The Joint Learning Initiative on Children and HIV/AIDS **Learning Group 2**

Inside-Out?
Strengthening Community Responses to Children Affected by HIV/AIDS

Compiled by JLICA Learning Group 2 Co-Chairs **Geoff Foster** (Family AIDS Caring Trust) and **Madhu Deshmukh** (CARE USA) and JLICA Executive Co-Director **Alayne Adams**

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JLIC

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JLICA — JOINT LEARNING INITIATIVE ON CHILDREN AND HIV/AIDS

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DFID Department for International Development

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unicef

Contents

Acronyms

CBO	community-based organization
CSO	civil society organization
FBO	faith-based organization
IATT	Inter-Agency Task Team on Children and HIV/AIDS
JLICA	Joint Learning Initiative on Children and AIDS
MAP	multi-country AIDS program
NGO	non-governmental organization
OVC	orphans and vulnerable children
PEPFAR	Presidential Emergency Plan for AIDS Relief
POS	programme of support
RAAAP	rapid assessment, analysis and action planning
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNICEF	United Nations Children's Fund

Introduction

The Joint Learning Initiative on Children and HIV/AIDS (JLICA) is an independent, time-limited network of researchers, practitioners, policymakers, community leaders and people affected by HIV and AIDS. Its goal is to improve the well-being of children, families and communities affected by HIV and AIDS by mobilizing the scientific evidence and producing actionable recommendations for policy and practice.

Launched in October 2006, JLICA brings together experts from more than a dozen countries. To date, the initiative has produced more than 50 original review and research papers and reports. These outputs mobilize knowledge from a broad spectrum of disciplines with the aim of enabling evidence-informed policy decisions to improve children's lives. JLICA addresses itself in the first instance to national policymakers in heavily-burdened countries and those who advise them. Many of its findings apply to low-prevalence and highly concentrated epidemics. JLICA also speaks to donors; international agencies concerned with children and AIDS; international and national non-governmental organizations; and local civil society organizations and movements.

JLICA's research activities are conducted by four thematic Learning Groups, organized according to the main recommendations of the widely endorsed *Framework for the Protection, Care, and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS* (UNICEF/UNAIDS, 2004). Learning Groups have undertaken a programme of work involving reviews of existing research; the commissioning of strategic studies in under-researched areas; disseminating results among stakeholders; fostering public debate on key policy issues; and providing information to decision-makers and national, regional and global policy forums. Each Learning Group is bringing together its key findings and recommendations in an integrated synthesis paper. Learning Group synthesis papers serve as key inputs to the JLICA final report. As they are completed, all JLICA research products will be freely available on the initiative's website at **http://www.jlica.org**.

JLICA's four Learning Groups are structured and led as follows:

- **Learning Group 1: Strengthening Families,** chaired by Linda Richter (Human Sciences Research Council, South Africa) and Lorraine Sherr (University College London, United Kingdom)

- **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)

JLICA was created in response to the enduring neglect of children in the context of HIV and AIDS. Many factors have contributed to this marginalization. In part, it has been perpetuated because children lack power, organization and voice to defend their interests politically. In part, it is because the responsibility of caring for affected children in the context of HIV and AIDS has been unobtrusively absorbed by families and communities on the front lines of the epidemic. A guiding aim of JLICA's analysis is to identify the specific ways in which national governments and other actors can most effectively support families and communities, as the latter must remain at the heart of any sustainable response to children's needs in the context of HIV and AIDS.

Shared values underpin JLICA's work. Most importantly, JLICA is committed to a human rights-based approach to issues of children and AIDS. This includes the right of children, young people and families to participate in key decisions that affect their lives.

A number of methodological and definitional principles are also shared across all Learning Groups. JLICA uses the Convention on the Rights of the Child to define a "child" as a person under 18 years of age. JLICA's research has highlighted the confusions caused by the definition of "orphan" adopted by United Nations agencies and used to generate international statistics. JLICA has called for the official UN definition to be reviewed and applauds recent indications that such a review may be imminent (Richter, 2008; Sherr et al., 2008).[1] Because of the associated definitional ambiguities, JLICA discourages reliance on the term "orphans and vulnerable children" and, in particular, the reifying acronym "OVC." The preferred inclusive term within JLICA is "children affected by HIV and AIDS."

The inclusive quality of this term has both practical value and ethical significance. Indeed, JLICA argues that, in addition to the categories specified under the UNAIDS and UNICEF definition, the term "children affected by HIV and AIDS" must be understood more expansively. In settings characterized by high HIV prevalence and widespread poverty, the meaning of this term extends to include:

• Children indirectly affected by HIV and AIDS because they are living in communities heavily burdened by HIV and AIDS, and

• Children especially vulnerable to exposure to HIV due to their circumstances.

JLICA is committed to the disaggregation of child-related data by gender, age, household economic level and other relevant stratifiers. Equally important, JLICA emphasizes that the information derived from disaggregated data should be, not merely reported, but also *used* to better understand the specific needs and risks faced by vulnerable groups, including girls and young women, and to develop appropriate responses.

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1 See UNICEF's recent call for a reevaluation of the UN definition of 'orphan': UNICEF (2008). 'Orphans'. Press statement published online, available at: http://www.unicef.org/media/media_44928.html (accessed 13 September 2008).

Executive Summary: Community Action is Crucial

Children are affected by HIV and AIDS in a multitude of ways, including the loss of teachers, health care providers, and most critically, the sickness and death of parents. When parents suffer AIDS-related illnesses, relatives provide needed economic and social support to affected children. Children must also cope with new burdens, including new care-giving chores and increased work responsibilities, often without adequate recognition or support. The economic and care-giving burdens imposed on extended families during parental illness, death and beyond deplete them of two resources essential for children's healthy development: time and money (Heymann and Kidman, 2008).

Many families facing these dual shocks receive essential support from surrounding communities—groups of people living in the same neighbourhood or sharing similar interests.[2] Commissioned research by the Joint Learning Initiative on Children and AIDS (JLICA) reveals the extent of community-initiated responses for children affected by HIV and AIDS. Most have been established recently, growing out of community solidarity, compassion and religious belief. Many are expanding, both in *scale*—more children served by increasing numbers of volunteers—and in *scope*—moving beyond welfare assistance into psychosocial support and household economic strengthening. Yet community initiatives are poorly documented, and little known outside their immediate locale. Few have access to support from external organizations, and those that do must cope with stringent monitoring requirements that divert energies away from the work at hand. It is shocking that the poor living in communities affected by HIV/AIDS are required to go on subsidizing the destitute whilst governments, both rich and poor, ignore obligations ratified in conventions and charters to provide resources necessary to ensure the social protection of vulnerable children (Wilkinson-Maphosa et al., 2005; Foster, 2005a). Strengthening communities so they can respond to the HIV/AIDS crisis is critical for today's children and vital for future generations.

2 Many other definitions of community exist, reviewed over 50 years ago (Hillery 1955)

How Little We Know

In the last decade, there has been a significant growth in numbers of international non-governmental organizations (NGOs) engaged in programming to support children affected by HIV/AIDS. However, the evidence base underlying programme strategies for children affected by HIV/AIDS is thin. Few evaluations or impact assessments have been undertaken to assess the effectiveness of community-level programming by outside agencies, while no known studies have assessed the effectiveness of community-led initiatives (Box 1, Table 1) (Schenk, 2008; Williamson, 2007). External agencies need to

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BOX 1

Evaluations of Community Programmes to Support Children Affected by HIV and AIDS (Schenk, 2008).

A recent review of the published and grey literature revealed only 21 evaluations, reviews or assessments of community interventions in high prevalence settings in Africa that possessed at least one round of post-intervention data focusing on health and welfare outcomes. Among the studies identified, few were administered by local NGOS or community groups. The large majority were reviews of programmes implemented by international NGOs, although often in partnership with local CBOs and NGOs. Evaluation data consisted of a variety of measures relating to programme processes and outcomes in children, with little consideration of impacts on other family members in target households or within the community. While the quality and rigour of evidence varied, several key findings warrant mention. First is the critical importance of collaboration and linkage between local government, community groups, faith-based organizations and NGOs in supporting the ongoing efforts of families in meeting children's needs. Second is the effectiveness of a holistic approach that addresses multiple resource constraints at the community and family level, and links people to services. Providing clear recommendations for the systematic evaluation of programmes for children affected by HIV and AIDS, the study concludes "Considering the widespread experience in implementing programmes for orphans and vulnerable children represented by spending to date, the evidence base guiding resource allocation is disappointingly limited."

