

# The Joint Learning Initiative on Children and HIV/AIDS **Learning Group 1** **Strengthening Families**

An obvious truth: Children affected by HIV and AIDS  
are best cared for in functional families with  
basic income security, access to health care and education,  
and support from kin and community

Compiled by JLICA Learning Group 1 Co-chairs **Linda Richter** (Human Sciences  
Research Council) and **Lorraine Sherr** (University College London)  
and **Chris Desmond** (Human Sciences Research Council)

December 2008



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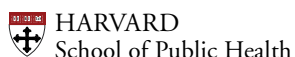
This paper was prepared for the Joint Learning Initiative on Children and HIV/AIDS (JLICA). The Joint Learning Initiative on Children and HIV/AIDS is an independent, interdisciplinary network of policy-makers, practitioners, community leaders, activists, researchers, and people living with HIV, working to improve the well-being of HIV-affected children, their families and communities.

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## Acronyms

<b>ARV</b>	antiretroviral
<b>CSO</b>	civil society organization
<b>ESARO</b>	Eastern and Southern Africa Regional Office
<b>IATT</b>	Inter-Agency Task Team on Children and HIV/AIDS
<b>JLICA</b>	Joint Learning Initiative on Children and AIDS
<b>LG</b>	learning group
<b>PMTCT</b>	prevention of mother-to-child-transmission
<b>UNICEF</b>	United Nations Children’s Fund

# 1. Preface

The Integrated Report of JLICA Learning Group 1 (LG1), on *Strengthening Families*, does not include citations or detailed references to primary or secondary literature or data. Twelve detailed review and research papers constitute the primary evidence for the conclusions drawn and the recommendations made by LG1. The papers, their authors in alphabetical order, and their affiliations are listed on page 5.

An attempt was made to requisition a thirteenth review, on child neglect and abuse in the context of HIV/AIDS, but we were not successful in achieving this in the time span agreed in JLICA.

It was agreed, through the Inter-Agency Task Team on Children and HIV/AIDS (IATT), not to duplicate work, but to incorporate into the LG1 findings the results of a review on low prevalence countries commissioned by the United Nations Children's Fund (UNICEF) — Franco, L. et al (2007). *The evidence base for programming for children affected by HIV/AIDS in low prevalence and concentrated epidemic countries*. Bethesda, MD: The Quality Assurance Project and UNICEF.

Other documents contribute important information and/or perspective to the LG1 report. While these are too numerous to list, the following deserve special mention:

- A range of UNAIDS, UNICEF, WHO and other United Nations documents.
- Belsey, M. (2006). *AIDS and the family: Policy options for a crisis in family capital*. New York: United Nations, Department of Economic and Social Affairs.
- Richter, L., Manegold, J. & Pather, R. (2004). *Family and community interventions for children affected by AIDS*. Cape Town: Human Sciences Research Council.
- Richter, L. & Foster, G. (2006). *The role of the health sector in strengthening systems to support children's healthy development in communities affected by HIV/AIDS*. Geneva: World Health Organization.
- Richter, L., Foster, G. & Sherr, L. (2006). *Where the heart is: Meeting the psychosocial needs of young children in the context of HIV/AIDS*. The Hague: Bernard van Leer Foundation.
- Richter, L. & Desmond, C. (2007). *Children in communities affected by HIV and AIDS: Emerging issues*. The Hague: Bernard van Leer Foundation.

In addition, papers from Learning Groups 2: Community Action, 3: Access to Essential Services and Protecting Human Rights, and 4: Social and Economic Policies, provided important additional information to the LG1 Integrated Learning Report. Specific papers include, among others:

- Cluver, L. & Operario, D. *The inter-generational link between the impacts of AIDS on children and their subsequent vulnerability to HIV infection: A study of the evidence to inform policy on HIV prevention and child and adolescent protection* (Learning Group 4).
- Participants in the debate (Francisco Bastos & Amy Nunn, Chris Desmond, Shanta Devarajan, Valerie Leach and Malcolm McPherson). *The economics of responding to children affected by AIDS* (Learning Group 4).
- Zoll, M. *Integrated health care delivery systems for families and children impacted by HIV/AIDS: Four program case studies from Kenya and Rwanda* (Learning Group 3).
- Partners in Health. *Integration and expansion of PMTCT-plus and early childhood intervention services* (Learning Group 3).
- Nshakira, N & Taylor, N. *Understanding and enhancing mechanisms for channelling resources to support community-level child protection and development: Learning from initiatives and households supporting vulnerable children in four districts of Uganda* (Learning Group 2).
- Zaveri, S. *Economic strengthening and children affected by HIV/AIDS in Asia* (Learning Group 2).

