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Home Truths

Facing the Facts on Children, AIDS, and Poverty

Home truths are, by definition, discomfoting.

A critical home truth confronted in this report is the neglect of millions of children and their families in the global response to the AIDS epidemic. More than 25 years into the epidemic, the latest statistics show that:

- Over 90% of the more than 2 million children living with HIV are infected before or during birth. Yet only one in three pregnant women with HIV in low- and middle-income countries receive the treatment they need to help prevent infection of their babies.
- Only a very small proportion of children living with HIV receive life-saving antiretroviral treatments. In sub-Saharan Africa, children are significantly less likely to receive treatment than adults.
- Only 8% of children born to HIV-positive women are tested for HIV before they are two months old. Without timely diagnosis, children lose their chance to benefit from treatment.
- In southern Africa, adolescent girls are 2 to 4.5 times more likely to be infected than boys of the same age.
- An estimated 15 million children alive today, 12 million of them in sub-Saharan Africa, have lost one or both parents to AIDS.

Well-intentioned but misdirected efforts have drained resources that could have been invested more effectively for children and young people. Responses to date have not been sufficiently grounded in either evidence about children's circumstances, or a clear understanding of the root causes of children's vulnerability.

This report summarizes the evidence emerging from two years of research and analysis by the Joint Learning Initiative on Children and HIV/AIDS (JLICA), an independent alliance of researchers, implementers, activists, policymakers, and people living with HIV. Its findings show that unless governments and their partners address the underlying issues of family poverty and gender inequality, large-scale AIDS programmes in severely affected countries will continue to fall far short of what is needed — and of what could be achieved.

The report identifies failures in existing approaches to children and families affected by HIV and AIDS, and calls for fundamental shifts in policies, programmes, and funding to squarely refocus the response along four critical lines of action:

- providing support for children to and through their families;
- strengthening community support for families;

- reducing family poverty;
- delivering integrated family-centred services in health, education, and social welfare.

Home Truths: Where Have We Gone Wrong?

This report considers a number of fundamental misperceptions that have undermined the global response to children affected by the epidemic, and sets out evidence on how to better respond to their needs.

While families care best for children, many efforts to assist children affected by HIV and AIDS ignore the clear benefits of supporting families and communities.

Families and communities currently bear approximately 90% of the financial cost of caring for infected and affected children in the areas hardest hit by AIDS. Many of these families are already living in extreme poverty, yet few receive any support from sources outside their communities.

The current response for children largely consists of uncoordinated, small-scale projects that are often poorly designed and underfunded. These well-meaning efforts may alleviate some of the distress experienced by vulnerable children and their families, but, overall, they are insufficient to the task. Adequately supporting children affected by HIV and AIDS in hard-hit countries will require large-scale, state-led assistance to families and communities. Such support will enable families and communities to provide the care that children need to grow and thrive.

Action in this area by government and international partners must build on local strengths. Community



organizations, in particular faith-based organizations, have unparalleled outreach in many sub-Saharan African countries and enjoy high levels of trust among the people they serve. Reinforcing the capacity of these organizations to support children and their families is a critical component of a more effective response.

It is not only orphaned children who are affected by HIV and AIDS.

To date, responses to children in the context of HIV and AIDS have been primarily focused on children who have lost one or both of their parents to the epidemic. This focus has created and fed a powerful myth, namely that the majority of children who have lost a parent to AIDS lack family and social networks and, therefore, require non-family or orphanage care.

JLICA's research, however, shows that:

- Some 88% of children designated as orphans actually have a surviving parent.
- Approximately 95% of all children directly affected by HIV and AIDS, including those who have lost parents, continue to live with their extended families.
- Children of HIV-positive parents face significant vulnerabilities long before their parents die.

The overwhelming majority of children who have lost a parent to AIDS can and should remain in the care of their families, provided that those families receive appropriate support. Building up the resources of families and communities that are already providing for children, rather than creating artificial structures to replace them, is key to developing a more efficient, effective, and sustainable response.

The ubiquitous term "AIDS orphan" has, in itself, caused enormous confusion. The definition of an orphan, adopted by United Nations agencies and employed in global statistics, is "a child who has lost one or both parents." This term has distorted programme goals by obscuring the fact that most of the children defined as AIDS orphans continue to receive support from their families or extended kin.

JLICA urges the United Nations to revise its definition of “orphan.” Differentiating between children who have lost a parent to AIDS, and those who are truly without homes and families, is essential to providing appropriate support and services.

In poor communities hard hit by HIV, differences in the daily realities and longer-term prospects between orphans and non-orphans are very small compared to the deprivation, suffering, and vulnerability that all children confront. In these circumstances, targeting interventions specifically to orphans is neither helpful nor efficient. Children’s needs, not their orphan or HIV status, must be the primary concern in designing and implementing policies and programmes.

