JLICA has been able to identify key factors shared by highly effective delivery models (Kim et al., 2008b). High-quality, high-impact programmes that show promise for national scale-up often have the following characteristics:

### 1. Government-Led Partnerships

Diversified partnerships coordinated by national governments have been found to yield strong results in delivering services for children. Contributing partners may include national and international NGOs; international agencies; academic institutions; donors; local governments; and community groups (Binagwaho et al., 2008; Sullivan et al., 2008; Zoll, 2008).

#### **Box 7: Meeting Children's Needs in Multiple Dimensions: Rwanda's National Strategy for Vulnerable Children**

Rwanda's post-genocide government under President Paul Kagame has made children's well-being a key policy focus. Rwanda established a National Policy on orphans and vulnerable children in 2003 and operationalized the policy through a National Strategic Plan in 2007. The plan features: (1) a comprehensive approach to children's welfare, embodied in a multidimensional service package; and (2) a distinctive programme structure that assigns key responsibilities to local government, NGO implementers, and community groups, under national government oversight.

The Strategic Plan identifies six essential areas in which children need services: health, nutrition, education, protection from abuse, psychosocial well-being, and social-economic support. The national government sets goals, directions, and standards to promote children's welfare holistically across these dimensions. Local governments, led by district mayors, formulate plans to meet national objectives within their

specific jurisdictions; objectives for vulnerable children become part of mayors' performance contract (*Imihigo*) with the national authorities. NGOs and community organizations are responsible for implementation of services, with local government ensuring coordination among providers and community members identifying children in need.

Rwanda's Strategic Plan for vulnerable children is still in its early stages of implementation. Key challenges include limited resources and the need to strengthen coordination and referral linkages among NGO implementers. Rwanda's family-centred approach to meeting children's needs has already yielded remarkable gains, however. While some 52% of the country's population is under the age of 18, and the total number of orphans and vulnerable children is estimated at 1.3 million, today only 3,500 Rwandan children remain in orphanages.

Sources: Binagwaho et al., 2008; Ngabonziza, 2008\*



Strong national government leadership facilitates the partnership by defining objectives in line with national development goals; setting and enforcing ground rules for collaboration; and ensuring that appropriate standards, including equity principles, are upheld as services roll out. National leadership and standard-setting are not incompatible with decentralization, flexibility, and responsiveness to local needs. On the contrary, successful decentralization of decision-making and resource flows depends on national coordination to ensure equity.

Rwanda's National Policy and Strategic Plan for Orphans and Vulnerable Children illustrate this approach. Rwanda is seeking to institute comprehensive national programming for children affected by HIV and AIDS and other vulnerable children, within a national political context of decentralization and ambitious institutional reform. Rwanda's policy is not focused solely on AIDS. It harnesses the resources of the AIDS fight to drive a more inclusive response to vulnerable children, in line with national development objectives (Box 7).

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In Kenya, beneficiaries refused fragmented service models — and demanded that programmes listen.

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## 2. Programmes that “Listen” and Respond to Multiple Needs

A key factor in some programmes' strong performance is the commitment to listen continuously to patients and their families and adapt service priorities to clients' needs. In many cases, this means ensuring links between medical care and additional support services in areas like food security and family economic strengthening.

Health care delivery typically tends to compartmentalize needs and separate clinical interventions off from other parts of people's lives. But patients themselves may refuse this fragmented approach — and demand that programmes

listen. The experience of Kenya's Academic Model for Prevention and Treatment of HIV/AIDS (AMPATH) programme is revealing. In response to patient demand, AMPATH first developed an ambitious family food support model as part of its AIDS treatment programme, which currently delivers free antiretroviral treatment (ART) to more than 50,000 patients. As food support to ART patients and their families rolled out, AMPATH implementers found that, after several months of treatment and an adequate diet, clients almost always began to request assistance to become more economically productive. The Family Preservation Initiative (FPI) was launched in response. The programme offers patients and their families access to a range of livelihoods services and opportunities, including skills training, microcredit, and opportunities to participate in farming cooperatives. For AMPATH, the take-home message is that successful AIDS care has to give attention to people's “stomachs, spirits and bank accounts” (Zoll, 2008).

Health care programmes need not themselves provide direct social support or livelihood opportunities to patients. Programmes can connect families to such opportunities through referral systems and linkages to public sector or NGO programmes for social support and family economic strengthening — including income transfers. As transfers and other social protection interventions expand their coverage, a critical requirement is to ensure functional, two-way referral linkages between these programmes and clinical health services. Proper handling of these links is vital to harness the ability of income transfers to drive expanded uptake of HIV and AIDS services. Already, pilot income transfer schemes such as Zambia's have begun to establish pathways for these links, for example, by partnering with local NGOs and community groups to offer health information and referral counselling at income transfer pay points (Kelly, 2008\*; cf. Adato & Bassett, 2008). Platforms of this kind, in which people can access “bundled” services that address a range of needs

simultaneously, offer a promising avenue for innovation to improve responsiveness. Ongoing operational research will be needed to test and refine solutions as programmes roll out.

### 3. Focus on Protecting Children's Human Capital

Highly effective programmes prioritize integrated interventions that secure children's human capital — in particular, nutrition, early childhood development (ECD), and education services.

Linking interventions in these areas to family-centred primary health care, including HIV and AIDS services, provides an especially effective means of strengthening children's chances for a better future, while responding to children's and families' short-term needs.

Integrated service models targeted at very poor families have been successfully rolled out to national scale in Latin American countries such as Brazil, Chile, and Mexico. Ways in which lessons from Latin American experiences and from high-income countries might be applied in Africa, despite the vast contextual differences, are being actively explored (Kim et al., 2008b; Adato & Bassett, 2008; Irwin, Siddiqi & Hertzman, 2007\*; cf. Commission on Social Determinants of Health, 2008\*). In Africa, NGOs have often taken the lead in developing integrated models and demonstrating their impact. CARE's "5x5" model of integrated, community-based early childhood services is one such promising programme framework. This model uses early childhood development centres in AIDS-affected communities as a base from which to deliver a range of services that reinforce human capital, including: education and early stimulation

#### **Box 8: Integrated, Family-Centred Support for Children: The FXB Village Model**

The Village Model, developed by the NGO FXB International, is an integrated strategy of support to children and families living in extreme poverty in communities affected by HIV and AIDS. Targeting those households that local community leaders identify as most vulnerable, the programme aims to create a lasting foundation for children's well-being by strengthening family capacities in multiple dimensions during a three-year, phased process. The model has been successfully implemented in communities in Burundi, India, Rwanda, Thailand and Uganda.