Table 1: Assessment of Community Responses To Vulnerable Children (Schenk, 2008)

Level of Response	Examples of Community Organizations	Assessment of Responses and Programmes
External, outside community	• International NGOs • National NGOs • Some local NGOs • Religious coordinating bodies	Some descriptive data of external programmes. A limited number of evaluation studies which vary in focus and rigour. Few studies of programme impact.
Community-level organization	• Community-based organizations • Congregations • Some local NGOs	Few descriptions of community-level organizations and associations exist. No systematic evaluation or impact studies.
Community-level, informal association	• Initiatives for children • Support groups for home-based care • Mutual assistance initiatives • Economic associations • Informal women's groups • Health committees • Cooperatives	

heed the voice of experience; years of accumulated work carried out selflessly by communities responding to children and AIDS. Learning from this experience may lead to more effective policies and programmes to strengthen communities that are on the front line of improving the lives of children affected by HIV/AIDS. *Inside-Out?* provides a mouthpiece through which communities can "speak" to external programmers and policymakers concerning the best ways of supporting children living in communities affected by HIV/AIDS.

"Considering the widespread experience in implementing programmes for orphans and vulnerable children represented by spending to date, the evidence base guiding resource allocation is disappointingly limited."

JLICA Learning Group on Community Action

The authoritative *Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV/AIDS* has served to guide responses to orphans and vulnerable children during the past decade (UNICEF, 2004). In 2006, the Joint Learning Initiative on Children and AIDS (JLICA) was established to mobilize the evidence base and produce actionable recommendations for policy and

practice concerning support to children affected by HIV and AIDS. Four Learning Groups were established based on principles contained in the *Framework*. Since publication of the *Framework*, three factors have emerged that influence analysis of community responses for children affected by HIV/AIDS:

1. Greater recognition of the scale and significance of community-led initiatives for children affected by the epidemic;
2. The emergence of governments as leaders of national responses; and
3. Increased resource provision and involvement of international agencies in response to children affected by HIV/AIDS.

The JLICA Learning Group on Community Action took these factors into account in analysing evidence underlying the second guiding principle of the *Framework*. The group focused its work on the following research question:

What are the most appropriate programmatic and policy roles for external organizations* in supporting effective community responses for vulnerable children living in communities affected by HIV/AIDS?

* External organizations include government line ministries, local government structures, inter-governmental agencies, international NGOs, national NGOs, religious coordinating bodies, the private sector, and donor organizations

The Learning Group commissioned seven groups of researchers from international and local non-governmental organizations (NGOs), faith-based organizations (FBOs), national AIDS councils and research organizations to study community responses. Commissioned research consisted of literature reviews and primary field work in Bangladesh; Cambodia; India; Kenya; Mozambique; Nigeria; Uganda and Zimbabwe, involving children and youth, caregivers, volunteers, local political, religious and traditional leaders, teachers, health workers, social welfare officers, and staff of NGOs and FBOs. Findings from two other critical studies were also incorporated into the Learning Group's analysis and recommendations (Heymann and Kidman, 2008; Schenk, 2008). In all cases, researchers were challenged to provide recommendations that went beyond the local level (Appendix 1).

Together, these nine studies reiterate that communities play critical roles in providing material and psychosocial support, social and economic safety nets and enhanced access to basic services that assist families in caring for children affected by HIV and AIDS.

External Responses

In recent years, HIV/AIDS responses for vulnerable children have been increasingly driven by agencies such as international NGOs and donors, with issues framed from external perspectives. There has been insufficient involvement of community-level actors in decision-making processes. Evidence collected by JLICA leads us to conclude that the effectiveness of externally driven programmes to support vulnerable children would be enhanced if affected communities were involved in their design. In addition, *Inside-Out?* argues that external aid for vulnerable children can be efficiently utilized by local communities if provided at appropriate levels, through appropriate mechanisms.

In 2004, an historic agreement was reached by donors and low- and middle-income countries to work more effectively together in scaling up national AIDS responses. They adopted the "Three Ones"—core principles for concerted country-level action: one action framework; one AIDS coordinating body; and one country-level monitoring and evaluation system. While for some time other areas of HIV/AIDS response, such as prevention of vertical

transmission and antiretroviral treatment, have been coordinated by national governments, it is only recently that governments have taken on coordination roles concerning children affected by AIDS. Weak government coordination on children's issues has led to what has been termed "alignment anarchy" (Foster, 2008b). Decisions concerning which services to provide and where to situate them have largely been made outside AIDS-affected countries. Diverse reporting systems proliferate with data being provided to donors, but bypassing local and government structures. The lack of local networks linked to national structures has encouraged the establishment of small, geographically diverse donor-linked networks. The recent, welcome expansion of external funding of activities for children affected by HIV/AIDS is being accompanied by increased calls for alignment through coordinated national responses.

Governments are becoming more involved in responses to children affected by HIV/AIDS through situation assessments, national plans of action and the establishment of coordinating structures and national monitoring systems. The involvement of state governments in the response provides opportunities for stakeholders to align themselves more closely with national strategies and local priorities. As well as expecting civil society and

international agencies to align with national plans, governments have the prime responsibility for ensuring the provision of quality health and education services through equitable resource allocation processes within state systems.

Inside-Out? recommends that governments lead efforts to coordinate and strengthen community initiatives and ensure that actions by external agencies are appropriate and do not damage or undermine community responses. In particular, community initiatives should not be forced to implement activities they do not want to, or are not equipped to fulfil. The JLICA Learning Group on Community Action recommends a set of principles to guide national programmes of action and activities that governments might implement in order to strengthen community initiatives.[3] These principles and actions are summarised below:

1. Principles

Community involvement is indispensable: Communities should have a determining voice in how resources for affected children are allocated and used in their local settings. Donors and

3 Some governments are in the process of establishing some of the suggested actions.

implementing agencies must create mechanisms for regular, substantive community consultation and involvement in the design, implementation, monitoring, and evaluation of externally-funded programs (including cash transfer schemes) that support children affected by HIV and AIDS.

Strengthening community responses is required: Community initiatives must be strengthened so that they can sustain and expand the scale and scope of their activities. Access to external resources is key, as is technical support. In delivering external resources, the context, needs and capacities of communities have to be taken into account. There is no single model for effective delivery of resources at the local level.

The role of government in coordinating responses is crucial: Government leadership is critical for ensuring coordination among stakeholders at national, district and local levels. Government facilitated networks can strengthen community-level initiatives, enable them to align with national plans, policies, and programmes and ensure community voice in decision-making

2. Actions

District committees: Where not present, district committees should be established. If already established, these should be enabled to coordinate and monitor activities and maintain active registers of community-level initiatives.

Resource tracking and aid effectiveness: Working groups involving both government and civil society should be convened to make recommendations on how to ensure that external resources intended for children are effectively utilized, and to engage communities in designing and using monitoring systems.

Frameworks for partnership and accountability: Coordination structures should develop charters of best practice to guide international development partners, governments and local civil society, including FBOs and communities, in supporting children and families affected by HIV and AIDS.

Strengthening Community Responses

Although often unrecognized or taken for granted, networks of relatives, friends, and community members offer daily support to children affected by HIV and AIDS (Foster, 2004; Webb et al., 2006). Together with families, communities provide children with 90 percent of the financial, material and psychosocial support they need (McDermott, 2006; Mutangadura et al., 1999). Children and youth are not only programme beneficiaries. Research commissioned by JLICA demonstrates the important contributions of children and youth in supporting themselves and providing for the psychosocial and material needs of other children and youth (Fleming et al., 2008). But communities in sub-Saharan Africa and beyond are increasingly challenged by poverty, lack of resources and the magnitude of the epidemic's impact. Reinforcing the capacity of communities to support and protect growing numbers of children affected by HIV and AIDS is necessary to match the scale and long-term impact of the crisis.