**Table 1: List of Authors, Affiliations and Paper Titles**

<b>Authors</b>	<b>Affiliation</b>	<b>Title</b>
Adato, M Bassett, L	International Food Policy Research Institute (IFPRI) – United States of America	What is the potential of cash transfers to strengthen families affected by HIV and AIDS? A review of the evidence on impacts and key policy debates
Belsey, M	Consultant – United States of America	The family as the locus of action to protect and support children affected by or vulnerable to the effects of HIV/AIDS: A conundrum at many levels
Chandan, U Richter, L	Human Sciences Research Council (HSRC) – South Africa	Programmes to strengthen families: Reviewing the evidence from high income countries
Desmond, C	Human Sciences Research Council (HSRC) – South Africa	The costs of inaction
Drimie, S Casale, M	International Food Policy Research Institute (IFPRI), Regional Network on AIDS, Food Security and Livelihoods (RENEWAL), Health Economics and AIDS Research Division (HEARD) – South Africa	Families' efforts to secure the future of their children in the context of multiple stresses, including HIV and AIDS
Haour-Knipe, M	Consultant – Switzerland	Dreams and disappointments: Migration and families in the context of HIV and AIDS
Hosegood, V	London School of Hygiene and Tropical Medicine (ISHTM), Human Sciences Research Council (HSRC) – South Africa	Demographic evidence of family and household changes in response to the effects of HIV/AIDS in southern Africa: Implications for efforts to strengthen families
Kimou, J Kouakou, C Assi, P	Ivorian Centre for Economic and Social Research (CIRES), Family Health International (FHI) – Côte d'Ivoire	A review of the socioeconomic impact of antiretroviral therapy on family wellbeing
Madhavan, S DeRose, L	University of Maryland – United States of America	Families and crisis in the developing world: Implications for responding to children affected by HIV/AIDS
Mathambo, V Gibbs, A	Human Sciences Research Council (HSRC) – South Africa	Qualitative accounts of family and household changes in response to the effects of HIV and AIDS: A review with pointers to action
Sherr, L	Royal Free and University College Medical School – United Kingdom	Strengthening families through HIV/AIDS prevention, treatment, care and support
Wakhweya, A Dirks, R Yeboah, K	Family Health International (FHI) – United States of America	Children thrive in families: Family-centred models of care and support for orphans and other vulnerable children affected by HIV and AIDS

# 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).<sup>1</sup> 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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<sup>1</sup> 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](http://www.unicef.org/media/media_44928.html) (accessed 13 September 2008).

### 3. Key Questions Guiding the Work of LG1

The co-chairs, secretariat, lead authors and stakeholders were guided in the work undertaken in LG1 by the following key questions. By and large, these were the critical research, policy and programme questions currently being debated in the field at the time JLICA was initiated.

1. On which children and families should we focus?
2. What evidence is available on which children are vulnerable; what can be done to assist vulnerable children; and how good is the research?
3. What aspects of the HIV/AIDS epidemic impact on children, how and why?
4. How are families changing as a result of adult illness and death associated with HIV and AIDS?
5. In what way are children's health, education and development affected by the HIV/AIDS epidemic?
6. What does knowledge and experience of other crises teach us about the AIDS response for children and families?
7. What can we learn from carefully evaluated family strengthening efforts in fields other than HIV and AIDS that can be usefully applied in hard-hit countries in eastern and southern Africa?
8. What programmatic experience in the HIV/AIDS field has been gained in strengthening families?
9. What promising directions are there for the future and what do they suggest?
10. What mistakes have been made, how can they be avoided in the future, and what now needs to be done?



These questions form the structure of the integrated report. As indicated in the Preface, detailed data and references are to be found in the respective LG1 papers. As far as possible, reference is made to specific papers.



## 4. Methods

### 4.1 Justification

The work conducted in LG1 is justified by the fact that families, in all their many forms, are everywhere the primary providers of protection, support and socialization of children and youth. As such, families generally exert the strongest influence on their survival, health, adjustment and educational achievement.

This influence is often greater under conditions of severe strain, such as that caused by HIV and AIDS, particularly in the context of poverty. Under stress, children and youth rely more on the support they get from families. The availability and quality of family support often makes the difference for children needing to cope with distress and deprivation.

In general, functional families everywhere love and protect children, and buffer them from the negative effects of adverse events. Family support is especially critical for young children as their developmental progress is dependent on consistent affectionate care. A functional family with children is one that has sufficient material and social resources to care for them, the motivation to ensure that they are nurtured and protected and, as a family, is part of a community of people who provide one another with mutual assistance and hope for the future.

From the start of the epidemic, families have absorbed, in better or worse ways, children and other dependents left vulnerable by AIDS-induced deaths, illness, household and livelihood changes, and migration. Similarly, families have contributed, more or less successfully, to the protection of young people from HIV infection.

Under the devastating effects of the epidemic, families need to be strengthened — economically, socially and with improved access to services — to enable them to continue, and to improve, their protection and support of children and youth. Families that neglect and abuse children need to be identified and provided with assistance. When children have to be removed from their family because of neglect and abuse, they must be placed in appropriate alternative forms of family care.

Families, peers, extended kin, clan, and near community are the mainstays of children's protection in the face of the AIDS epidemic — as they have been in poor countries under other severely debilitating social conditions, including war, famine and natural disaster. It is estimated that less than 1 percent of orphans in sub-Saharan Africa are living outside of family care. Only a very small proportion of AIDS-affected children and families, estimated to be fewer than 15 percent, are currently reached by any efforts additional to support they receive from kith and kin. **The most effective, scalable and sustainable strategy for children is to strengthen the capacity of families to provide better care for more children.**

### 4.2 Co-Chairs

Dr Linda Richter is the Executive Director of the Child, Youth, Family and Social Development Programme at the Human Sciences Research Council in South Africa.

Dr Angela Wakhweya was a Senior Technical Officer in the Orphans and other Vulnerable Children Unit in the Prevention and Mitigation Division at Family Health International in the United States.<sup>1</sup>

Professor Lorraine Sherr is the Head of the Health Psychology Unit at the Royal Free and University College Medical School in London.

### Secretariat

The LG1 Secretariat consisted of Dr Linda Richter (co-chair), Dr Chris Desmond (researcher), and Hema Somai (research and administrative assistant). Leane Ramsoomar and later Cecile Gerwel replaced Hema Somai.

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<sup>1</sup> Dr Wakhweya withdrew as co-chair in September 2007 because of a change in her work commitments. She was replaced as LG1 co-chair by Dr Lorraine Sherr.