Each participating family receives a comprehensive package of support and skills-building. The package addresses basic survival needs such as food, water, sanitation, and health care (including HIV prevention and antiretroviral therapy, if required). It also encompasses psychosocial support to family members and legal protection for children. In addition, the programme provides skills to prepare families for a better future, including education for all school-age children and training to develop long-term,

independent livelihoods strategies. Families with FXB's support participate in both individual and group income generating projects. Group activities are important not only because they are sources of revenue, but also because they strengthen community relationships and reduce stigma. Programme support to families is progressively scaled back over the three years until families "graduate" and can live autonomously.

Independent evaluations have documented significant, sustained gains in well-being for children and families that participate in the Village Model programme. Children in FXB Villages enrol, remain, and advance in school at higher rates than their peers. Over 85% of participating families progress from extreme poverty to self-sufficiency within three years and maintain steady levels of income thereafter. The Village Model shows that strengthening family capacities through integrated support enables sustained improvement in children's outcomes.

Sources: FXB International, 2008\*; Desmond, 2007\*.

for young children; nutrition; essential child health interventions; family economic strengthening; and other social support services (Zoll, 2008). FXB International’s “Village Model” is a comprehensive family-centred support system that builds children’s human capital in multiple dimensions by strengthening family caring capacities (Box 8).

In some African countries, governments are increasingly capitalizing on the potential of schools as platforms from which to deliver integrated services that can support children’s physical, cognitive, and social development and strengthen families. UNICEF has advanced this agenda through its “Learning Plus” initiative (Box 9).

#### 4. Community Health Workers

JLICA’s analysis found that programmes achieving exceptional results for children and families generally incorporate community-based delivery systems. They often use well-trained and appropriately compensated community health workers to deliver key interventions. In the best cases, a community health worker model is the “glue” that binds together the different dimensions of an integrated, family-centred approach.

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Community health workers bring services directly to families in their homes, strengthening programme impact.

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As the backbone of a local primary health care system, community health workers are able to bring key services directly to families in their homes, multiplying programme coverage and impact, especially in rural areas. Skilled local workers can provide health interventions and referrals but also crucial forms of culturally appropriate psychosocial support. Training and compensating community health workers also tangibly boosts the local economy. Successful programmes demonstrate that community health workers can relieve excessive workloads on more specialized health care personnel and accelerate

scale-up of key programmes by breaking human resources bottlenecks that are often the major obstacle to programme expansion (Baingana et al., 2008; Kim et al., 2008b; Zoll, 2008).

The deployment of lay HIV counsellors has been an important enabling factor in rolling out Botswana’s widely-acclaimed national PMCT programme (Khan et al., 2008; Sullivan et al., 2008). Early in the programme’s development, the burden of counselling duties on nurses was identified as a bottleneck to expanding coverage. Botswana’s Ministry of Health noted Uganda’s

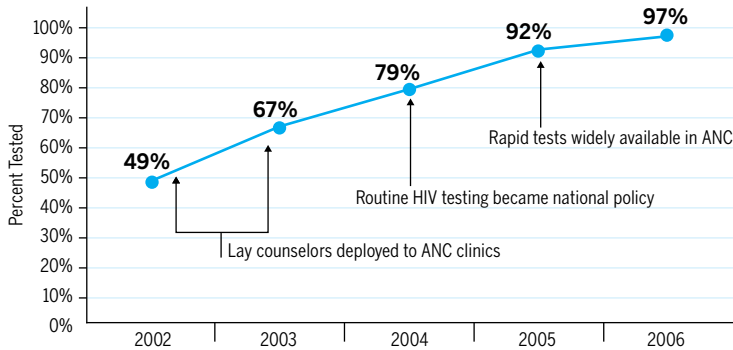
#### **Box 9: Delivering Multiple Services Through Schools: “Learning Plus”**

In September 2005, 13 countries in Eastern and Southern Africa jointly committed to strengthening their national education systems using the UNICEF-sponsored “Learning Plus” approach, which harnesses schools as integrated support centres for children and families. Learning Plus uses schools to deliver child and family welfare services, such as feeding programmes; health interventions, including vaccination, micronutrient supplementation, and deworming; and HIV prevention.

Swaziland is one of the countries in which this strategy has advanced most successfully. The Ministry of Education began bringing additional child and family services into schools in pilot areas under the “Schools as Centres of Care and Support” initiative in 2005, and initial results convinced the government to expand the programme to reach schools throughout the country. Donor agencies have complemented government action by supporting the construction of additional classrooms at many sites, expanding access to education and reducing school crowding. Communities have participated in equipping schools to fulfil their new role. Parents have organized to transport clean water to schools and provide labour to build kitchens for school feeding.

Source: UNICEF, 2008c\*.

**Figure 6: Percentage of Women in Botswana Delivering in a Hospital Who Were Tested for HIV During Pregnancy or Postpartum, and Interventions Undertaken to Increase Testing**



Source: Sullivan et al., 2008; Data from BOTUSA.

successful engagement of lay HIV counsellors as a means of unburdening health professionals from time-consuming counselling demands. Botswana began training and deploying lay counsellors to perform HIV counselling and testing services for pregnant women in 2003. The lay worker model has enabled improvements in adherence and contributed to the PMTCT programme’s subsequent rapid gains in uptake (Figure 6).

## Tools to Inform Practice and Policy: Value Chain Analysis and the Learning Collaborative

In addition to analyzing high-performing programmes to understand the factors that have enabled their success, JLICA has tested tools that policy-makers, planners, and implementers can use to improve programmes on the ground. Two promising approaches are: (1) programme planning using the Care Delivery Value Chain; and (2) the Learning Collaborative model of health care quality improvement.

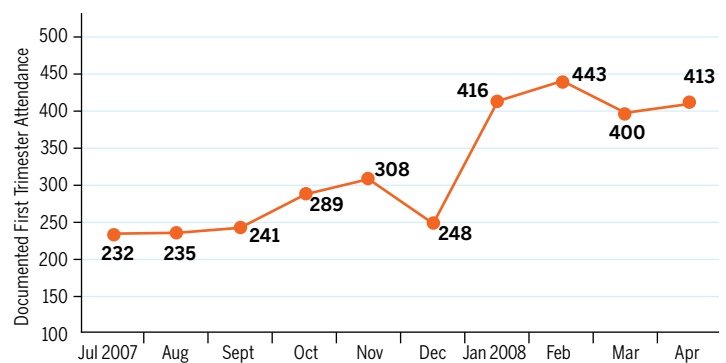
Programme design for children and families affected by AIDS has much to learn from

the experience of the business world in managing complex delivery processes. The Care Delivery Value Chain (CDVC) is a management tool that shows promise to strengthen health care programme planning in low-resource settings. JLICA used the CDVC lens to locate structural flaws in PMTCT delivery and identify options for strengthening programme design and performance. The results suggest that value chain analysis can be an important tool for realigning programmes to deliver maximum health benefit for children and families (Box 10).

To better understand what the delivery challenges are in frontline services and how they can be overcome, JLICA joined with the Government of Rwanda, NGO partners, and community groups in launching a quality improvement implementation project to strengthen maternal and child health services at 17 health centres in rural eastern Rwanda, beginning in July 2007.