The backdrop to much of the AIDS epidemic is extreme poverty. Unless family poverty is addressed, key long-term investments in children will be compromised.

Poverty does not cause AIDS. But AIDS does cause and compound poverty, and impedes efforts to reduce its impact. Over 60% of children in southern Africa live in poverty. Families who are already poor when HIV strikes may be unable to compensate for further loss of income that occurs as a result of AIDS-related illness or death.

Poverty is also the single biggest barrier to the scale-up of HIV treatment and prevention. Poor people’s capacity to access and benefit from services is limited when they lack the resources to purchase food and medicines, pay for transport to service facilities, and compensate for income that is sacrificed for health care.

Failure to implement basic measures to address the extreme poverty in which many families affected by HIV live is reducing the impact of large global investments in AIDS programmes.

Children’s needs continue to outstrip available resources, and coverage of key services in affected communities remains unacceptably low.

Families must be able to access quality health care, education, and social welfare services, in order to

protect and improve the life prospects of children. Major new funding from some donor agencies is beginning to spur real advances, but resource levels in the most severely affected countries remain far below what is required to build robust, comprehensive programmes for children and families affected by HIV and AIDS on a national scale.

Evidence from Uganda illustrates some typical gaps in implementation of health services. Here, health sector funding amounts to US\$9–12 per person per year, inclusive of donor funds. Overburdened staff do not have time to provide labour-intensive services or follow-up care for mothers and children. Basic laboratory and testing equipment is unavailable in many districts, and problems in coordination and management of supplies hamper the provision of treatment, including paediatric formulations that require special handling and storage. Awareness and availability of services at the community level remains very low, and fear of stigma and discrimination continues to isolate caregivers and patients from family and community support systems.

Despite improvements, implementation of key services still falls far short of need, especially for children.

Focusing HIV prevention on campaigns to change behaviour overlooks the harsh realities of many children’s and young people’s lives.

Young women and girls are at particular risk of HIV infection as a result of gender inequality, disempowerment, poverty, and the lack of tools, information, and resources needed for self-protection.

Current HIV prevention efforts, notably those emphasizing the well-known ABC formula — Abstain, Be faithful, or use a Condom —, focus primarily on changing behaviour, and are based on a belief that informed individuals can control the situations in which they find themselves.

JLICA’s research shows, however, that a focus on changing the behaviour of young people, especially young women, is insufficient to protect them from HIV infection. Adolescent girls are too often in

situations in which they are extremely vulnerable to sexual harassment and abuse. In this context, messages about changing their behaviour have limited relevance. Other measures are urgently needed, including increased efforts to ensure girls' physical safety at school, at work, on public transport, and in places of recreation; to tackle behaviours and attitudes that allow men to take sexual advantage of girls and young women with impunity; to keep girls in school; and to improve the economic independence of young women.

A New Action Agenda to Address Children's Needs

JLICA research has identified four key lines of action that will deliver better results for children affected by HIV and AIDS:

1. Providing support for children to and through their families

The first step to delivering better outcomes for children affected by HIV and AIDS is to redirect policies, programmes, and funding to provide support for children within their families.

JLICA research has identified five practical thrusts of an effective family-centred approach:

■ **Keep children and parents alive:** Ensuring the survival and health of both children and the adults who care for them is critical. Yet, despite recent progress, HIV testing, prevention and treatment services, including interventions to prevent parent-to-child transmission, often fail to deliver their intended outcomes. In the case of parent-to-child transmission, this is partly the result of a prevailing focus on the mother alone, which can result in missed opportunities to reach out to other family members. Improving these outcomes will require strengthening both HIV prevention and treatment through family-centred action. Targeting families as a whole, for example through efforts to expand access to testing and treatment for both adults and children, brings important additional benefits for all concerned.

■ **Keep children in families:** Promoting family care for children who have lost their parents is crucial. Orphanage care, particularly in large residential settings, leads to worse outcomes for children and can cost up to 10 times as much per child as community-based care. Providing additional resources to families and extended kin will enable them to give children the personal, responsive care and support that families are uniquely suited to provide.

■ **Build family caring capacities:** Enabling a family-centred approach requires enhancing the capacities of parents and other caregivers to support children through the critical stages of development. Two promising strategies are home visits and early childhood interventions:

- Home visits by community workers seek to enhance parenting knowledge and to provide practical assistance to families. Home visiting can be particularly effective in rural areas, where travel to local service outlets can be both time-consuming and costly.
- Investing in children's well-being and development in their early years is critical. Well-designed early childhood interventions in the United States, for example, have led to higher educational attainment and lifelong increases in earning potential. Currently, however, fewer than 10% of young children in sub-Saharan Africa have access to early stimulation or pre-school programmes — despite the existence of promising models for the delivery of such interventions in low-resource African settings.