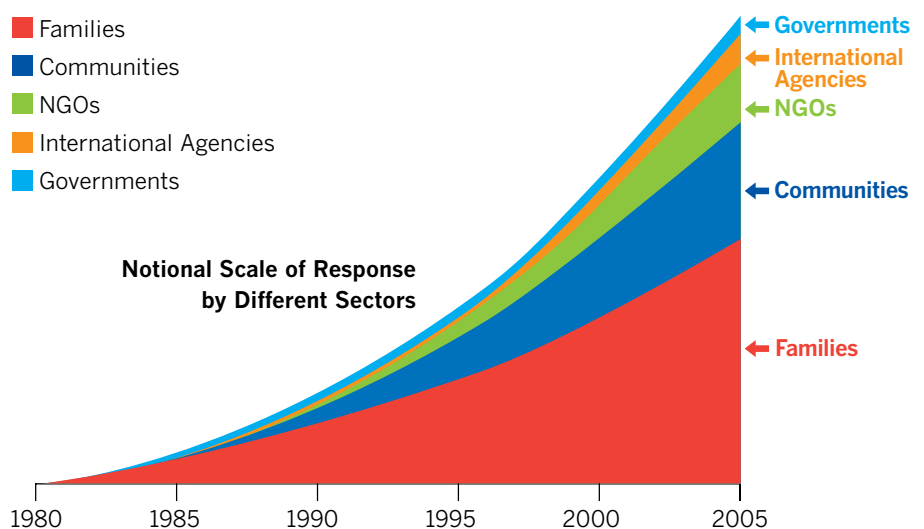## Family Networks — The First Line of Response

In countries with inadequate social protection services and high HIV prevalence, extended family networks are the most important source of support to children affected by HIV and AIDS, providing care and protection to those orphaned by the epidemic, or living with sick parents (Figure 1) (Beer et al., 1986; De Waal, 2008; Foster, 2005b). Analysis of data from a nationally representative household survey in Malawi indicates that over 75 percent 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 (National

Figure 1: Circles of Support for HIV/AIDS-Affected Children

NGOs, Government Services etc

Caregivers

Community Supports

Family Networks
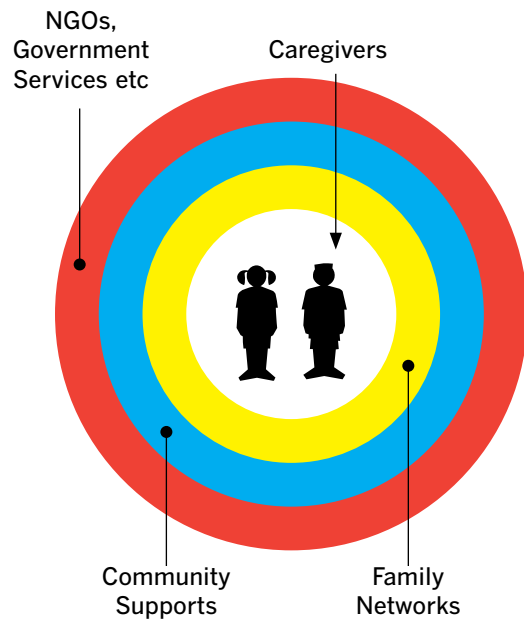
Statistics Office, Malawi, 2005a, 2005b; Kidman and Heymann, 2008). However, in Malawi, the value of such support tends to be small, and those in greatest need are least likely to benefit. Poor households with uneducated heads — in other words, those already least able to meet the essential needs of children in their care — received transfers of lesser value than other groups (Kidman and Heymann, 2008). In relatively well-off Botswana, assistance from family and friends to households caring for orphans lowered their likelihood of reporting financial difficulties by 70 percent overall (Miller et al., 2006).

Figure 2: Notional Onset and Scale of Responses to Children Affected by HIV/AIDS in Sub-Saharan Africa by Sector (Foster, 2006)

- Families
- Communities
- NGOs
- International Agencies
- Governments

Notional Scale of Response by Different Sectors

← Governments
← International Agencies
← NGOs
← Communities
← Families

Communities Backstop Families

The impacts of the epidemic on households are most severe during terminal illness, death and funeral of the breadwinner and afterwards when relatives commit themselves to the long-term care and protection of children left behind (Donahue, 2005). Often weakened and impoverished themselves, extended families frequently lack the time and money to feed, clothe, stimulate and educate children in their care (Aniyom et al., 2008; Kidman and Heymann, 2008). In response to these constraints, and motivated by their religious persuasion, experience, compassion or a simple desire to help, community members often organize additional financial and psychosocial support, acting as safety nets to affected children and their families (Foster, 2007; Foster et al., 2002).

Community action for children affected by HIV and AIDS is typically channelled through local organizations such as churches, schools and associations. While community initiatives vary widely in capacity and scope, their proximity to those they serve allows them to recognize, adapt and respond quickly to changing needs and priorities. Initiatives established by those directly affected, especially if they involve children and youth, are more likely to address important psychosocial dimensions of impact (Loewenson, et al., 2008).

In Africa, community initiatives for children affected by HIV/AIDS preceded programmes established by NGOs, international agencies and governments (Figure 2) (Foster, 2006). As early as 1987, community-based organizations in Tanzania provided educational assistance, food, and clothing to children orphaned by AIDS (World Bank, 1993). The proliferation of local initiatives for HIV/AIDS-affected children in recent years is an example of this ability to quickly mobilize around important community concerns. A recent study undertaken by JLICA partners found that some 40 percent of children in Malawi lived in communities with local support groups for the chronically ill, offering counselling (31 percent), support for vulnerable children (25 percent), food or other in-kind gifts (24 percent) and medical care (20 percent) (Kidman and Heymann, 2008; National Statistics Office, Malawi, 2005a, 2005b).

Though community-led initiatives are a lifeline for many destitute households, they are no panacea. At times they can contribute to stigma: marginalizing
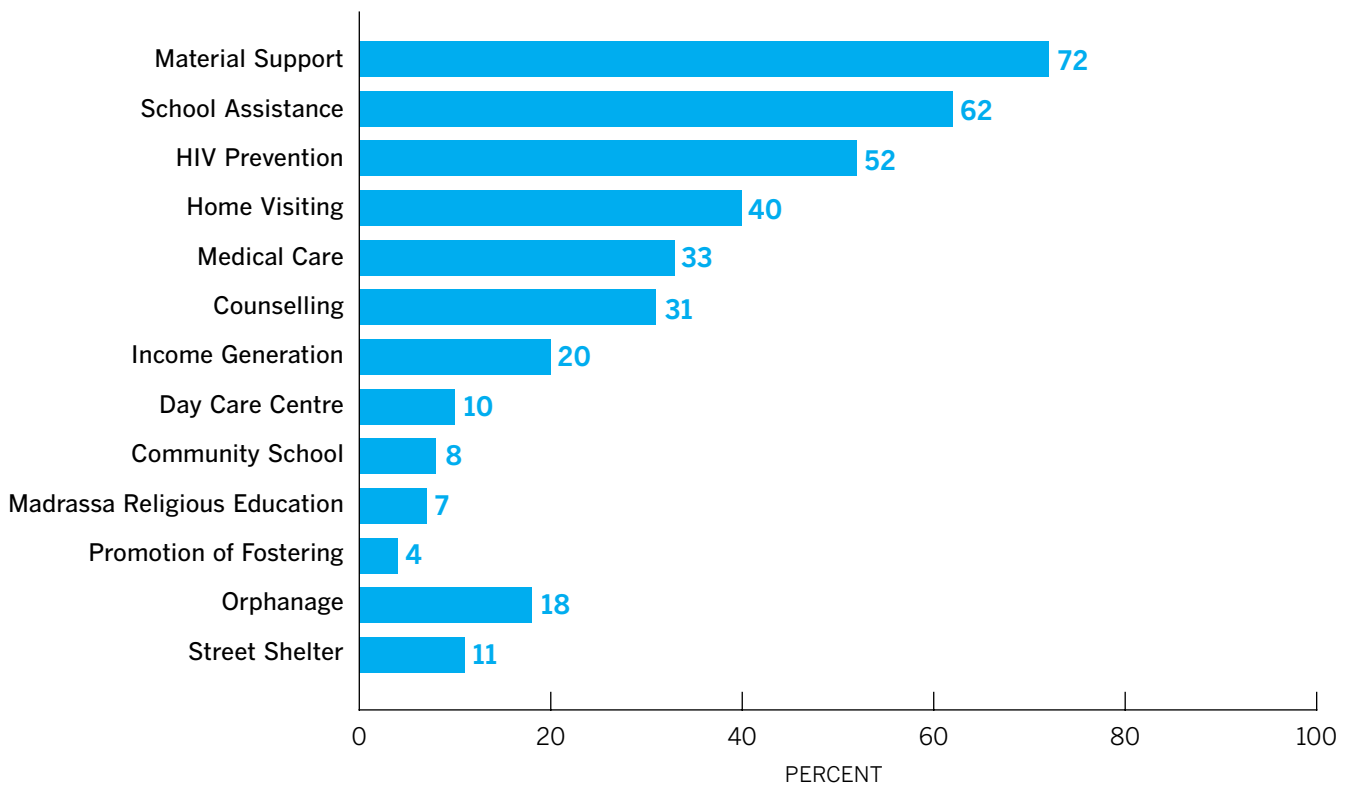