The project aimed to improve delivery of PMTCT and other services at participating health centres but also to examine the effectiveness in a low-

**Figure 7: Increase in First-Trimester Antenatal Clinic Attendance at Health Centres Participating in the Rwanda Learning Collaborative**



Source: JLICA Learning Group 3, 2008.

### **Box 10: Improving PMTCT Programmes with the Care Delivery Value Chain (CDVC)**

The CDVC is a strategic framework that facilitates analysis of how health interventions deliver *value* for patients, defined as “health outcome per dollar spent”— in other words, how much the patient’s health is improved for each dollar invested. The CDVC framework helps planners: (1) determine how best to configure health care programmes to maximize value for patients; and (2) study the structure of the delivery process to identify critical bottlenecks in care delivery that reduce value.

JLICA applied the CDVC framework to the design of PMTCT programmes. CDVC analysis identifies the later postpartum period as a phase in which breakdowns in the care delivery cycle are very frequent, particularly for HIV-exposed infants. Administration of antiretroviral prophylaxis to the newborn child should be linked to timely, reliable HIV diagnostics for the infant, as well as a broader set of child health services that can counterbalance the high risks of loss to follow-up during this phase. Home visits to new mothers and infants by community health workers during the postpartum phase can help break a dangerous bottleneck in the flow of care. Programmes that actively maintain contact with families through home visits can substantially reduce loss to follow-up, compared with programmes that rely on new mothers’ bringing infants to the clinic.

Source: Khan et al., 2008.

resource setting of a specific quality improvement methodology: the Breakthrough Series Learning Collaborative model, developed by the Institute for Healthcare Improvement (Institute for Healthcare Improvement, 2003\*). The Learning Collaborative provides a framework for teams of health-care providers to implement and test changes in their care delivery procedures using structured cycles of planning, action, evaluation, and knowledge sharing over an 18-month period.

The Rwanda Learning Collaborative generated impressive results, enabling improvements in programme performance indicators for PMTCT and other services at participating health centres (JLICA Learning Group 3, 2008) (Figure 7).

The positive results point to potential wider applications of the Learning Collaborative approach in facilitating multi-stakeholder policy and implementation processes. Such processes are vital to scale up essential services in areas affected by AIDS and poverty, where delivery capacities are constrained, and many partners must coordinate their efforts to achieve results. In Rwanda, the Learning Collaborative created a structured forum for dialogue among NGOs and other stakeholders that have tended to view programme challenges differently and to adopt contrasting solutions. Communication, mutual understanding, and collaboration improved as a result. The engagement of the Government of Rwanda as principal convener in the Collaborative process was important in achieving these outcomes.

The Rwanda experience also suggests that CDVC analysis and the Learning Collaborative approach can help programmes use resources more efficiently, carefully targeting investment to overcome delivery bottlenecks and, in many cases, finding “low-cost or no-cost solutions” (JLICA Learning Group 3, 2008).

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With new learning tools, programmes can strengthen collaboration among implementers and stakeholders—improving results for children.

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## Taking Effective Models to Scale Through National Policy

The evidence base on programme implementation for children and families affected by AIDS is expanding, but the body of evidence remains weak in many respects. Countries in sub-Saharan Africa aiming to scale up integrated health and social service delivery models for children can draw scant guidance from the available peer-reviewed and programme evaluation literature.

The lack of evidence has hampered national policy efforts but not halted them. In the face of urgent need, some countries have taken innovative action to expand promising programmes towards national coverage. The Government of Rwanda's National Strategy for vulnerable children and its rural primary health care scale-up under the District Health System Strengthening framework are two examples (Binagwaho et al., 2008). Others include Botswana's widely acclaimed national PMTCT policy, which substantially reduced rates of vertical transmission in the country over a four-year span (Sullivan et al., 2008). Important lessons can also be drawn from policy processes outside the health sector, such as Tanzania's progress towards Universal Primary Education (Mamdani et al., 2008). As the results of these and other national scale-up efforts emerge, they are establishing the early foundations of an implementation evidence base.

Drawing on this evolving evidence, JLICA has tentatively identified success factors in national scale-up of key programmes for children and families. Lessons include the following:



■ **Drive from the top:** Strong national government leadership on children's health and family health issues is irreplaceable. Such leadership has been rare, but decisive when it does emerge. National political leadership from the highest levels was crucial in accelerating Botswana's national AIDS response, including countrywide PMTCT scale-up. In Rwanda, high-profile commitment from the executive branch has been decisive in building political and social momentum on children's health and translating it into programmes.

■ **Build inclusive partnerships:** Scale-up and programme impacts can be facilitated by sustained partnerships between national governments, donors, academic/research institutions, civil society, and community groups. These partnerships appear to work best when donors, bilateral cooperation agencies, NGOs, and academic institutions make a long-term commitment and build strong working relationships with national and local partners over time, under the clear authority of the national government. Botswana's PMTCT programme provides an example of how the distinctive contributions of different stakeholders can be integrated to generate robust outcomes. The approach aligned partners in an accelerated cycle of research to policy to implementation and back to new learning (Sullivan et al., 2008).

■ **Systematize task-shifting; harness the skills that exist within communities:** Programme expansion can be accelerated by using well-trained and compensated lay counsellors, community health workers, and other less specialized cadres to take on a broad range of care delivery tasks. Recruitment, training, and deployment of these cadres enable task-shifting that can optimize the use of highly specialized health-care personnel and expand programme capacity. Botswana's current move from a physician-centred towards a nurse-centred model of HIV/AIDS care shows task-shifting on a systemic scale.

■ **Combine domestic and international financing:** The financing models that appear to work best in promoting national scale-up

involve substantial investments from both affected-country governments and international sources. Stable donor commitments over an extended period have a significant enabling effect (Binagwaho et al., 2008; Zoll, 2008).

■ **Connect centres of excellence with a national relay network to disseminate solutions:** Some especially successful scale-up processes have tested innovative solutions through ongoing operational research in centres of clinical excellence, with a focus on finding strategies that can be rolled out quickly. Results have been rapidly tracked and evaluated, and successful innovations have been disseminated to service providers in other parts of the country through government information networks. This strategy was used effectively in Botswana, where innovations in PMCT delivery were tested in Francistown, then rapidly relayed countrywide (Sullivan et al., 2008).

■ **Reinforce accountability:** Innovative strategies can be deployed to strengthen political accountability for children’s outcomes. In conjunction with the countrywide scale-up of HIV and AIDS services and the roll-out of the national vulnerable children’s strategy, Rwanda has introduced novel mechanisms to increase programme transparency and reinforce office holders’ accountability for results. These strategies include public reporting sessions broadcast on national media, in which district mayors must give a detailed account of programme performance on AIDS and vulnerable children in their jurisdictions. The President of the Republic chairs these sessions, which are carried live on national television and radio. The sessions provide constituents with clear and detailed information on how well local officials are delivering on their responsibility towards vulnerable children (Binagwaho et al., 2008).