■ **Empower families to educate children, in particular girls:** For girls, the simple fact of being enrolled in school is protective against HIV. Girls who attend school are less likely to begin having sex at an early age, and are more likely to use condoms when they do have sex. Girls enrolled in school also demonstrate increased understanding of health issues, including HIV; exhibit a greater sense of control in relationships; and have more capacity to benefit from the protective effects of social networks.

■ **Back up families with child protection:** Approaches that support children in and through their families must also acknowledge and respond

to situations in which family care breaks down. In these cases, child protection services must be provided. JLICA urges building community networks that involve traditional authorities, health and education services, local organizations, police, and others to identify and protect abused children.

2. Strengthening community support for families

In the absence of adequate government response, local community groups across sub-Saharan Africa have organized to address a broad range of needs—from supplying basic material necessities to caring for the psychosocial and spiritual well-being of children and families affected by HIV and AIDS.

Communities have a number of irreplaceable competencies that are central to an effective response to the epidemic. But urgent unmet needs have also forced community groups to provide other forms of support they are less well suited to deliver, such as efforts to generate cash that often yield little relative to the time invested. Extending government-led social protection to vulnerable children and families could free communities from responsibilities they are less able to shoulder and thus reinforce community action in areas in which it adds unique value.

Funding for externally administered activities for children affected by AIDS in sub-Saharan Africa has recently increased. Used wisely, these funds could have an immense positive impact on the lives of millions of children. To date, however, it is unclear how effective donor funding for community organizations has been. Concerns include the weakness or absence of systems for tracking resource flows to communities; the lack of coordination among international, national and local actors working to help children; and the need for greater community participation in the design, implementation, and evaluation of programmes.

JLICA research has shown that following certain core principles of coordination between external actors and communities can help ensure that resources brought into communities by outside

agencies yield maximum benefit for local people. Among these principles are the following:

- External resources and technical assistance from external agencies should complement, not replace, community action.
- Communities should be given specific assistance to access external resources that will allow them to sustain and expand their activities.
- External agencies and civil society groups should align their activities with national plans.
- Communities should have a determining voice in how resources for affected children are allocated and used in their local settings.
- Affected children and young people should take part in defining the goals and methods of programmes conducted for their benefit.

This report recommends the adoption of three specific strategies to ensure that community action is effective and appropriately supported:

- District committees should be established to maintain an active register of community-level activities supporting children and families affected by HIV and AIDS.
- Working groups of government and civil society representatives should be set up to recommend strategies for monitoring external resources intended for children affected by HIV and AIDS, and to develop systems of accountability that are understood by, and useful to, communities.
- Frameworks of best practices should be developed by national authorities to guide all actors (international development partners, government, civil society, and communities) in supporting children and families affected by AIDS.



3. Reducing family poverty

While multiple channels exist to address poverty, from private charity to efforts to stimulate economic growth, national social protection policies have proved best at responding to the urgent needs of families and children living in extreme destitution. “Social protection” is an umbrella term for measures that aim to reduce the vulnerability and risks faced by the poor and other disadvantaged groups.

Many countries now categorized as “high-income” have adopted social protection policies during phases of rapid economic expansion or crisis in order to reduce poverty, overcome social exclusion, and build human capital. As evidence of the effectiveness of these approaches mounts, social protection is now also moving firmly onto the development agenda of low- and middle-income countries.

Choices in the development and implementation of social protection programmes must reflect national contexts, priorities, and political opportunities. While no single solution can be applied in all countries, “income transfer” programmes score well compared to other options in terms of their cost, the organizational capacities they require, and the ease and speed with which they can be scaled up.

The basic principle of income transfers is simple: put money in the hands of poor people. Many families affected by AIDS and poverty are too weakened or destitute to take advantage of schemes such as “cash for work” or microcredit projects. They can, however, immediately and effectively utilize additional funds provided through income transfers for the benefit of children.



Income transfers are comparatively simple to administer and have operated successfully, even in low-income countries with fragile infrastructures. Forms of income transfer programmes especially relevant to African policy contexts include unconditional income transfers to households living in extreme poverty; child support grants; and old age pensions. Designating women to receive and manage family income transfers has been linked to several benefits, including strengthening women’s economic status; contributing to a more equitable distribution of decision-making power within families; increasing family spending on food and health; and improving outcomes for children. Income transfers are not, however, 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.

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 such a package for low-income African countries — consisting of a small universal old age pension, universal primary education, free primary health care, and a child benefit of us\$0.25 per day — at between 1.5 and 4.5% of Gross Domestic Product. A recent Zambian pilot project provided us\$15 per month to each of the poorest 10% of households. If this were implemented in all low-income countries in sub-Saharan Africa, it would cost 3% of the aid to Africa agreed at the 2005 Gleneagles meeting of the G8.