BOX 2

Faith-Based Organizations and Children Affected by HIV and AIDS (Foster, 2008a; Matthai, 2008)

Faith-based groups represent a majority of community-level HIV/AIDS responses in many African countries. Amongst 181 community-level organizations involved in health-related activities in Zambia, 63 percent were congregations or religious support groups and one-quarter were involved in assisting children. It is estimated there are 5,000 faith-based support groups in Lesotho that support people living with HIV/AIDS, children and the chronically ill through home-based care initiatives (ARHAP, 2006). A six-country survey of 690 faith-based organizations found most supported children affected by HIV and AIDS (Foster, 2004). In Namibia, most of the 95 Christian congregations surveyed had HIV/AIDS responses whilst one-third implemented community-based or institutional responses for children affected by HIV and AIDS. The majority of respondents (61 percent) did not belong to a network or affiliation that supported their HIV/AIDS response. An additional 19 percent belonged to a network but had not received any support. Almost all respondents stated that they would like to be affiliated with a network supporting HIV/AIDS work (Yates, 2003).

One faith-based initiative was established with four volunteers who identified 187 orphans. Three years later, it had grown to 30 volunteers supporting 467 children. Comparing new and more established initiatives within the Zimbabwe Orphans through Extended Hands Network, an evolution in the types of services provided is apparent. In established initiatives activities have broadened beyond the provision of relief to individual orphans, to a more development-oriented approach that includes psychosocial support, and the social and economic empowerment of HIV affected children and their families (Foster et al, 2002).

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single women, disempowering girls, and overlooking young children. Though well-endowed in personal dedication, most volunteers have limited resources to support other households and lack necessary knowledge and skills in care and support. Many community initiatives function independently, and lack connections with networks of best practice

Figure 3: Services for Orphans and Vulnerable Children Provided by Faith-Based Organizations (Foster, 2004)

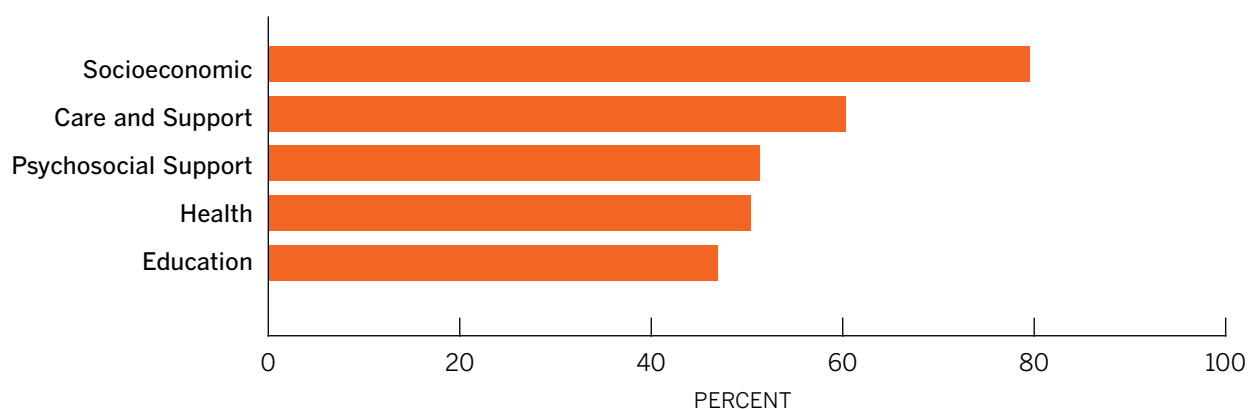| Service	Percent
Material Support	72
School Assistance	62
HIV Prevention	52
Home Visiting	40
Medical Care	33
Counselling	31
Income Generation	20
Day Care Centre	10
Community School	8
Madrassa Religious Education	7
Promotion of Fostering	4
Orphanage	18
Street Shelter	11

PERCENT

(Box 2). 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).

Growing evidence from high-burden settings suggests that the cumulative burden of HIV/AIDS, coupled with poverty and food insecurity, is stretching community capacities as never before. Enormous good will and desire to help exists in communities, but local safety nets are fragile in the face of compounded stresses and unprecedented levels of demand.

Mushrooming Community Responses

When Ugandans were asked what most concerned them about the impact of the AIDS epidemic, most responded "it's the children!," reflecting widespread public concern for the welfare of children affected by HIV/AIDS (Bolton and Wilk, 2004). A mushrooming of community initiatives has occurred throughout Africa, many of which are expanding their reach and broadening their activities (Box 3) (Foster, 2002; Foster et al., 2002). A six-country survey of 651 faith-based organizations (FBOs) with initiatives for children affected by HIV/AIDS, found that one-half

Figure 4: Unmet Needs of Orphans in Uganda (n = 1701)

Need	Percent
Socioeconomic	~79
Care and Support	~60
Psychosocial Support	~51
Health	~50
Education	~47

PERCENT

were established in the preceding four years (Foster, 2004). Initiatives provide children affected by HIV/AIDS with a wide range of services, such as the provision of food and clothing, assistance with the costs of health care or education, psychosocial and spiritual support and HIV prevention activities (Figure 3).

Despite external assistance, the needs of many vulnerable children remain unmet (Figure 4). In a JLICA study of the effectiveness of external resource provision in Uganda, most external support was focused on education-related needs. Many service providers narrowly interpreted psychosocial support to mean strengthening counseling services through training non-family members, rather than enhancing family capacity to provide 'parental care and love' to children. General welfare needs such as shelter, clothing, bedding, and cooking utensils, though often requested, were infrequently delivered (Nshakira and 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 percent reported that they received no external HIV/AIDS funding whatsoever (Yates, 2003). The overwhelming source of support came from member contributions, private donations and local fund-raising. This was also observed in a South African study of 162 FBOs where local donations represented the major source of funding for HIV/AIDS activities (Birdsall, 2005). While FBOs are distinctive for their commitment to sustaining community and spiritual life even in difficult situations of conflict, oppression or disease, the growing burden of HIV/AIDS in highly affected communities places considerable strain on the pockets of church members and faith-based volunteers.

Research by JLICA suggests that volunteers from community initiatives effectively identify vulnerable children, supervise resource distribution, provide psychosocial support and supply labour assistance to affected households (Blackett-Dibinga and Sussman, 2008; Family AIDS Caring Trust, 2001; Loewenson et al., 2008; Nshakira and Taylor, 2008). But in addition, many volunteers feel obliged to supply food, provide clothing and raise cash for the medical and education fees of other people's children, activities that require financial resources that few possess. Lack of financial resources has led many groups to establish income

BOX 3

Economic Strengthening and Vulnerable Children — the Asian Experience (Zaveri, 2008)

Some organizations in Asia have translated their successful history of civil society mobilization and poverty alleviation to the HIV/AIDS sector. Groups and collectives have proved to be effective managers of economic activities. Both economic groups (self-help groups, savings groups, microfinance groups) and solidarity groups (positive women's groups, sex workers collectives, and children's collectives) have enhanced economic security. Some examples include Cambodia's farmers' collectives, Bangladesh's sex workers' collectives and India's self-help groups. Economic activities include access to group micro-credit and finance, creation of community risk funds, community rice banks, educational funds for children affected by HIV/AIDS (through fund-raising activities by collectives) and provision of internal loans freeing sex workers and HIV affected widows from rapacious money-lenders.