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Implementation challenges constantly evolve; policy-makers and implementers need strategies for continuous learning.

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## **Advancing Implementation: New Ways of Learning**

In the countries most heavily impacted by HIV and AIDS, efforts to expand essential services for children face financial, technical, and political obstacles. Implementation challenges are not static; they continuously evolve. Policy-makers and implementers need strategies for continuous learning as they work to take promising programme models to scale.

JLICA’s collaboration with the Government of Rwanda showed the effectiveness of the Learning Collaborative framework, but the Joint Learning process itself also offers a useful model. As a strategy for collectively producing knowledge oriented to action, Joint Learning is a way to tackle complex challenges that demand multiple forms of expertise. The method intentionally engages a broad spectrum of disciplines and constituencies whose initial views may be opposed, in order to work through to agreed, evidence-informed solutions that can be widely endorsed. Adopting this approach, JLICA has engaged academic researchers and frontline implementers; government officials and civil society activists; and senior policy analysts and the voices of children. The result has been an “activation” of the evidence base and a set of insights that no single constituency could have generated on its own.

JLICA is now bringing its work to a close, but the Joint Learning method has much more to contribute. This method has gained strength and clarity through JLICA’s experience, as through the earlier Joint Learning Initiative on Human Resources for Health, which pioneered the approach (Joint Learning Initiative, 2004\*). Joint Learning as a strategy shows increasing promise in the complex landscape within which national and global health action must be taken forward. Countries working to promote children’s well-being in the context of AIDS and poverty may harness the evidence and recommendations emerging from JLICA’s work, and also the method that produced the results.





# CHAPTER 6 Key Recommendations

The preceding chapters analysed the challenges facing the global response to children affected by HIV and AIDS and summarized JLICA's findings in critical areas. This closing chapter sets out the main policy lessons emerging from JLICA's work. On the basis of JLICA's evidence, it identifies the most important actions that national governments and their partners can take to improve children's outcomes in the context of AIDS. The chapter begins by specifying the character of JLICA's recommendations and their timeline. Then it spells out the principles that ground JLICA's policy proposals and presents the Initiative's key recommendations to national governments in heavily-burdened countries. Finally, it indicates what actions partners should undertake to support national responses, and it describes how success can be tracked.

## Quick Action, with Lasting Impact

JLICA's role is not to lay down detailed blueprints for specific national policies and programmes, but to indicate broad directions for action that will enable countries to craft national responses that are evidence-based and appropriate to their specific contexts.

The precise sequencing of policy steps will vary by country context. In general, however, action needs to unfold in an integrated way across the priority areas highlighted in this report. For example, income transfers can have a crucial catalytic effect on the use of services, but to achieve full impact,

family-centred service delivery structures should be strengthened simultaneously to meet rising demand as transfers roll out.

Governments and their partners should take this need for coordination into account as they plan and implement interventions. This also places responsibility on donors and international partners to ensure that national authorities are adequately resourced to take action on multiple fronts. An unstable global economy challenges donor governments, as well as those in high-burden countries. But, in times of crisis, governments and partners can and must work in concert to protect the most vulnerable, including children affected by AIDS.

If action is taken boldly across the areas that JLICA describes, countries will quickly begin to see results. Programmes can be jump-started in a matter of months and subsequently refined as they roll out. JLICA advises that countries and their partners plan action for rapid start-up, with commitment to sustain and enhance programmes over time. Stable funding from domestic and donor sources should be committed for a period of at least five years. A five-year timeframe will bring countries to the threshold of the target date for the Millennium Development Goals, an appropriate moment for comprehensive review and assessment of policy directions.

Accelerated action in the areas that JLICA describes will lay foundations for long-term benefits: notably, lasting synergy between HIV and AIDS programmes and national social protection measures that will sustain development efforts over the long haul. With this approach, the policy

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Asterisks indicate non-JLICA sources.

response to HIV and AIDS will improve outcomes for children and families directly affected by the epidemic and also reinforce social equity and the well-being of children and carers more broadly.

## Principles

■ **Child rights:** The Convention on the Rights of the Child and the African Charter on the Rights and Welfare of the Child represent the normative framework for policy.

■ **National leadership:** National governments must lead in setting policy priorities within a framework that facilitates the appropriate participation of local and international partners.

■ **Equity:** Equitable provision of quality services to children and families in education, health, and social protection is a fundamental responsibility of the state.

■ **Evidence-based action:** Policies and programmes for children’s well-being should be evidence-based and informed by continuous learning to improve results.

## Policy Directions for National Governments

**Harness national social protection for vulnerable families as a critical lever to improve children’s outcomes in the context of HIV and AIDS.**

- Identify and implement priority social protection options appropriate to specific national contexts.
- Use income transfers as a “leading edge” intervention to rapidly improve outcomes for extremely vulnerable children and families.

**Provide benefits to families and children based on need, not on HIV or orphan status.**

- Adopt national social policies that are AIDS-sensitive, not AIDS-targeted.
- Revise the existing United Nations definition of “orphan” to give recognition and support to children’s surviving parents and extended families.

**Reinforce families’ long-term caring capacities as the basis of a sustainable response to children affected by HIV and AIDS.**

- Keep children and parents alive and healthy by using family-centred programme models to expand access to HIV prevention, treatment, care, and support. These programmes should also include palliative care and treatment for co-infections, such as TB, that have severe health and social impacts. In the scale-up to Universal Access, treatment of children should match adult levels.
- Promote the care of children within extended families and communities. Orphanage care should always be a last resort and a temporary measure, and must be monitored to ensure adequate standards.



**Strengthen community action in support of children affected by AIDS and ensure that community voices inform decision-making on all policies and programmes.**

- Establish an agreed national framework for collaboration between external agencies and community organizations, mandating community involvement in the design and decision-making for all programmes that affect children’s well-being. To accelerate implementation, link the national framework to district committees maintaining a register of community-level activities supporting children and families.
- Task a national working group, including public sector and civil society representatives, to recommend how resources for children affected by HIV and AIDS can be better monitored and how communities can better access external resources to assist children and families.

**Implement family-centred services integrating health, education, and social support.**

- Roll out family-centred HIV and AIDS services within a community-based primary health care model that integrates nutrition, education, and social support. Accelerate scale-up using community health workers and community workers from other sectors who are well trained, supervised, and compensated.



- Apply innovative planning and quality improvement tools, including Care Delivery Value Chain analysis and the Learning Collaborative model, to overcome bottlenecks in implementing integrated services and to inform policy.