## LG1 Advisory Group

An LG1 Advisory Group was established at the start of JLICA to assist with the selection of key issues to be addressed in the lead papers, as well as to adjudicate the commissioning of papers. The Advisory Group consisted of: Dr Larry Aber (New York University), Dr Carl Bell (University of Illinois at Chicago), Dr Mark Belsey (Consultant), Dr Alan Berkman (Columbia University), Dr Tom Franklin (UNICEF), Aaron Greenberg (The Better Care Network), and Dr John Williamson (Displaced Children and Orphans Fund). When possible, the Advisory Group participated in LG1 email exchanges, telephone conferences and face-to-face meetings. The Advisory Group also received early drafts of the papers and several Advisory Group members also reviewed LG1 papers.

## 4.3 Stakeholder Community

A stakeholder community for LG1 was established through newsletters, distributed electronically and in hard copy, as well as through announcements and news published on the LG1 website (<http://www.hsrc.ac.za/JLICA-81.phtml>), the JLICA website (<http://www.jlica.org>) and the websites and bulletin boards of interested networks and organizations — such as the *Better Care Network*. We estimate that, by these means, we communicated regularly with more than 6,000 networks, organizations and individuals working in the field of children and HIV/AIDS.

## 4.4 Work Commissioned

As indicated earlier, 12 papers were commissioned through an advertised call for proposals. Every attempt was made to balance disciplinary expertise with familiarity with the issues affecting children and families in high HIV prevalence conditions. In general, LG1 lead authors undertook comprehensive or systematic reviews and analyses of secondary data. One paper undertook a small amount of primary research: interviews with international and local organizations providing services for children affected by HIV and AIDS (*Wakhweya, Dirks & Yeboa*). Another paper made close reference to primary data collected previously by the authors (*Drimie & Casale*). All the lead authors are experts in their fields and published in

the areas in which they undertook the LG1 work. As such, they incorporate and refer also to their own past and current work.

Where reference is made to children and families in low prevalence countries, we draw heavily on the Franco et al. (2007) review mentioned earlier, as agreed through the Regional Inter-Agency Task Team on HIV/AIDS.

Regular email and telephone contact was maintained with lead authors, as well as group communications. LG1 authors exchanged important papers and the LG1 Secretariat regularly updated an annotated bibliography of work on children and HIV/AIDS. Two face-to-face meetings were held, first to conceptualize LG1 papers, and second to share findings and arrive at an agreed set of LG1 recommendations.

## 4.5 External Review

External review panels for each LG1 paper were compiled from known experts in the field, individuals who responded to calls to be reviewers published in LG1 newsletters, and suitable people nominated by LG1 authors. Each LG1 lead paper was reviewed by at least three reviewers from the fields of research, policy, programming and government (see Appendix: Learning Group 1 Reviewers).

The LG1 integrated report was reviewed by LG1 Lead Authors, by the LG1 Advisory Group, and by independent global experts in the field, including Stefan Germann (World Vision International, Geneva), Sudhanshu Handa (UNICEF ESARO, Nairobi), and Josef Decosas (PLAN International, Accra).

## 4.6 Presentation and Publication

In the course of the work of JLICA, LG1 methods and early findings, as well as specific findings from particular lead papers were presented at international and local meetings, have appeared in print and are in press (see Appendix: Learning Group 1 Papers and Presentations).

## 5. Findings

In terms of overall findings, the following conclusions are drawn from the LG1 work:

1. In high-prevalence countries, HIV/AIDS is a family matter. Transmission occurs predominantly between cohabiting partners and from parent to child. Family-focused preventive efforts and treatment, care and support services help sustain families as well expand access to those people most at risk of, and affected by, HIV and AIDS.
2. HIV and AIDS affect many children, not only those whose parents have died. Children become infected with HIV, and are affected by the illness of parents and caregivers; the migration of adults and children into and out of their households; the loss of breadwinners' income and livelihood support; stigmatization in the community; and deterioration of health and education facilities due to HIV infection among service-providers. High HIV prevalence in sub-Saharan Africa occurs in the context of extensive and deep poverty. Many children live in destitution. Under these conditions, targeting programmes and services exclusively to children orphaned by HIV/AIDS is neither appropriate nor effective. Inappropriate targeting contributes to stigma and discrimination against children and families affected by HIV and AIDS.
3. The vast majority of affected children, including over 95 percent of orphaned children live in families. Despite the difficulties involved, extended kin continue to foster and care for relatives' children. This must be maintained, because families are the best environment for children. Families generally have children's best interest at heart, and they provide a stable and consistent environment for children. However, family and kin are taking on more responsibility for more children, with very little support from governments or civil society organizations. Only 15 percent of affected families are reached by outside support agencies. This is affecting the capacity of families to protect children from the worst effects of poverty, deprivation and loss.
4. Families must be strengthened, most specifically through efforts to achieve universal access to health and education; family-focused services, as

indicated above; and through social protection, including income transfers. The evidence that income transfers will relieve distress, and increase consumption, especially for children, is very good. Given the experience already available, income transfer programmes should be implemented without further delay by bringing together the combined skills of government, civil society organizations and donors.

5. An extensive review demonstrates that the problems experienced by children and families in low-prevalence and concentrated epidemics are very much like those experienced by children and families in high-prevalence environments. Impoverishment and isolation due to stigma and discrimination cause children's care, nutrition, and schooling to deteriorate, and prompt increased demands on their labour. Many of the conclusions reached and recommendations made in this report are thus also applicable to low prevalence settings.

The findings are organized according to the 10 key questions addressed in the LG1 lead papers. There is, inevitably, overlap, across the sections. In addition, discussion of the issues is much shorter and less detailed here than in the LG1 papers.