Self-help groups in India provide an interesting example of an economic collective. A group typically has 10 to 15 women, each of whom contributes a small amount of money every month that is matched by government funds. HIV-positive women can be members of HIV-positive women's groups, other women's groups or saving and loans groups. By participating in these groups, women have been able to obtain loans and to gain employment in the group's income generating program. As members of the self-help group, these women are eligible for health insurance and other social security schemes. Further, the women are able to attain economic and social security and to create advocacy platforms to discuss their needs and rights.

Children's collectives also deserve particular mention. The Shishu Parishads (Children's committees) in the Daulatia Brothel area in Bangladesh have been successful in reducing child marriages and the trafficking of children. Many of its child members have a high perception of risks in sex work and have resisted recruitment by the brothel owners — and sometimes their mothers — into sex work. In another example, the Children's Clubs that arose through the "Life Skills Program" in India have ensured that children continue their education. By enabling HIV-affected communities to come together to design their own development initiatives, communities are able to control and manage their livelihood resources.

generating projects to raise needed funds. However, many of these small scale efforts yield little relative to time invested. The provision of cash transfers to families supporting children affected by HIV and AIDS could relieve communities from some of these financial obligations, and enable them to focus on those activities to which they are best suited. The support of microfinance and economic strengthening initiatives may also serve to increase available resources for HIV/AIDS-affected children (Box 3) (Zaveri, 2008).

Communities are already engaged in making decisions concerning the implementation of initiatives supporting children affected by HIV/AIDS, and have proven capable of administering their own finances. Assessments indicate that the cost-per-child of community-level service provision is considerably less than that of international NGOs, though admittedly, studies do not control for quality of services which are frequently less when delivered by resource-constrained community initiatives (Catholic Relief Services, 2004; Phiri et al., 2001). A multi-community study in South Africa similarly notes that requests for institutional development and personnel remuneration by community initiatives are minimal, indicating cost-effectiveness and low transaction costs in delivering support to those in greatest need (Birdsall and Kelly, 2005).

External technical and financial support to help community initiatives expand and improve their services to AIDS-affected children is urgently needed, but difficult to acquire even after significant effort (Birdsall, 2005; Taylor, 2005a, 2005b, 2006). All but one of 94 FBOs surveyed in Namibia identified a need for training in HIV/AIDS-related technical skills, and only 20 percent belonged to a network or affiliation that actively supported their HIV/AIDS work (Yates, 2003). Linkages with religious coordinating bodies and faith-based NGOs are critical to the effectiveness of local FBO responses. Yet, hundreds of thousands of congregations and faith-based support groups in the AIDS belt of east and southern Africa remain unconnected to external sources of support. This disconnect is also apparent between community initiatives and the government sector. Establishing or strengthening district-level networking structures is a first step in allowing community-level groups supporting children affected by HIV/AIDS to integrate into broader service delivery frameworks and receive needed technical assistance (World Health Organization, 1994).

BOX 4

Provision of Resources to Community Initiatives and Children Affected by HIV/AIDS in Uganda

In 2007, JLICA researchers conducted an evaluation of the effectiveness of external resource provision to support children affected by HIV/AIDS in four sub-counties in Uganda (pop. 141,811). The study identified 108 community-level initiatives that were responding to vulnerable children. The prevalence of community-level initiatives for children affected by HIV/AIDS was one per 1,300 people. Most initiatives were independent groups or linked to local churches, schools, or clinics. Around one-quarter were associated with national NGOs or FBOs and 14 percent were linked to international NGOs. Nearly two-thirds of the initiatives had received external support, though 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 percent received cash, 59 percent received material support and 41 percent received technical support in the form of capacity building, training or mentoring.

The study interviewed 541 households containing orphaned children. Though 52 percent of households received some kind of external support, only 36 percent of children in need were assisted, largely with education-related expenses. Fifty-nine percent of external support received by households was targeted exclusively at individual children, while 8 percent was specifically dedicated to strengthen households containing vulnerable children. Support frequently overlooked young children. Of the 612 beneficiaries, 18 percent of children of preschool age received support compared to 44 percent of 6–14 year-olds and 38 percent of 15–18 year-olds. (Nshakira and Taylor, 2008)

Getting Resources to Where They Are Needed

Increasingly, local organizations involved in supporting AIDS affected children and their families are interacting with external agencies, including donors; national and international NGOs; and governments. When provided in the right way,

external resources in the form of money or technical assistance can provide a critical boost to community-level efforts to support vulnerable children. In recent years, a significant increase in donor funding has occurred. However, it is not clear how effective that investment has been, given the lack of impact assessments and systems for tracking resource flows to communities. JLICA researchers (Nshakira

and Taylor, 2008) (Box 4) and others (Birdsall and Kelly, 2007) investigating the provision of resources to community-level programs for vulnerable children make the following observations:

1. **Most external support for community initiatives is in the form of cash grants:** Externally-led initiatives have more likelihood to access cash

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Examples of Resource Flow Mechanisms to Community Initiatives Supporting Children Affected by HIV/AIDS in Uganda (Nshakira and Taylor, 2008)

"Pipelines" represent a range of repeated commitments, usually small amounts of funding, from a donor to an initiative in a distant community, with limited direct engagement between the two parties. The primary criteria and justification for sustained partnership is often based on mutual trust between giver and receiver. There is limited emphasis on technical program proposals, little expectation on formalized monitoring and reporting, and rare in-depth analysis of impact. These factors may partly explain the paucity of information on the "actual work and services" in these initiatives and the "impact or life-change results" they achieve among the children and families they reach. A common example of pipelines is the relationship between churches, Christian agencies, and individual Christians in the north, and local congregations or individuals with a similar faith foundation in supported communities. Private foundations and bilateral donor agencies may also have funding arrangements through pipeline mechanisms when they make repeated small grants to the same organization. Pipelines constitute an important source of "steady" funding for a number of community initiatives, often sustained over long periods of time. Initiatives supported through pipelines often remain small but are consistent within their local context, and may not be easily noticeable in evaluations and impact assessments that focus on large numbers and evidence of growth or expansion over time.

"Watering cans" describes initiatives where an external agency establishes itself in a local community as a direct program implementer, usually with considerable resources and a commitment to be present for several years. International NGOs such as World Vision International, Action Aid and Christian Children's Fund use this approach to implement area development programs with a specific program focus. Watering can resource flow mechanisms are based

on the need for other programs and service delivery frameworks in addition to those already existing in the community. The assumption is that these needs will no longer exist at the time of program exit. Such mechanisms are common in crisis or post-crisis situations and assume that ordinary recovery processes will enable government and community service institutions to sustain the programs initiated. Some watering can programs include deliberate investment in community capacity building through partnership with existing local initiatives, creation of new frameworks of agency-community partnership and seeding multiple new initiatives.

"Rainstorms" represent the mobilization of considerable resources which are made available at multiple levels (national, district/sub-national, community). These resources serve to provide a critical boost to massively scale up delivery of services responding to specific needs. Two broad categories of such resources for AIDS have been mobilized in recent years: the poverty reduction initiatives led by the World Bank (e.g., Social Action Funds); and global initiatives targeting AIDS, and other diseases such as: the World Bank Multi-Country AIDS Program; The Global Fund for AIDS, TB and Malaria and the Presidential Emergency Plan for AIDS Relief (PEPFAR). The first major rainstorm fund that reached communities in Uganda was the World Bank MAP Program, through the Community HIV/AIDS Initiatives (CHAI), implemented between 2002 and 2007. It provided a key opportunity for district-led mobilization of communities to analyse the local impact of AIDS, plan appropriate responses, and identify and assign specific actors at the community level to lead and manage implementation. The CHAI fund provided cash grants to selected community initiatives for a one-year implementation process. A total of US $11.3 million was spent on the CHAI fund, largely on activities targeting children affected by AIDS.