**Redirect HIV prevention to redress the social and economic inequalities that increase girls' and women's vulnerability.**

- Education is protective; increase secondary school enrolment and retention, especially among girls.
- Tailor prevention to local contexts and include: physical safety for women and girls; measures addressing men and adolescent boys; and special attention to the most vulnerable girls, such as migrants, school dropouts, young mothers, and girls who have lost a parent.
- Use social protection measures to enhance women’s economic and social participation, for example, by designating female family members to receive income transfers and providing micro-enterprise training and opportunities for women.

**Strengthen the evidence base on policies and programmes that work for children.**

- Strengthen research to ensure that policy issues are accurately framed and understood and that responses match needs.
- Incorporate (and budget for) evaluation research to document the impacts of income transfers, family-centred testing and treatment, and other programmes being implemented in developing countries, especially in sub-Saharan Africa.
- Strengthen community-based monitoring and evaluation systems, build local technical capacity for evaluating intervention processes and outcomes, and ensure that community and children’s voices are heard in programme assessment and subsequent changes to programme design.

## Creating an Enabling Environment and Tracking Success

The agenda that emerges from JLICA’s research sets a new direction for policy on children affected by HIV and AIDS — and for AIDS policy overall. Support from international, national, and local partners is needed to create an environment in which governments can undertake innovative policies and state action can achieve full impact. Five tasks are critical:

**1. Build political momentum:** The evidence marshalled by JLICA shows the way towards a more effective response to the needs of children affected by HIV and AIDS. But evidence alone is rarely sufficient to spur action. Research results must be communicated compellingly to decision-makers, opinion leaders, and the broader public. Sustained effort is required to make the political case for action on children and AIDS in a context of competing priorities. African regional bodies, national and international civil society, United Nations agencies, media, and other partners will have critical roles in mobilizing support.

JLICA urges the UN agencies to rapidly incorporate new research findings into their normative work, country-level policy dialogue, and advocacy. Innovative regional and country-level processes that these agencies are currently supporting provide opportunities to advance policy dialogue with national decision-makers. High-profile public advocacy campaigns will also be important to inform

opinion and create a climate of support. Building on the advances spurred by the “Unite for Children, Unite against AIDS” campaign, UN agencies and partners should undertake a broad global advocacy effort, with strong regional focus in sub-Saharan Africa, to accelerate momentum for connecting the AIDS and social protection agendas to secure children’s future, in the timeframe of the Millennium Development Goals. The scientific and political consensus achieved at the Fourth Global Partners Forum on Children Affected by HIV and AIDS (October, 2008) opens the way to speed progress.

Regional bodies, alliances, and forums, notably the African Union (AU) and the Southern African Development Community (SADC), are vital platforms for surfacing additional opportunities and building a sense of shared commitment among political leaders. JLICA calls on the AU, SADC, and other regional bodies to promote awareness and action on the synergy of health, social protection, and national development agendas among Member States. These bodies should take forward the recommendations emerging from the Livingstone 2 process on social protection in Africa, in particular the October 2008 Windhoek Declaration on Social Development, issued by African Ministers in charge of Social Development.

JLICA urges civil society and activist networks to inform constituencies and build momentum for coordinated action on health and social protection at national, regional, and international levels. A primary focus of civil society action should be



mobilizing and articulating popular demand for state social protection and family-centred services at scale.

An important goal is to move quickly beyond time-limited, local pilot projects to country-wide implementation of social protection under government leadership. To accelerate and sustain progress, social protection needs to be inscribed in national legislation. This removes social protection measures from the realm of charity or emergency response and anchors them as the expression of legal rights. With the appropriate legislation in place, delivering social protection becomes an acknowledged, long-term government responsibility, not vulnerable to the fluctuations of international development discourse or to domestic political power shifts.

**2. Mobilize resources:** A new agenda of evidence-based action for children's well-being will require significant new resources. Some countries in sub-Saharan Africa are already implementing income transfer programmes, such as old age pensions, financed largely through domestic budgets. However, in most heavily-burdened countries, implementation and scale-up of social protection programmes will require substantial funding from international partners in the short and medium term.

In an adverse global financing environment, mobilizing additional resources for ambitious new policies and programmes will pose challenges. At the same time, strained economic conditions deepen risks for children affected by AIDS and poverty and so increase the urgency of rapidly implementing the policies that JLICA recommends. The very conditions that make policy action difficult simultaneously make it more imperative.

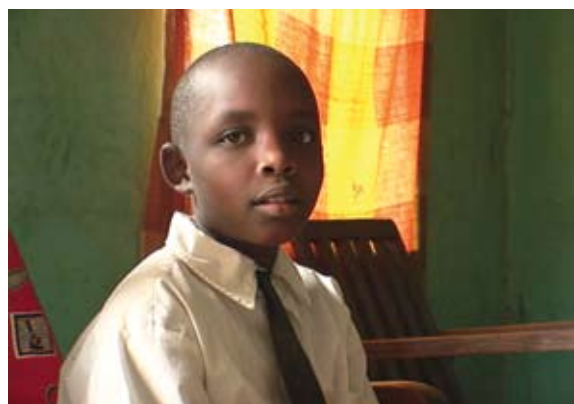
JLICA calls on bilateral and multilateral donors and private philanthropic organizations to break this deadlock by expanding the resource envelope for integrated, family-centred policy and programming on HIV and AIDS, in particular, AIDS-sensitive social protection. The example of donors

that have already established dedicated support streams for social protection in low-income countries should be followed and the resources provided through these channels expanded. These changes should be undertaken in coordination with national governments in affected countries.

**3. Accelerate implementation and foster continuous learning:** Key implementing agencies, including bilateral and multilateral agencies and nongovernmental organizations, need to support national governments in delivering results on the ground. JLICA urges implementing agencies to take on board the evidence and recommendations brought forward in this report and to incorporate them into operational plans, guidance to partners, and funding decisions.

As programmes roll out, continuous learning will be vital to improve results. International organizations, foundations, and other funders should be prepared to support systematic, multi-country evaluations to analyse and compare policy and programme models and document effective strategies.

International agencies and donors should also make financial, technological, and human resources available to support communities of practice among actors designing and implementing innovative policies to meet children's needs. Platforms for peer-to-peer knowledge-sharing among programme managers, frontline implementers, and communities will help rapidly



expand the evidence base on implementation for children’s well-being. “Joint Learning” processes, diversely configured, may consolidate evidence and advance action on a range of issues.

**4. Broaden participation at regional, national, and local levels:** To be effective and sustainable, policies need to be understood and supported by the people meant to benefit from them. Ensuring that communities have a voice in programme design and decision-making is crucial. Governments and their partners should build substantive consultation with civil society and communities, including children and youth, into processes for selecting national policy options on children and AIDS. Ongoing community participation and monitoring should also be included in programme roll-out processes, so that the voices of civil society and community groups, including children, can continue to be heard. Regional consultative processes engaging civil society can lend support to national efforts. The September 2008 conference organized by the Regional Interagency Task Team on Children Affected by HIV and AIDS for Eastern and Southern Africa (RIATT), in Dar es Salaam, is an example of what constructive regional participatory processes can achieve. The RIATT conference created space for substantive participation by children, youth, and older carers, alongside representatives of governments, international agencies, donors, and NGOs.