Given below are short conclusions drawn in response to each of the questions.

### 1. On Which Children and Families Should We Focus?

- With respect to the impacts of HIV and AIDS on children, few differences have been found between low and high prevalence countries, and lessons learnt can be applied in both contexts, especially with respect to family strengthening through family-focused services and increased social protection, including income transfers.
- Children affected by HIV/AIDS should not be singled out for special assistance in settings where large numbers of other children are affected by situation-wide hardships including poverty, violence or natural disaster. Provision of assistance and services must instead respond to children in the greatest need. For example, families experiencing hunger need help to acquire food for their children; families in which children are undergoing severe emotional strain need support; children excluded from school as a result of stigma must be protected and their access to education secured.

- Attempts by external agencies to assist children affected by HIV and AIDS should be re-framed and directed to strengthening families who, in turn, are in the best position to support children.

## 2. What Evidence is Available on Which Children are Vulnerable, What Can be Done to Assist Vulnerable Children, and How Good is the Research?

- Better research is needed, including long-term studies on child and family vulnerability, predictors of medium- and long-term outcomes, and on the efficacy and cost-effectiveness of interventions. Large-scale community-level trials are especially important to address effectiveness, implementation challenges and intervention costs. Such studies require funding at a scale considerably increased from current levels of research expenditure.
- To assist policy makers, funders, and programme implementers to make better use of evidence, the results of good research must be widely disseminated, and approaches that are contra-indicated by good research must be challenged. Comprehensive and systematic reviews that bring together available knowledge and experience, such as those conducted for JLICA, are particularly useful. The Inter-Agency Task Teams on Children and HIV/AIDS (IATT), the Better Care Network (BCN), Global Action for Children and other agencies can facilitate dissemination of research findings to groups implementing programmes.

## 3. What Aspects of the HIV/AIDS Epidemic Impact on Children, How and Why?

- Mitigating the impacts of HIV and AIDS on children depends on improved prevention for and treatment of the adults on whom they depend for care and services, as well as for the children themselves.
- Everywhere, the major impact of HIV and AIDS at the household level is lower economic capacity, risk of asset loss, and destitution. For this reason, economic assistance to families, through social protection and income transfers, is a necessary foundation for other complementary services.
- In high prevalence countries, HIV and AIDS cluster in households. Family-focused services will support families and expand access to needed services.



- Universal access to health care and education will help to protect children from family economic stress.

## 4. How are Families Changing as a Result of Adult Illness and Death Associated with HIV and AIDS?

- A large number of changes have been occurring in household and family structure across sub-Saharan Africa for a very long time — most of them in response to colonization, modernization and urbanization. For this reason, it impossible to isolate changes in family structure due solely to HIV/AIDS.
- Families are not dying out or diminishing. Families are a constant feature of human life, and they continually evolve in response to changing external conditions, including the stresses of adult death.
- Most children who are called orphans (because they have lost one or both parents) actually have a surviving parent. The vast majority of children orphaned by HIV/AIDS (more than 95 percent) live in family care.
- Households get poorer when they take in and care for dependents from the wider family circle. They need economic and other forms of support to be able to cope.

- Young adults play important, but as yet unrecognized, roles in family life (as they do in HIV prevention and infection), by being active in both production (income and livelihood activities) and reproduction (bearing and caring for children).

## **5. In What Ways are Children's Health, Education and Development Affected by the HIV/AIDS Epidemic?**

- Due to the generally adverse physical and social conditions in which many children live in the poorest parts of the world, it is difficult to isolate the specific effects of HIV and AIDS on children. If untreated, children living with HIV tend to have neurological and other developmental difficulties, and HIV-negative children living with HIV-positive mothers have also been reported to show a number of development and adjustment problems.
- Where food insecurity is as pervasive as it is in much of sub-Saharan Africa, nutritional challenges exist for children regardless of their exposure to HIV and AIDS.
- Orphanhood, broadly defined, has been found to affect children's education, but whether the cause is poverty or other factors is not yet clear.
- The impact of parental death on children is likely to vary, especially given the large number of children reared partially by relatives. Strengthening and supporting families to provide comfort and security to affected children is likely to be the most effective way of addressing children's distress due to loss and stigmatization.
- Orphanages and the institutionalization of children in non-family residential care should be strongly opposed. The health, social and psychological damage caused by orphanage care compounds the problems of poor children affected by HIV and AIDS, and their families. The high cost of non-family residential care draws funds away from much-needed family support. Where children have to be placed in institutional care because all efforts at family placement have failed, the state and providers of institutional care must put in place strong monitoring and protection systems to avert potential abuse and neglect, and to facilitate speedy alternative family placement.
- As social protection mechanisms are adopted to support children and families, attention needs to

turn also to strengthening social justice systems to prevent abuse and neglect, and to assist children and families affected by abuse and neglect.

## **6. What Does Knowledge and Experience of Other Crises Teach us About the AIDS Response for Children and Families?**

- Children and families in eastern and southern Africa have been exposed to HIV/AIDS for more than two decades. It is no longer a crisis, but part of the broad social context influencing family and personal life.
- Nonetheless, there is much to be learnt from responses to previous large-scale crises of a similar nature and duration about, for example, the fostering of children within extended family networks; the withdrawal of children from school to conserve resources; and an increase in child labour to compensate for lost adult work.
- Because of its long-term nature, and the fact that it clusters within families and households, HIV and AIDS is likely to have an unprecedented impact on the regenerative capacities of families and human capital. This is especially probable because HIV and AIDS also compromise the educational and health systems necessary to restore human capital in the future.