4. Delivering integrated family-centred services in health, education, and social welfare

The well-being and life-chances of children affected by HIV and AIDS are undermined by failures in many essential services. Addressing these will require both substantial new investments in national health systems and innovative strategies to deliver services more effectively at the local level.

JLICA's analysis shows that the best results for children are achieved through strategies that provide a range of services to the whole family. Key approaches underpinning effective responses include:

■ **Listening and responding to the diverse needs of families:** A key factor in effective service delivery is the commitment to listen to patients and their families and adapt priorities to their needs. Among other things, this means ensuring links between medical care and other support services, such as food security and economic assistance for families. Platforms in which people can access “bundled” services that simultaneously address a range of needs offer a promising approach to improving outcomes for children and families.

■ **Protecting children's development potential:** Highly effective programmes integrate interventions — such as nutrition, early childhood development, and education services — that protect children's development potential. Such integrated services, targeted at very poor families, have been successfully rolled out to national scale in various Latin American countries. African governments are increasingly utilizing schools as venues from which to deliver services that can support children's physical, cognitive, and social development and also strengthen families. UNICEF has advanced this agenda through its “Learning Plus” initiative.

■ **Involving community workers:** JLICA's analysis found that programmes achieving exceptional results for children and families generally involve community workers who are well-trained, well-supervised, and appropriately compensated. Community health workers and community workers from other sectors are the “glue” that binds together the different dimensions of an integrated, family-centred approach.

JLICA has also identified several components that are essential to successfully scaling-up national programmes for children and families:

- **Strong leadership:** Strong national government leadership is essential and irreplaceable.
- **Inclusive partnerships:** Partnerships work

best when donors, bilateral agencies, NGOs, and academic institutions make long-term commitments and build strong working relationships with national and local partners, under the authority of the national government.

- **Combined domestic and international financing:** The financing models used to promote national scale-up require substantial and sustained investments from both affected-country governments and international sources.
- **Systematized task-shifting:** Programmes can be expanded more rapidly through the appropriate use of well-trained and compensated lay counsellors, community health workers, and other less specialized cadres that are able to take on a broad range of tasks.
- **Innovative use of centres of excellence:** Some especially successful scale-up processes have tested innovative solutions in centres of excellence linked to a national relay network to disseminate solutions. Such systems are designed to identify strategies that can be rolled out quickly, and to disseminate information on successful innovations to service providers country-wide.
- **An emphasis on accountability:** Innovative strategies can be deployed to strengthen political accountability for children's outcomes. In Rwanda, programme transparency has been increased through public reporting sessions, broadcast live by national media, in which district mayors give accounts of programme performance. The sessions provide detailed information on how well local officials are delivering on their responsibilities towards vulnerable children.

Actions for Short-Term Gains, with Long-Term Impact

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. Advancing this agenda, however, demands major shifts — in both thinking and action.

This report presents an integrated model of public health and development with the potential to repair the damage to many families and communities created by the simultaneous assaults of disease, poverty, inequalities, and food insecurity.

Significant gains are achievable in the short term, if accelerated action is taken by governments and their partners in the following policy directions:

- Develop national social protection schemes for vulnerable families as a critical measure to improve children’s health and well-being in the context of HIV and AIDS.
- Provide benefits to families and children based on need, not on HIV or orphan status.
- Reinforce families’ capacities to provide long-term care, as the basis of a sustainable response to children affected by HIV and AIDS.
- Strengthen community action in support of children affected by AIDS and design interventions with local participation and ownership.
- Implement family-centred services that integrate health, education, and social support.
- Redirect HIV prevention to redress the social and economic inequalities that increase girls’ and women’s vulnerability.
- Strengthen the evidence base on policies and programmes that work for children — and act on it.

A new focus on children’s well-being in the context of AIDS and poverty can help move AIDS policy beyond the emergency response mode that has guided action to date. It can lay the foundation for a lasting synergy between AIDS programmes and national social protection measures that will sustain health and development efforts over the long haul.



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This new agenda will require significant new resources. In an adverse global financing environment, mobilizing additional funding for ambitious new policies and programmes poses very real challenges. At the same time, strained economic conditions aggravate the hardships of those affected, and so increase the urgency of rapidly implementing the policies JLICA recommends. The very conditions that make policy action difficult also make it more imperative.

For too long, the global AIDS response has ignored “home truths” about children, AIDS, and poverty. By confronting and acting on these truths now, however, governments and communities can achieve substantial and rapid gains for children and families that will have lasting impact.

Now is the time to face the facts on children, AIDS, and poverty, and to take the action that can secure the health and well-being of future generations.

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