At the local level, community participation in decision-making on critical issues affecting children’s well-being is both a human right and a pragmatic requirement for programme success. Participation and the incorporation of local knowledge are essential to continuously improve implementation models and outcomes.

**5. Track success and maintain accountability:** Maximizing the impact of policy and programme innovation demands rigorous monitoring. Success must be tracked and the factors that enable strong outcomes documented. Countries must be prepared to build solid monitoring and evaluation (M&E) mechanisms into programmes from the start, but monitoring is an area in which many affected countries face significant challenges. The situation is made more complex because “cookie-cutter” programme models will not work. Each country faces a different configuration of opportunities and constraints and must prioritize a distinctive set of policy options in AIDS-sensitive social protection and related areas. Given the need for each country to construct its own solutions and roll these out quickly, but also to measure processes and results; share learning; and maintain accountability, JLICA recommends that:

- **Governments** engaged in scaling up family-centred service delivery and AIDS-sensitive social protection in sub-Saharan Africa move quickly to define, through consultative processes, their specific models of “what success will look like,” along with benchmarks, targets, and timelines appropriate for their national contexts;
- **UN agencies, in particular, UNICEF and UNAIDS,** support countries in defining national objectives and M&E strategies for family-centred service delivery, community engagement, and social protection, and in tracking results as programmes unfold;
- **UNICEF and UN partner agencies** develop an inclusive global monitoring framework and knowledge-sharing platform that will capture innovation and results from diverse country experience in advancing this new agenda;
- **Policymakers, implementers, civil society partners,** and others use this platform to share learning; build communities of practice; and accelerate roll-out of quality health, education, and social protection services relevant to children and families affected by AIDS;

■ **International agencies, donors, and governments** expand support for research on children affected AIDS and poverty, along with broad dissemination of findings, so that results can rapidly inform policy;

■ **The African Union** integrate assessment of child-focused, AIDS-sensitive social policies into regional processes and structures, including the New Partnership for African Development (NEPAD) and the African Peer Review Mechanism;

■ **UNICEF and African regional bodies** convene regular regional consultations in sub-Saharan Africa through 2014 to examine progress in the implementation of AIDS-sensitive social protection policies in countries heavily burdened by AIDS and poverty; analyse the impacts of these policies; and reinforce accountability for results;



■ **UNICEF, UNAIDS, and UN partner agencies** sponsor a major evaluation of evidence, progress, and challenges in rolling out AIDS-sensitive social protection, with results to be presented at the XXth International AIDS Conference in 2014 and incorporated into high-level policy deliberations in the context of the Millennium Development Goals and in the definition of future national and global objectives.

Numerous challenges face governments and their partners in advancing a new agenda for children. But the evidence assembled by JLICA shows a clear way forward that policy-makers can be confident will yield results. To improve children's well-being and life chances in communities heavily burdened by HIV and AIDS, a critical lever is family-centred social protection, anchored in national legislation and delivered at scale through government-led programmes. In many settings, income transfers will be an efficient "leading-edge" social protection strategy to provide support rapidly to very vulnerable families. By implementing income transfers while strengthening family-centred services in education and health through community-based delivery mechanisms, governments can empower families and communities to break intergenerational cycles of destitution and disease. This approach tackles development challenges at the root. It protects and enhances the core human capacities that are the most essential factor for progress in a rapidly changing world.

# Conclusion

The global AIDS response has neglected “home truths” about children, AIDS, and poverty. By acting on these truths now, governments and their partners can improve children’s outcomes and multiply the impact of investments in controlling AIDS.

The evidence presented in this report points to concrete, specific, and affordable policy measures to deliver results. These measures follow four strategic lines:

- Support children through families
- Strengthen community action that backstops families
- Address family poverty through national social protection
- Deliver integrated, family-centred services to meet children’s needs

If governments in hard-hit countries take the actions JLICA recommends, substantial gains in health and wellbeing for children and families are achievable in a short timeframe.

A new focus on children’s wellbeing in the context of AIDS and poverty can help move AIDS policy beyond the emergency response mode that has guided action to date. Focusing on children points the way to strategies appropriate for controlling a long-wave epidemic that is deeply entwined with poverty and social inequality.

Advancing this agenda demands a major shift in thinking. To see the AIDS struggle through this lens expands our understanding of what AIDS policy is, whom it serves, and what priority actions it requires. The strategy described in this report will strengthen families affected by HIV and AIDS, while moving beyond narrow labels and forms of targeting that have divided communities, deepened stigma, and undermined programme results. This strategy points to a new model of public health and development action that has the potential to repair the damage inflicted on families and communities by entwined crises of disease, poverty, inequality, and food insecurity.

As JLICA’s work has progressed and engaged a widening group of partners, there has been increasing receptivity to JLICA’s evidence and arguments; increasing convergence with the findings of other research; and increasing resonance in policy circles. Today, a consensus is emerging on topics critical for children affected by HIV and AIDS that a few years ago seemed unattainable.

We must take advantage of this emerging consensus to accelerate action. As food insecurity deepens in parts of Africa and a global economic crisis unfolds, the vulnerability and needs of children and families in areas affected by AIDS grow more acute. The time is now to face the facts on children, AIDS, and poverty—and take the action the facts and the wellbeing of future generations demand.



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# Milestones of the Joint Learning Initiative on Children and HIV/AIDS (JLICA)

## Steering Committee

**24–25 March 2006:** Founding partners Bernard van Leer Foundation, UNICEF, Human Sciences Research Council, and FXB International attend project inception meeting in The Hague, Netherlands.

**10–11 October 2006:** JLICA launches its programme of work in Foxhills, UK.

**9–10 May 2007:** Steering Committee meeting held near Durban, South Africa, to refine JLICA's mission, objectives, and strategy in the current global context.

**25–26 September 2007:** Steering Committee assembles in Boston, Massachusetts, USA, to identify strategies for JLICA communications and advocacy at the International AIDS Conference in Mexico.

**13–16 February 2008:** Steering Committee meets in Great Fosters, UK, to assess and synthesize findings across LGs.

**17–18 April 2008:** Steering Committee refines JLICA's "storyline" and communications strategy and identifies priority messages and actions in Dublin, Ireland.

**26 May 2008:** Final report drafting committee meets in Boston, including Global Co-Chairs, LG representatives, the Secretariat, and the communications team.

**9 September 2009:** Final report drafting committee deliberates in Boston and via teleconference on report strategy and structure.

## Learning Groups

**7–8 March 2007:** LG1, LG2, LG3, and LG4 convene their membership in Durban, South Africa.

**25–26 March 2007:** LG3 and Rwanda's National AIDS Commission co-host a national expert consultation in Rwinkwavu, Rwanda, on challenges of prevention of vertical transmission.