## **7. What Can We Learn from Carefully Evaluated Family Strengthening Efforts in Fields Other than HIV and AIDS That Can be Usefully Applied In Hard-hit Countries in Eastern and Southern Africa?**

- Large-scale systematic interventions are needed to strengthen international, national and community-level responses that enhance protection for children affected by HIV and AIDS.
- Parenting and family support programmes need to include a range of services generally targeted to children under five years of age, because early intervention is more efficacious and cost-effective than attempts at remediation implemented later.
- The best evidence for scaled-up interventions comes from early child development programmes with parental involvement and training, and home visiting, implemented in the West. In all programmes that have been rigorously evaluated,

quality of services is critical, as are well trained staff and intensive provision over an extended period of time.

- To be effective, programmatic family strengthening activities must unfold alongside or build upon efforts to strengthen families economically.

## **8. What Programmatic Experience in the HIV/AIDS Field Has Been Gained in Strengthening Families?**

- Families and communities provide by far the major share of care and support for children affected by HIV/AIDS, and very few families receive any form of assistance additional to that provided by kith and kin.
- Although considerable effort is being made by some field programmes to provide comprehensive services using a family-centred approach, these are generally not widespread and need to be expanded. Very few field programmes have been subject to systematic evaluation, and none to evaluation using scientifically rigorous methods.
- Family-centred approaches could also help to provide support for the elderly and for young adults who, together, have assumed the major responsibility of care for children affected by HIV and AIDS.

## **9. What Promising Directions are There for the Future and What Do They Suggest?**

- HIV and AIDS cluster in families. Therefore, providing prevention, treatment and care to, and through, families will help both to support families and expand access to needed services. Earlier detection, longer survival, issues of disclosure, adherence, family stresses associated with treatment regimens, and the desire of infected and discordantly infected couples to bear and raise children all make it imperative to adopt family-centred approaches to prevention, treatment and care.
- HIV and AIDS interact with other drivers of poverty to simultaneously destabilize livelihoods systems and family and community safety nets. This has necessitated international, regional, and national commitments to social protection programs in heavily AIDS-affected countries.

- Among different forms of social protection, a momentum is gathering around direct income transfers to the poorest households. Income transfers have demonstrated a strong potential to reduce poverty and strengthen the human capital of children through improved health and education. Income transfers can thus form a central part of a social protection strategy for families affected by HIV and AIDS.
- Income transfers can be implemented immediately by governments in countries severely affected by HIV and AIDS, with technical assistance and support from donors.

## **10. What Mistakes Have Been Made, How Can They be Avoided In the Future, and What Now Needs to be Done?**

Seven specific recommendations are made based on the combined work of Learning Group 1: Strengthening Families. These are:

- Improve prevention of HIV infection among adults and children;
- Expand the treatment of adults and children living with HIV;
- Focus on families to better support children affected by HIV and AIDS;
- Support extended families;
- Adopt family-focused approaches to HIV/AIDS prevention, treatment and care;
- Implement income transfer programmes; and
- Foster relationships between the state and civil society that build on their comparative advantages.

### **5.1. On Which Children and Families Should We Focus?**

In addressing focus and targeting of interventions, we consider three issues: similarities and differences between low and high HIV prevalence countries; specific groups of children affected by HIV and AIDS; and the advantages of focusing on families in efforts to support children.

“The review **did not find documentation of differences in vulnerabilities between children affected by HIV and AIDS from low prevalence and those from high prevalence countries.** Low prevalence countries varied so much among themselves in terms of economics, culture, government response, and the ability of their health systems to carry out effective case identification and treatment, that researchers and program planners must ask themselves if perhaps prevalence is not the best factor upon which to group countries.

In any case, while children in both low and high prevalence countries exhibit resilience and cope in many instances, they also face the following challenges: 1) exposure to stigma and discrimination, emotional distress, and material deprivation; 2) possible separation from siblings, relocation to unfamiliar surroundings, and loss of opportunities and entitlements; 3) heightened risks of further HIV infection in the family; and 4) illness and possible death.

**The dynamic effects on the household — deteriorating socioeconomic status, increased food insecurity — are also universal.** However, it might be expected that heavily affected settings may experience them more severely, as families, communities and governments, regardless of their commitments and intentions, simply surpass their absorption capacity for meeting the needs of affected families.”

—Franco et al.

### High and Low Prevalence Countries

Considerable debate in JLICA concerned its appropriate scope and focus. As a global initiative, it was deemed appropriate to include both low and high prevalence countries in the reviews. However, it was agreed that this scope was too broad to do the issues justice, and that JLICA would concentrate on children and families in high prevalence settings, particularly in sub-Saharan Africa.

In order to take account of potential differences experienced by children in low prevalence settings, by agreement with UNICEF and the IATT, LG1 drew on the findings of the Franco et al. review of 363 papers. One of the main conclusions of this review, with respect to children in high and low prevalence countries, is given in the box above (p. 106).

On the basis of this review, **we conclude that issues affecting children and youth are common across low and high prevalence settings, despite differences in the nature and key drivers of the epidemics in the two types of settings.**

### Children Affected by HIV and AIDS

Children affected by HIV and AIDS are often quite narrowly thought of as only those orphaned as a result of AIDS. The UNAIDS/UNICEF definition of an orphan is a child who has lost one or both parents (often presumably) to AIDS. The initial intention behind defining a child who had lost one or both parents to AIDS as an orphan was to expand considerations of vulnerability to a larger group of children than only so-called “double” orphans. This was because HIV is transmitted between partners, increasing the likelihood both parents will be infected and, in the absence of treatment, die.