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and technical support. Locally-led initiatives are more likely to receive in-kind support.

2. **Community-led initiatives frequently fail to access external support:** Community groups frequently request external support to expand their responses without success, even after significant effort (Birdsall, 2005; Taylor, 2005a, 2005b, 2006). Community groups deem the criteria determining which applicants should receive grants as too selective, with application processes favouring those with connections, writing skills and adaptability to donor requirements. Community members involved in activities supporting children are also dissatisfied with disbursement delays, unrealistically tight timeframes, inflexibility and lack of dependability and trustworthiness of intermediaries.

3. **Different funding mechanisms exist to get resources to community initiatives:** In Uganda (Box 3), three externally funded multi-year programmes provided by the World Bank, Global Fund and the Presidential Emergency Plan for AIDS Relief (PEPFAR) designate over US $100 million of funding to the support of vulnerable children at the community level. A study of community initiatives in Uganda categorized three mechanisms for delivering support to communities: "pipelines" (81 percent of communities receiving external support), "rainstorms" (30 percent) and "watering cans" (28 percent) (Box 5). Some organizations received support through more than one mechanism. All three mechanisms contribute uniquely to enhancing access to resources at community level.

4. **Assistance is frequently targeted at individual children rather than to affected households containing vulnerable children:** This raises concerns about equity as non-targeted children living in the same household do not benefit.

5. **Support frequently overlooks younger children.** This is largely a consequence of the education focus of most programmes supporting vulnerable children. Yet evidence suggests that investments made in early childhood have the greatest long-term impact, based on neuro-developmental considerations.

6. **Many vulnerable children are excluded from support.** Conditions often limit the ways in which support can be used, namely: (Aniyom et al., 2008)

   • strict adherence to specific ages of children

   • focusing only on specific groups, such as orphans (Loewenson et al., 2008)

   • limiting assistance to specific types of support, such as school fees

External agencies can learn from communities that have developed context-appropriate methods of identifying and supporting vulnerable children. Key constraints to effective resource flows to the community level that need to be addressed include: poor communication; mismatch between donor and community priorities; the small amount of resources available; and inadequate coordination among actors at the community level and between community initiatives and donors. Evidence of coordination with national AIDS action plans and responses to children affected by HIV/AIDS (e.g., the "Three Ones" framework) was not evident at district and community levels, and needs to be enhanced.

Monitoring Impact — Who Needs to Know?

JLICA research in Mozambique indicates dissatisfaction amongst many community groups about the imposition of externally designed monitoring systems that require the collection of specified data as a condition for funding. Some community groups receive funds from several sources, each requiring the use of different forms and systems for data collection. Time spent in fulfilling donor requirements was perceived to be incompatible with the goal of assisting vulnerable children and their families, to the point that certain CBOs felt that they were being transformed into service delivery agents for donors and intermediary NGOs. Monitoring indicators were also thought to lack relevance, with data collection focused more on counting children and activities rather than monitoring children's well-being. As a result, local use of data by community implementers for decision-making, planning and advocacy for better services was minimal (Box 6) (Blackett-Dibinga and Sussman, 2008). Some governments are establishing national coordination systems that may protect communities from inappropriate monitoring systems imposed by external agencies (Foster, 2005a; 2008b).

Community Perspectives on Monitoring PEPFAR-Funded Programmes for Children Affected by HIV/AIDS in Mozambique (Blackett-Dibinga and Sussman, 2008)

As part of the Scale Up Hope Program, Save the Children/US mobilized fifty committees in five districts to provide support to vulnerable children. Community "OVC Committees" met frequently and monitored the number and types of services provided to children as required by the donor. Data was reported on a quarterly basis. Focus group discussions were conducted in 10 villages in Gaza Province with community groups responsible for gathering data. The research found that:

• No community committee was involved in development of data collection instruments, and the donor's frequent changes of reporting formats was a major cause of confusion;

• Data collection forms lacked information on the impact of services and child well-being. Yet community members repeatedly explained they lived with the children, knew them, and were aware of how they were doing;

• 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 decision-making and few had feedback and planning sessions or used data to advocate for services. Volunteers lacked time to analyze data as most of their energies were focused on caring for children and fulfilling reporting requirements.

• There was no linkage of community level data to government structures at any level.

Monitoring Aid Effectiveness — Who Cares?

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 (Nshakira and Taylor, 2008). Current funding initiatives often benefit intermediaries more than intended beneficiaries, eat up external resources before they reach affected children and lead to recipients being accountable to external donors rather than to national governments or community groups (Foster, 2005a). Insufficient systematic evaluation and learning has occurred to permit needed modifications in how resources are channeled to communities. While some local NGOs have documented the proportion of funding spent on children affected by HIV/AIDS within communities, few international organizations possess data which enable assessments of whether aid designated for children affected by HIV and AIDS children is reaching its target (Lee et al., 2002). More attention has been given to monitoring the effectiveness of recipient activities than on assessing the impact and cost-effectiveness of aid delivery.

Lack of monitoring systems that track and evaluate aid delivery to community-based programmes supporting orphans and vulnerable children makes it difficult to assess whether intended beneficiaries are being reached effectively.

Community groups in Uganda complained that donors do not make public the explicit criteria used to select beneficiaries or determine the amounts of grants that are intended to reach communities and households. It was impossible for communities applying for grants to know whether criteria were applied fairly and this made the task of monitoring resource flows difficult. Nearly half of household respondents expressed concerns about the "dependability and trustworthiness" of external initiatives directed toward children affected by HIV/AIDS. Respondents reported delays in provision of resources, obstacles to their use, problematic local agents who were frequently not selected by the community, lack of consultation with community leaders and demands for bribes (Nshakira and Taylor, 2008). In Zimbabwe, communities

perceived themselves as playing an important role in holding systems and organizations with resources accountable, keeping written records of beneficiaries and ensuring that resources reached vulnerable children. Community members insisted that a transparent means of identifying vulnerable child beneficiaries using explicit written and agreed protocols was required. They recommended that external monitoring of resources occur, and that people and organizations who stole or misused resources meant to benefit children affected by HIV/AIDS should be prosecuted (Loewenson et al., 2008).

In Zimbabwe, communities perceived themselves as playing an important role in holding systems accountable.

Impact of External Funding on Communities

Funding for externally administered activities for AIDS-affected children in sub-Saharan Africa has increased substantially in recent years. Further increases are projected — for instance, the US government has earmarked 10 percent of its HIV/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 to 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, the provision of external resources, might, if precautions are not taken, actually make matters

worse by flattening local responses. Some negative consequences of external programming are already being observed, including (Foster, 2002a):

- A proliferation of "briefcase CBOs" is occurring as enterprising individuals seek to take advantage of external funding opportunities. External organizations may wrongly view these CBOs as representing and benefiting the community, and overlook more legitimate community-led responses needing support (Butcher and Adupta, 2006).

- Some community groups are redirecting their accountability to external sources of funding and away from the communities they serve.

- With the influx of external funding, community contributions are being withdrawn; community initiatives risk complete collapse when external funding is reduced, interrupted or discontinued (Heymann and Kidman, 2008).

- Community initiatives are being "mobilized" by external organizations, based on the willingness and availability of unpaid labour by volunteers, mostly women, who have little say in program design, delivery or monitoring (Blackett-Dibinga and Sussman, 2008; Heymann and Kidman, 2008).

The establishment of government social protection programmes involving cash transfers to needy households may also impact the functioning of community initiatives. Cash transfers are likely to reduce demand on community safety nets for food, cash and material support to needy households, freeing communities to deliver services that they are better able to provide. At the same time, new burdens may be imposed if communities are required to mobilize volunteers to identify needy households and monitor cash transfers.

The Need for Coordination

Successful programmes supporting children affected by HIV/AIDS coordinate state support, provide resources to households containing vulnerable children and involve community-based organizations and beneficiaries, including children and youth, in channelling these resources (Box 7) (Loewenson et al., 2008). Coordination between communities, international agencies and government is an essential requirement for scaling up.