**5–6 June 2007:** The LG3 Learning Collaborative holds its first learning session in Rwamagana, Rwanda, with more than 60 local service providers, NGO leaders, and government officials, including the Minister of Health of Rwanda.

**22–23 September 2007:** LG3 and LG4 meet in Boston to review, consolidate, and refine their respective research agendas.

**23–24 January 2008:** LG1 convenes "lead" authors and representatives from LGs 2, 4, and 4 in Pretoria, South Africa, to identify areas of consensus, overlap, and neglect within LG1 and across the Initiative.

**14–18 April 2008:** LG2 and LG4 review and finalize research products in Dublin, Ireland.

**4 June 2008:** LG3 invites authors and Co-Chair representatives from LG1, LG2, and LG4 to Kampala, Uganda, to review and finalize LG3 technical papers.

**3–4 July 2008:** A bridging session between LG1 and LG2 assesses the available evidence on community-level support of children affected by HIV/AIDS in London, UK.

## Conferences, Symposia, and Workshops

**17 August 2006:** JLICA organizes a special satellite session, “From Evidence to Action,” at the XVI International AIDS Conference, Toronto, Canada. Stephen Lewis, United Nations Special Envoy for HIV/AIDS in Africa, delivers keynote speech.

**24 September 2007:** JLICA’s international symposium, “Meeting Children’s Needs in a World with HIV/AIDS,” brings 350 global leaders and opinion shapers in children and HIV/AIDS to Boston. UNAIDS Executive Director Peter Piot delivers the keynote address.

**20–21 November 2007:** LG2 Co-Chair Geoff Foster (FACT) participates in “Scaling-up Response for Children,” an eastern and southern Africa consultation on the role of faith-based organizations in strengthening responses for children and families affected by and living with HIV and AIDS. Involving over 40 delegates from 8 countries, the meeting is hosted in Nairobi, Kenya, by the Catholic Medical Mission Board.

**29–30 November 2007:** LG1 Co-Chair Linda Richter and LG1 members Chris Desmond and Michelle Adato participate in Save the Children UK London consultation, “The Role of Social Welfare Services in Social Protection: Towards a Policy-Relevant Research Agenda.”

**5 December 2007:** With sponsorship from the UK Department for International Development, JLICA and the Inter-Agency Task Team on Children and HIV and AIDS (IATT) co-host an international workshop in London on how to accelerate implementation of social transfer programmes to support children and families affected by HIV/AIDS. LG1 Co-Chair Linda Richter gives keynote address.

**3–7 June 2008:** JLICA Global Co-Chair Agnes Binagwaho (Rwanda National AIDS Control Commission) profiles JLICA in several presentations, including a plenary speech at the HIV Implementers’ meeting in Kampala.

**2 August 2008:** JLICA highlights its work in a plenary session of the Symposium “Children and HIV/AIDS: Action How, Action Now,” organized in Mexico City by the Coalition on Children Affected by AIDS (CCABA). Moderated by Helene Gayle, President and CEO of CARE USA, the interactive discussion focuses on family-centred social protection strategies, innovative approaches to channeling resources to community-based organizations, and models of successful, integrated, family-centred service delivery. LG Co-Chairs Jim Kim, Linda Richter, and Geoff Foster address an audience of over 500 participants.

**6 August 2008:** JLICA LG1 Co-Chair Linda Richter delivers the first-ever plenary on children affected by HIV/AIDS in the 23-year history of the International AIDS Conference. The audience numbers well over 5,000 persons.

**6 August 2008:** JLICA presents a satellite session at the Mexico International AIDS conference entitled “Beyond the Orphan Crisis: Findings of the Joint Learning Initiative on Children and HIV/AIDS,” before an audience of over 250 delegates. Speakers include Michel Sidibé (UNAIDS); Julio Frenk (Dean, Harvard School of Public Health, and former Minister of Health, Mexico); JLICA Global Co-Chair Agnès Binagwaho; LG1 Co-Chair Lorraine Sherr, LG3 Co-Chair Jim Kim, and LG members Nathan Nshakira and Jerker Edström.

**27 September–2 October 2008:** JLICA evidence and recommendations stimulate critical policy discussions in Dar es Salaam, Tanzania, at the Regional Inter-Agency Task Team on Children and HIV and AIDS (RIATT) conference on children. With the theme, “Getting it Right for Children,” the meeting convenes delegates from governments, civil society groups, UN agencies, as well as youth and older carers, from 19 countries in eastern and southern Africa. LG1 Co-Chair Linda Richter (plenary speaker), LG2 Co-Chair Geoff Foster, LG2 researcher Nathan Nshakira, LG3 Co-Chair Lydia Mungherera, LG4 Co-Chair Masuma Mamdani, and Executive Co-Chair Alayne Adams present



on themes of social protection, community support, and family-centred care.

**6–7 October 2008:** JLICA participates in the Fourth Global Partners Forum on Children Affected by HIV and AIDS, which is held at the Royal Hospital Kilmainham in Dublin, Ireland, and co-hosted by Irish Aid and UNICEF. Linda Richter summarizes JLICA’s findings in a plenary address, and JLICA evidence is further highlighted in panel sessions by Alex de Waal, Lydia Mungherera, Nathan Nshakira, and Lorraine Sherr, and in the plenary remarks of Jimmy Kolker of UNICEF and Paul De Lay of UNAIDS.

**3–7 December 2008:** LG3 Co-Chair Lydia Mungherera, LG1 member Michelle Adato, LG2 member Nathan Nshakira, and JLICA Global Co-Chair Agnès Binagwaho present JLICA findings at the International Conference on HIV/AIDS and Sexually Transmitted Infections in Africa (ICASA), held in Dakar, Senegal.

## Funding

**August 2005:** Harvard’s Global Equity Initiative receives inception grants from Bernard van Leer Foundation, FXB International, and UNICEF to explore the potential for focused, policy-oriented research to address the needs of children affected by HIV/AIDS.

**August 2006:** On behalf of the Government of the Netherlands, Paul Bekkers, the Netherlands’ Ambassador for HIV/AIDS, pledges support to JLICA at the International AIDS Conference in Toronto, Canada.

**September 2006:** FXB Center for Health and Human Rights, Harvard School of Public Health, and Geneva-based FXB International agree to provide JLICA with formal in-kind administrative and financial management assistance for the duration of the project.

**November 2006:** The UK Department for International Development (DFID) provides a significant grant towards JLICA’s plan of work.

**December 2006:** The Bernard van Leer Foundation, a JLICA founding partner, pledges additional support to the Initiative, adding to the Foundation’s earlier commitments to JLICA’s inception phase.