As recognized by UNICEF and UNAIDS, many children are affected by HIV and AIDS besides those whose parents have died. These include children living with HIV and AIDS, that is, HIV+ children; children exposed to HIV *in utero*, yet born HIV negative; children who have a parent or caregiver who is living with HIV; and children who are living in families that foster children directly affected by HIV/AIDS.

We argue that in very poor communities with high HIV prevalence, it is necessary to extend the definition of children affected by HIV and AIDS and poverty to include all children living in communities greatly affected by HIV and AIDS, Children especially vulnerable to exposure to HIV due to their circumstances (e.g., they live outside of family care, they are living on the street, they have physical and mental handicaps, and the like) should also be included.

“AIDS orphan/s” is a much used term; however, it creates enormous confusion in the field for a number of reasons (*Sherr*). The term is, amongst others:

- Imprecise because the cause of parental death is seldom known;
- **Poorly defined and, in the majority of cases, confusing because it labels children with a surviving parent as “orphans;”**
- **Stigmatizing, in that it forces upon children a mantle of shame attributed to their parents and caregivers; and**

- **A poor proxy for vulnerability. Some non-orphaned children or children orphaned as a result of other causes may be equally or more vulnerable as a result of extreme poverty, parental disability, substance abuse, and the like.**

While orphaning due to HIV/AIDS is increasing as the epidemics in sub-Saharan Africa mature, **orphaning *per se* should not be the basis of the HIV/AIDS response to children, or the basis of targeting assistance to specific children (Hosegood, Sherr). While children affected by HIV/AIDS may experience a range of disadvantages, other vulnerable children in affected communities experience much the same, or even, greater adversity (Drimie & Casales, Madhavan & DeRose).**

Further, there is a view, validated by field reports, that programmes which try to reach only specific children within communities where most children live in adversity generate more problems than they solve. They lead to stigma, perverse incentives to receive benefits, and sometimes harassment and abuse of beneficiaries (Desmond, Haour-Knipe, Mathambo & Gibbs). Targeting is best done with respect to geographic or social communities where assistance is directed to children identified as being the most in need.

### **Children and Families**

To date, the literature on children affected by HIV and AIDS, as well as policy and programmes, have focused overwhelmingly on children, especially individual children, outside of the context of their families and communities. **Policies, funding and programmes have generally been framed “for children,” as if external agencies could directly assist all affected children in appropriate and sustainable ways during their childhood years, for the duration of the epidemic.** However, families and communities are the natural sites for the lifelong care and socialization of children, and, to date, families and communities have provided the greatest and most extensive assistance to children made vulnerable by HIV and AIDS.

In the context of JLICA, families are defined in the broadest way in recognition of their heterogeneity and inherent complexity. Nonetheless, families are generally agreed to be social groups connected by



kinship, marriage, adoption or choice that have clearly defined relationships, long term commitment, mutual obligations and responsibilities, and share a sense of togetherness. While the structure of families differs widely, family groups generally share universal functions, technically referred to as reproduction, production and protection.

Although socio-demographic data is usually collected on households (or co-residential groups), family is a more extensive term. Families are linked across households, and family networks provide crucial support for poor families and families experiencing difficulties of one kind or another. In many parts of the poor world, families maintain connections across rural and urban households in order to retain the relative advantages of both. Nonetheless, there are important differences between rural and urban households.

In light of the long-term nature of the HIV/AIDS epidemic, families play unique and particularly crucial roles in prevention, and in the treatment, care and support of infected and affected individuals, including children. **The discourse on direct assistance by external agencies for**



children needs to change to a focus on families as the social units best equipped to provide ongoing care and support for children. But care should be taken not to repeat the same mistakes as before, and target only AIDS-affected families for assistance. There is substantial inter-household and inter-family dependence, and all families who take in vulnerable kith and kin, are destitute, or who face other severe challenges, also require assistance.

## 5.1 Conclusions

1. With respect to the impacts of HIV and AIDS on children, few differences have been found between low and high prevalence countries. Lessons learnt can be applied in both contexts, especially with respect to family strengthening through family-focused services and increased social protection, including income transfers.
2. In settings in which large numbers of children are affected by poverty, and/or other situation-wide factors such as violence or natural disaster, children affected by HIV and AIDS should not be singled out for special assistance. Provision of assistance and services must instead respond to children in the greatest need. For example, families experiencing hunger need help to acquire food for their children; families in which children are undergoing severe emotional strain need support; children excluded from school as a result of stigma must be protected and their access to education secured.
3. Attempts by external agencies to assist children affected by HIV and AIDS should be re-framed and directed to strengthening families who, in turn, are in the best position to support children.

## 5.2. What Evidence is Available on Which Children are Vulnerable, What Can be Done to Assist Vulnerable Children, and How Good is the Research?

Studies of the vulnerabilities of orphans and other children affected by HIV/AIDS are often conceptually and empirically weak due to the inadequate or inaccurate definitions of the subjects of enquiry. This was established from a search and filtering strategy to find and analyze papers in which an *orphan* group was identified (*Sherr*). **The majority of the 383 studies identified (71 percent), did not differentiate or clearly define the concept orphan.** The minority of studies that did define the subject category used a variety of definitions; namely, one or both parents had died (17 percent), both parents had died (3 percent), mother had died (6 percent), father had died (1 percent), or multiple definitions involving varying combinations, including death of primary caregiver (2 percent).

Most studies refer to an agglomeration of vulnerable and poor children, making the results difficult to interpret and limited in their ability to inform policy and programme choices. In addition, where control groups are included, they are also not well defined. **These findings indicate that the conclusions drawn from research are ambiguous because they do not refer to a common or homogeneous group, and seemingly related studies are not comparable.** This problem occurs in other, overlapping fields as well; for example, with respect to the meaning of what a “migrant” is (*Haour-Knipe*).