Alignment is a process whereby external agencies and civil society engage with government with the aim of aligning their activities with the vision, principles and strategies contained in national plans of action (Foster, 2008b). Alignment involves donor harmonization, national coordination of activities and unified reporting systems, and conforms to commitments made by states, and bilateral and multilateral institutions (Box 8) (OECD, 2008). Alignment can be expected to bring major benefits for children affected by HIV and AIDS, who are more likely to receive the support, protection and access to essential services they need in order to thrive. Other benefits of alignment include:

- Increased coverage with focus on difficult-to-reach areas and risk groups and less duplication of services;

- Better access to external resources, networks and capacity-building activities for implementers;

- Improved national information systems with reduced reporting burdens on implementers;

- Availability of good practice information enabling implementers to improve services; and

- Greater cost efficiency.

Consol Homes: An Innovative Model of Youth Engagement in Programs Serving Children Affected by HIV and AIDS.

Located in Namitete, Malawi, Consol Homes is a community-based organization that provides comprehensive care for AIDS-affected children and youth. It is particularly well known for its Orphans Affairs Unit (OAU), a program run every week during after-school hours by and for children orphaned by AIDS. Children aged 10 to 18 years old come together from surrounding villages to discuss the issues, challenges, and problems they and others face in their communities. Youth Members of Parliament (MPs) are elected to represent each village, and an executive is appointed. In parliamentary fashion, the executive receives reports from MPs regarding the well-being of orphans in their community including concerns about child abuse, child labour and children not attending school. These issues are discussed within the OAU respectfully and professionally with everyone being given the opportunity to express their opinion in a non-judgmental manner. At the end of their discussion, MPs issue a resolution of action for implementation by OAU members, Consol Homes staff, village leaders, or community members as appropriate. The OAU also conducts community-oriented awareness-raising activities on the themes of children's and orphans' rights, the importance of education, HIV/AIDS prevention and the impact it has on children. Delivered through song, dance and drama, these presentations are entirely conceived and organized by OAU children and youth.

Since its creation in 2001, Consol Home's model of youth engagement has expanded to 60 different locations across Central and Southern Malawi, reaching an average of 30–40 children at each site. The model has also been adopted by other organizations in neighboring countries including Uganda (HOPEHIV) and Zambia (Christian Children's Fund).

For further information, see: *Youth Engagement in Programs Serving AIDS-Affected Children* by Olivier Drouin, Gillian Morantz and Jody Heymann. McGill Institute for Health and Social Policy. Policy Brief forthcoming. www.mcgill.ca/ihsp

Pooled Funding Arrangement to Support Vulnerable Children in Zimbabwe (Lewnes and Monasch, 2008)

After developing a national action plan, Zimbabwe established a Programme of Support (PoS) for orphans and other children affected by HIV/AIDS in 2007. In its first year, over 165,000 orphans and vulnerable children were reached. The programme aims to reach 400,000 children in all 68 districts. The PoS is supported by six major donors with US $85 million committed over three years through a pooled funding arrangement.

The PoS led to 26 NGOs (including 16 local NGOs) being selected to administer sub-grants through consortia involving some 170 implementing CSOs. Priority was given to channelling support to communities, expanding the scale of activities for affected children, and providing a range of

services and linking activities with existing social protection schemes. The selection process involved government ministries, the National AIDS Council, UNICEF and donors.

The pooled-funding arrangement simplified donor-NGO partnership arrangements and minimized the reporting burden on partners by establishing a unified reporting system. The PoS is believed to have increased cost efficiency, enabling more communities to be reached. Eighty percent of funds were delivered directly to 26 partner organizations from a single account containing the pooled funds. Donors played an active role in the development of the mechanism through an active forum chaired by UNICEF.

Support to Orphans and Vulnerable Children in Zimbabwe—
NGOs Before the Programme of Support
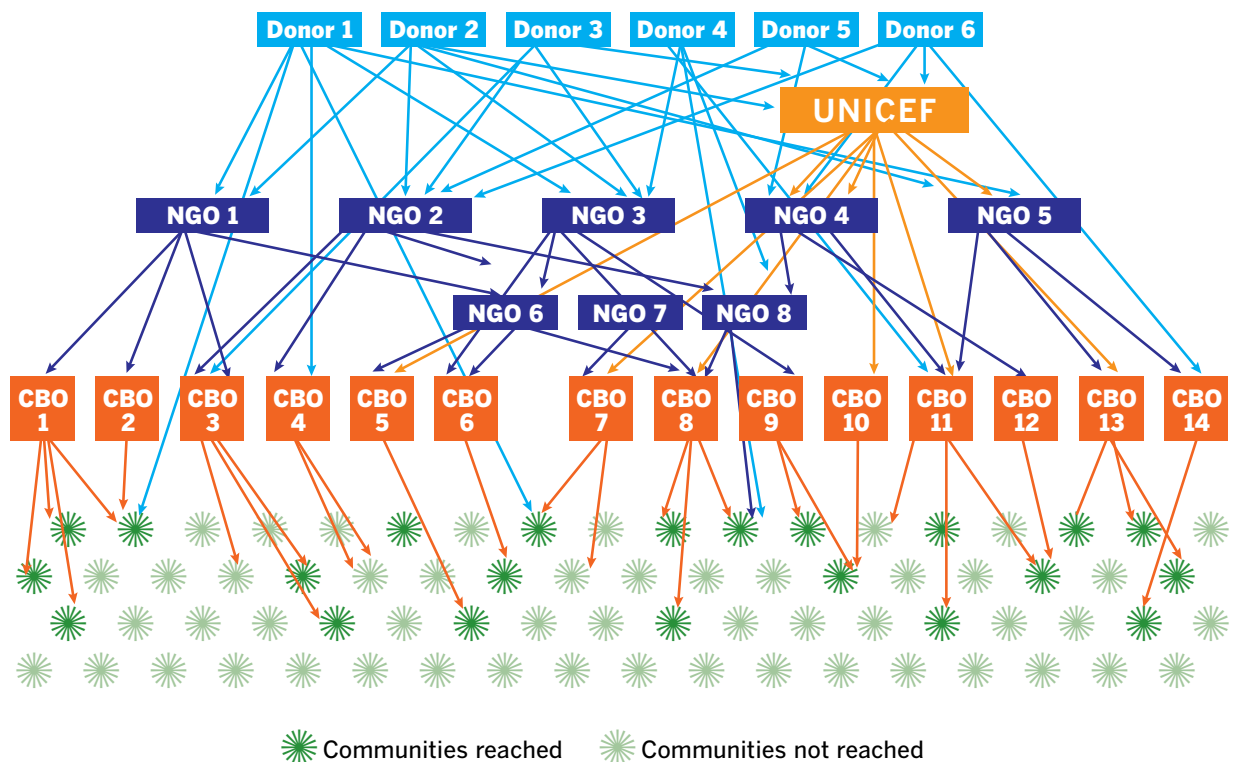
Getting in Line — Coordinated Community, International and Government Responses[4]

Coordination cannot be achieved by piecemeal negotiations between 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 delivering better outcomes for children (Foster, 2008).

Recent initiatives undertaken by governments in the region have facilitated alignment of activities for orphans and other vulnerable children (Box 9). The Rapid Assessment, Analysis and Action Planning (RAAAP) process assisted the development of national plans of action, coordination structures and monitoring and evaluation systems. Though important, these measures in and of themselves are unlikely to lead to alignment of CSOs to national efforts because of underlying constraints:

1. Civil Society Is Aligned with External Donors Rather than National Structures

Funding for local CSOs is frequently provided by international donors. Many donors and intermediaries establish their own programme priorities, monitoring systems and coordination structures. The absence of national policies or guidelines requiring external programmes to engage with national coordination structures means these national structures are frequently bypassed during the establishment and implementation of donor-supported programmes for AIDS-affected children. Alignment is more likely to be achieved as national coordination structures develop policies to address the needs of children affected by HIV/AIDS, establish regional and local coordination structures and monitoring mechanisms, and engage with funders through arrangements such as pooled donor funds (Nshakira and Taylor, 2008).