**March 2007:** Irish Aid announces a generous commitment to JLICA’s programme of work.

**September 2007:** The Bill & Melinda Gates Foundation provides a grant to support JLICA’s international symposium, “Meeting Children’s Needs in a World with HIV/AIDS.”

**October 2007:** UNICEF announces a grant to JLICA to support LG1 and LG2.

## Advocacy, Partnerships, and Outreach

**13–15 March 2007:** LG3 Co-Chair Lydia Mungherera represents JLICA at the Global HIV/AIDS & Children Advocacy Action Planning Summit in Brussels, co-sponsored by UNICEF’s “Unite for Children, United against AIDS” campaign and Global Action for Children (GAC).

**23–25 April 2007:** LG2 Co-Chair Madhu Deshmukh, LG1 Co-Chair Linda Richter, and former Co-Chair Angela Wakhweya brief IATT members on JLICA’s goals, structure, methods, and research agenda in Washington, DC.

**16–19 June 2007:** JLICA Global Co-Chair Agnès Binagwaho, representing the Government of Rwanda, co-hosts PEPFAR HIV Implementers’ Meeting in Kigali.

**25 September 2007:** A joint session in Boston brings the steering committees of the IATT and JLICA together to map opportunities for synergy and sustained collaboration.

**November 2007:** LG1 Co-Chair Linda Richter participates in the 23rd South African Development Community (SADC) parliamentary forum, where she presents on the effectiveness of cash transfer programmes in improving the health and well-being of children living in poverty.

**19 April 2008:** JLICA and IATT hold a joint working session to coordinate evidence-based policy recommendations for the Global Partners Forum in Dublin.

**7 May 2008:** Jim Kim, LG3 Co-Chair, addresses US Congressional representatives on World AIDS Orphans Day, in Washington, DC.

**4–7 August 2008:** Meetings between JLICA and high-level leadership of The Global Fund, PEPFAR, and UNAIDS occur during the 2008 International AIDS Conference, Mexico City.

**6 August 2008:** LG3 Co-Chair Lydia Mungherera, founder of Mama’s Club, receives the UNAIDS 2008 Red Ribbon Award on behalf of her organization at the International AIDS Conference in Mexico.

**27–31 October 2008:** LG1 Co-Chair Linda Richter addresses the meeting of African Union Ministers in Charge of Social Development in Windhoek, Namibia.

**17 November 2008:** Meetings with Geneva-based international agencies, including UNAIDS, the Global Fund, and WHO, held jointly with the Coalition on Children Affected by AIDS (CCABA), assess opportunities for technical consultation and collaboration around JLICA policy recommendations.

**19–20 November 2008:** LG3 Co-Chair Lydia Mungherera and LG4 Co-Chair Alex de Waal participate in the 6th African Development Forum of the African Union Commission and the Economic Commission for Africa in Addis Ababa, Ethiopia.

**1 December 2008:** Irish Aid publishes a supplement in the *Irish Independent* to mark World AIDS Day. An article by LG1 Co-Chair Linda Richer is featured: “Protecting society’s most vulnerable.”

**3 December 2008:** LG4 researchers Valerie Leach (Research on Poverty Alleviation, Tanzania) and Jerker Edström, Institute of Development Studies (IDS) discuss JLICA social and economic policy recommendations at a UK Parliamentary seminar.

**Mid-late January 2009:** Planned technical consultations with UNAIDS, Global Fund, and WHO in Geneva, and with PEPFAR in Washington, DC.

**9–11 February 2009:** Scheduled launch of JLICA final report.

**February–March 2009:** Planned regional roundtables on JLICA recommendations with policymakers in eastern and southern Africa.

**Late February–March 2009:** Planned USA West Coast stakeholders briefing on JLICA findings and recommendations with foundations and research institutions.

## Media and Publications

**October 2006:** *Lancet* comment on JLICA, co-signed by Global Co-chairs Peter Bell and Agnès Binagwaho.

**7–10 August 2008:** JLICA receives substantial press coverage during the 2008 International AIDS Conference, Mexico City.

**November 2008:** LG4 releases special issue of the *IDS Bulletin* (Institute of Development Studies, University of Sussex) entitled “Children, AIDS and Development Policy” (Volume 39, Number 5), featuring key research papers.

**Fall 2009:** LG2 plans special issue of *Vulnerable Children and Youth Studies* to highlight work on community action.

**Fall 2009:** LG1 in process of planning an issue of *AIDS Care*.

# APPENDIX 1 JLICA Core Leadership Team

## JLICA Global Co-Chairs

**Peter Bell**, President Emeritus of CARE USA/ Senior Research Fellow, Hauser Center for Nonprofit Organizations, Harvard University, USA

**Agnès Binagwaho**, Permanent Secretary, Ministry of Health, Rwanda / formerly Executive Secretary, National AIDS Control Commission, Rwanda

## Learning Group Co-Chairs

**LG1: Linda Richter**, Executive Director of Child, Youth, Family and Social Development, Human Sciences Research Council, South Africa

**LG1: Lorraine Sherr**, Head of the Health Psychology Unit, Royal Free and University College Medical School, University College London, UK

**LG1: Angela Wakhweya**, Deputy Director, HIV/AIDS Administration for Maryland's Department of Health and Mental Hygiene, USA / formerly Family Health International

**LG2: Geoff Foster**, Founder, Family AIDS Caring Trust (FACT), Zimbabwe / Specialist Paediatrician, Government of Zimbabwe

**LG2: Madhu Deshmukh**, Deputy Director Policy Analysis, Policy Advocacy Unit / formerly Director HIV/AIDS, CARE USA

**LG3: Jim Yong Kim**, Chair of the Department of Global Health and Social Medicine, Harvard Medical School / Chief of the Department of Global Health Equity at Brigham and Women's Hospital / Director of the François-Xavier Bagnoud Center for Health and Human Rights, Harvard University, USA

**LG3: Lydia Mungherera**, Founder, Mama's Club / Policy and Advocacy Programme Officer, The AIDS Support Organisation (TASO), Uganda

**LG4: Alex de Waal**, Programme Director, Social Science Research Council, USA / Director, Justice Africa, UK

**LG4: Masuma Mamdani**, formerly Senior Researcher, Research on Poverty Elimination (REPOA) / now Research Specialist, Social Policy, UNICEF Tanzania

## JLICA Secretariat

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# APPENDIX 2 Acknowledgements

The Joint Learning Initiative on Children and HIV/AIDS acknowledges the following individuals and organizations for their contributions to JLICA's work.

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**Association François-Xavier Bagnoud — FXB International**

**Bernard van Leer Foundation**

**FXB Center for Health and Human Rights, Harvard University**

**Global Equity Initiative, Harvard University**

**Human Sciences Research Council**

**UNICEF**

## Major Supporters

**Irish Aid**

**United Kingdom Department for International Development (DFID)**

**Government of the Netherlands Ministry of Foreign Affairs**

**Bill & Melinda Gates Foundation**

**UNAIDS**

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