There is agreement among LG1 lead papers that **the quality of evidence about children affected by HIV and AIDS, and how they can best be assisted, in general, is weak.** Of 408 studies examined in low prevalence settings, only about half were judged to have good quality documentation. Most studies were descriptive (*Franco et al*). Only 15 studies examining schooling outcomes among children affected by HIV and AIDS could be found that had minimally acceptable methodology. Methods were deemed acceptable when the target group of interest was defined, a control group was included and empirical data was reported (*Sherr*). Very seldom are common variations (for example, household socioeconomic circumstances, or children’s age and gender)

included in research designs. Overall, there is very weak evidence to support programming, with only a small minority of studies having sufficient methodological rigour to support the conclusions drawn (*Belsey, Hosegood, Franco et al, Mathambo & Gibbs, Sherr, Wakhweya et al*).

Moreover, as in other fields, the knowledge base with respect to children affected by HIV and AIDS is constrained by publication bias, language bias, and availability bias — applying to both the published and grey literature. This is exacerbated by **the large number of documents produced by international agencies, which are not peer-reviewed and frequently re-cycle the same conclusions, even when they are based on methodologically poor studies.**

There are few large-scale long-term prospective longitudinal studies that can answer questions regarding, amongst other things, family dissolution, fostering, migration, subsequent partnering, and child care associated with HIV/AIDS. In addition to being long-term, such studies also require micro-level household data, including cause of death, and detailed outcome measures of children. The studies that are ongoing, such as those in demographic surveillance sites (for example, Manicaland in Zimbabwe, Mtubatuba in South Africa and Rakai in Tanzania) show changing patterns of family and relationship formation, and vulnerabilities linked to HIV risk and hardship. However, **it is generally not possible to isolate demographic changes due solely to the HIV/AIDS epidemic from changes due to other factors that have been occurring for many years** — such as urbanization, migration, and changes in marriage and fertility (*Hosegood, Madhavan & DeRose*).

**Evidence on the effectiveness of interventions is generally poor, and almost non-existent in low prevalence and concentrated epidemic settings.**

While there are many programmes described in the grey literature, reviews of more than 100 documents found that less than a quarter applied any methodology that would allow comparisons, such as before-after or case-control group designs (*Wakhweya et al, Franco et al*).

While there is general agreement that more evidence is needed, **the evidence that is available is not being fully used** (*Chandan, Madhavan*

*& DeRose, Desmond, Sherr, Hosegood, Haour-Knipe*). There is a host of good data from censuses, demographic and health surveys, household panel studies and demographic surveillance systems. These data point to the importance of supporting families and extended kin networks in their care of children; the impoverishing effects of HIV and AIDS on households; the vulnerability of children's education to family socioeconomic stress; the important roles played by young people in family production and child care; and the potentially supportive role of men. Instead of taking up this evidence and basing programmes on these findings, advocacy groups continue to focus policies and programmes on skip-generational households (households with only children and older people, but no working aged adults), and child-headed households — both of which are reported in very small numbers (less than 1 percent) in representative surveys (*Hosegood*).

There is also a very substantial literature on interventions at the level of the child, family and community that are both directly and indirectly applicable to children affected by HIV and AIDS. These include interventions targeted at children living in poverty, children exposed to violence, street children, children declared to be in need of care, and children in a variety of what UNICEF refers to as *extremely difficult circumstances*. It is a notable failing that the issues of children affected by HIV/AIDS are being approached *de novo* when, in fact, valuable information and experience, which is generalizable to children made vulnerable by HIV and AIDS, has already been accumulated.

## 5.2 Conclusions

1. Better research is needed, including long-term studies on child and family vulnerability, predictors of medium- and long-term outcomes, and on the efficacy and cost-effectiveness of interventions. Large-scale community-level trials are especially important to address effectiveness, implementation challenges and costs of interventions. Such studies require funding at a scale considerably increased from current levels of research expenditure.
2. To assist policy makers, funders, and programme implementers to make better use of evidence, the results of good research must be widely disseminated, and approaches that are contra-indicated by good research must be challenged. Comprehensive and systematic reviews that bring together available knowledge and experience, such as those conducted for JLICA, are particularly useful. The Inter-Agency Task Teams on Children and HIV/AIDS (IATT), the Better Care Network (BCN), Global Action for Children and other agencies can facilitate dissemination of research findings to groups implementing programmes.

## 5.3. What Aspects of the HIV/AIDS Epidemic Impact on Children, How and Why?

Two questions will be addressed here — why do HIV and AIDS impact children; and how and in what specific respects?

### **Why Do HIV and AIDS Impact Children?**

The HIV and AIDS epidemic presents a number of challenges which have the potential to impact on the lives of children. It is, however, not inevitable that impacts will be felt by children (*Desmond*). **In supportive contexts and with fully implemented effective responses, almost all impacts on children could be avoided, or at least minimized, as follows:**

While obvious, it is worth emphasizing that **impacts on children occur, first, as a result of failed prevention**. If adult infections are avoided, so too are the impacts on children, including the vertical, parent-to-child, infection of children.

Even after failed prevention, adult infections do not lead inevitably to impacts on children. While adults are asymptomatic, their infection should have minimal impact on children, with the important exception of potential transmission. Children may experience difficulties in communities in which HIV infection continues to be stigmatized, and children may also face problems in families in which parents struggle to adjust to the fact of their own or their partner's infection, and parental anxiety or conflict results with consequences for children's wellbeing.