2. International Responses are Often Not Aligned with National Strategies

International organizations have in some cases inadvertently undermined nationally coordinated

4 This work is drawn from a UNICEF commissioned study on Alignment undertaken by Geoff Foster.

responses to children affected by HIV/AIDS. Donor-CSO networks frequently fail to engage with local or national structures focused on orphans and vulnerable children. Competitive funding processes have led to organizations becoming unwilling to collaborate with one another. Donors have also been slow to collaborate with one another and to align with national plans, resulting in a large number of uncoordinated responses, each with its own funding processes, strategies, networks and reporting requirements. The multiplication of international contributions to HIV/AIDS prevention and mitigation responses often strains the capacity of CSOs and national coordinating bodies, and increases the likelihood of wasted effort and duplication.

3. International and National Responses Need to Align with Community Responses

The roles and responsibilities of governments, external agencies and civil society in responding to the impact of the epidemic on children are becoming better defined with increasing collaboration and growing awareness of each other's roles. The RAAAP initiative, and the development of national plans of action have led to greater mutual understanding between government agencies and larger CSOs. But community-level perspectives are noticeably absent in many forums and processes. Many agencies believe they have obtained community perspectives because they have engaged with NGOs. But NGOs do not necessarily reflect community perspectives. Indeed, some NGOs are perceived by communities to underrate CBO capacity in order to maintain control of project governance and finance (Foster, 2006). Alignment does not only consist of civil society organizations modifying their activities to fit in with national plans of action (Foster, 2008b). "Alignment down" is as important as "alignment up." External agencies, whether government departments, donors, or international or local NGOs, must engage with communities and ensure that community views are represented.

4. Community Responses Need to be Helped to Align With National Strategies

Many FBOs and CBOs are locally-conceived, self-supported initiatives whose main concern is to provide services to vulnerable children. These groups are often unaware of national plans of action since they have little contact with external organizations involved in responses to children affected by HIV/AIDS. National policies, legislation and mandatory reporting requirements are unlikely by themselves to lead to alignment by independent CBOs and FBOs that lack connections with external agencies. Another strategy may be to provide such groups with incentives to encourage their engagement with external organizations, coordination committees

and local networks. Better-established NGOs that already interact with national structures and implement activities that support national plans of action are well placed to provide support to community-level CBOs and thereby encourage their alignment with national plans of action.

Recommendations to External Agencies

The ongoing work of community groups described in this report challenges external organizations to emulate their intensity, generosity, and persistence in addressing the needs of children affected by the AIDS epidemic. Increasingly, responses to children living in the context of HIV/AIDS are being driven by international organizations with issues framed from external perspectives. Externally-driven programmes to support vulnerable children can gain in impact by incorporating the knowledge, skills, and leadership present in communities. External aid for vulnerable children can be more effectively utilized if sufficient financial resources are provided to local communities through appropriate mechanisms.

Today an opportunity exists to supplement the principles contained in the 2004 *Framework*, making them more relevant to current contexts. In some cases, additional research is required to inform specific areas of action.

Inside-Out? presents a set of recommendations and actions to be implemented to strengthen community responses for vulnerable children, addressed to two main audiences:

A. National or State governments (through National AIDS Councils, National AIDS Control Programmes, Ministries of Health, Social Welfare, Education and Finance and President's and Prime Minister's Offices)

B. Funding and technical support organizations, including donors, bilateral and multilateral agencies, foundations, religious organizations, philanthropic bodies and international NGOs

1. **Community participation in decision-making is indispensable**: Community initiatives need to be strengthened so that they can continue to provide support to households and families affected by HIV and AIDS. Communities should be enabled to lead decision-making processes concerning the design, implementation and

monitoring of externally-funded projects for children affected by HIV/AIDS. To enable this, external organizations should:

a. identify and engage with community initiatives for affected children, including child- and youth-led initiatives;

b. align with national policies and strategies governing the functioning of external organizations that are flexible and adapt to the needs and aspirations of communities; and

c. develop channels through which appropriate technical and financial support can be delivered

2. **Scaling up and strengthening community responses:** There is no single model for effective delivery of resources at national or local levels. 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. One area for exploration and possible strengthening is the role of communities in supporting direct cash transfers to families.

3. **Government is key to coordinating responses to AIDS-affected children and their families:** Government is critical to ensuring coordination among stakeholders at national and district levels. Government initiated networks can strengthen community responses, enable them to align with national strategies, plans, policies, and programmes and facilitate community participation in decision-making.

Inside-Out? recommends that governments lead efforts to strengthen community initiatives, through the following set of activities:

1. **District committees:** Where not present, district committees should be established. If already established, these should be enabled to coordinate and monitor activities and maintain active registers of community-level initiatives.

2. **Resource tracking and aid effectiveness:** Working groups involving both government and civil society should be established to make recommendations on how the utilization of external resources can be monitored and how communities can better access and monitor external resources to support children affected by HIV/AIDS.

3. **Frameworks for partnership and accountability:** Coordination structures responding to children affected by HIV/AIDS should develop charters of best practice to guide all actors (international development partners, government, local civil society — including FBOs, and communities) in supporting children and families affected by AIDS. Some areas of concern that might be included in national Charters include:

- Mapping and regularly updating information on the needs of children and families; initiatives in place to meet these needs at all levels (community, district, national); and the flow of resources to support them;

- Defining and implementing partnerships among actors at different levels, which clearly spell out mutual rights, responsibilities and expectations;

- Periodic participatory monitoring, review and learning as an integral element in all on-going interventions; with specific focus on how to strengthen monitoring and learning within community-based initiatives to inform action for program improvement; and

- Defining and implementing comprehensive community capacity-building (including necessary supervision and compensation for the work of community-based providers of child support and cash transfer services), as the ultimate mechanism for sustainable child support and development.

JLICA
JOINT LEARNING INITIATIVE
ON CHILDREN AND HIV/AIDS

Appendix: Learning Group 2 Reports

Background Reports

Nr	Name of Background Report	Authors	Lead Agencies
1	Child and youth participation in programming for children affected by HIV/AIDS: A literature review of the evidence of effect	Vatsia U	Christian Children's Fund, USA and Kenya
2	Review of links between external, formal support and community, household support to Orphans and Vulnerable children in Zimbabwe	Training and Research Support Centre (TARSC), Zimbabwe National AIDS Council, New Dimensions Consulting	TARSC, Zimbabwe

Final Reports

Nr	Name of Final Report	Authors	Lead Agencies
1	Making external resource flows through communities work better for vulnerable children: the experiences, concerns and suggestions of initiatives and care-giving households in Uganda	Nshakira N, Taylor N	FARST Africa, Uganda
2	Review of links between external, formal support and community, household support to orphans and vulnerable children in Zimbabwe	Loewenson R, Mpofu A, James V, Chikumbirike T, Marunda S, Dhlomo S, Milanzi A, Magure T	TARSC, Zimbabwe
3	Strengthening the response for children affected by HIV and AIDS through community-based management information systems	Blackett-Dibinga K, Sussman L	Save the Children, USA
4	The impact of child and youth participation on programs for children affected by AIDS: A look at the literature and evidence from Kenya	Fleming W, Vatsia U, Brakarsh J	Christian Children's Fund, USA and Kenya
5	Economic strengthening and children affected by HIV/AIDS in Asia: Role of communities	Zaveri S	Consultant, India
6	Strengthening community and civil society response to orphans and vulnerable children in Cross River State, Nigeria	Aniyom I, Obono O, Oyene U, Laniyan C, Adebayo B	State Agency for the Control of AIDS, Cross River State, Nigeria
7	The role of faith-based organizations in providing care and support to children living with and affected by HIV and AIDS and FBO collaboration with and integration within national HIV responses	Mathai R	Catholic Medical Mission Board, USA
8	What have we learnt? A review of evaluation evidence on community interventions providing care and support to children who have been orphaned and rendered vulnerable	Schenk K	Consultant, USA
9	Weaving a tighter safety net: Supporting children and families amidst the AIDS pandemic	Heymann J, Kidman R	McGill University, Toronto, Canada

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