The transmission of HIV to children, particularly young children, occurs mainly from mother to child during pregnancy, birth or as a result of breast feeding. **Children are, therefore, infected because of lack of access to appropriate services, and the inadequacies of the rollout of PMTCT programmes.** To compound this, children are often failed again because antiretroviral treatment for children lags behind relative to adult treatment in terms of assessment, compound availability, roll out and management (*Sherr*). With appropriate intervention, mother-to-child transmission rates can be reduced to below 2 percent. Rates above this level result from poor quality or limited coverage of preventative treatment that has been available for more than 10 years.

Aside from transmission, **the bulk of impacts on children start to occur as parents and other caregivers and providers infected with HIV become increasingly ill and incapacitated.** If these adults could maintain their health, the impacts associated with such declines would not occur, or would be severely curtailed. The evidence suggests that once on treatment, adults are able to return to work and resume parenting functions. This allays pressures on household budgets and labour demands, and the associated negative impacts on children are reduced (*Kimou et al*). Again, the impacts of HIV/AIDS on children occur not simply because of the virus but because of a poor response to the challenges it poses to families. The effects of the epidemic are compounded by the lack of service provision to children and families at all levels.

Even after failed prevention and treatment, not all impacts need be felt by children. **Families can deflect or absorb much of the impact of the epidemic on children if they are willing, have**

**sufficient human and financial resources, and can access appropriate services.** Family demands on both human and financial resources in families increase at a time when their availability decreases as a result of illness or death (*Desmond*).

How these resource constraints impact on children is determined by a range of factors, including children's age and gender; parental psychosocial wellbeing; family functionality; the integration of families in their communities; family reservoirs of social and material support; the degree of stigmatization of HIV and AIDS in the community; available services; and country policies and provisions. Younger children are more susceptible to many of the impacts, while gender may play a role in the reallocation of financial resources and the deployment of human resources.<sup>1</sup>

**Children experience a cascade of negative impacts as a result of HIV because of failed prevention and treatment and because of the inability of families to shield children from the impoverishing effects of illness and death on the household.**

### **In What Contexts Do HIV and AIDS Impact on Children?**

Even though HIV mortality affects all socioeconomic strata, it is clear that **pre-existing conditions of poverty intensify the effects of mortality and make it more difficult for families and households to cope with additional deprivation and stress** (*Adato, Desmond, Haour-Knipe, Hosegood, Kimou et al, Madhavan & DeRose*).

In contexts where families are already facing multiple stressors such as poverty, food insecurity, climate change, meager government protection, and limited access to health and education services, the ability of the family to respond to any additional stress is compromised. Such difficult situations can frustrate efforts at recovery, especially because **HIV infections, and their consequences, cluster in households.**

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<sup>1</sup> It is clear that there are a range of gender effects in transmission and risk of infection that require further study. For example, the few studies included in the analysis suggest that girls may be more susceptible to delivery transmission, while boys seem to be at a significantly higher risk for breastfeeding transmission and drug resistance (Sherr).

While conditions are frequently very difficult, families generally try to respond if they can. Detailed case studies of parental planning for children in Malawi and South Africa, for example, reveal the anguish and frustration of families whose demands for basic survival limit their choices to secure the longer-term livelihoods of their children. Caregivers juggle the many competing family needs in the face of scarce resources; for example, the purchase of food at the expense of school fees (*Drimie & Casales*).

**Families affected by HIV/AIDS express concern about meeting their children's basic needs in both low and high prevalence settings.**

Migration, for example, is commonly used by families to diversify livelihoods and distribute the care burden, especially of children, amongst the extended family. But the option of migration is only open to those with the ability and resources to travel and willing recipient kin. In turn, it brings with it a new set of challenges and vulnerabilities, including to HIV infection (*Drimie & Casales, Franco et al, Haour-Knipe*).

**The impacts HIV and AIDS have on children result from failed prevention and treatment, as well as the incapacity of families to shield children from the effects of the epidemic, largely because of poverty.** HIV/AIDS exerts its impacts on children and families largely because it is an impoverishing and, because of stigmatization, an isolating, condition. It causes income, livelihoods, skills and capacities, and social connections to be lost, and it results in additional expenses related to illness, care and death. Long-term food insecurity in sub-Saharan Africa, together with the current food crisis and effects of climate change in the region, are exacerbating enormously the impact of HIV and AIDS on already very poor families.

The evidence on socioeconomic impacts is extensive, from both low and high prevalence countries. Households with HIV-positive or recently deceased adults have lower incomes and more expenditure on illness-, care- and burial-related costs.

“Despite the lack of empirical, longitudinal impact data, significant evidence from low prevalence countries (as well as high prevalence countries) in multiple regions indicates that **HIV-affected households experience a worsening of their socioeconomic status, specifically as a result of income losses due to declining productivity and expenditure increases related to health.** These families are also more likely to become indebted and to sell off assets ... While many children affected by HIV/AIDS were already living in poor households, clearly, HIV infection in the household worsens overall household economic status” (Franco et al, p. 52).

**Thus, children affected by HIV/AIDS need to be understood in the context of the family, and the family in the context of pre-existing conditions, especially poverty.**

Some families meet the increased expenditure occasioned by HIV and AIDS from savings. Others, without this safeguard, reallocate and reduce other expenditures; most often they buy and eat less food and they fail to pay school fees. In situations where household expenditure was already low, the impact of HIV/AIDS may well push consumption of basic items to dangerously low levels that can result in negative short- and long-term health and education consequences for children.

Differential treatment of children — due to variations in gender, age, ability, degree of relatedness and parentage — might occur when resources are strained. Families may make uneven allocations to children across time in an effort, for example, to alternately give children a chance to have another year in school. In countries where national educational and health provision is part of government policy, these effects are ameliorated. Global access to health care, school and social welfare services can provide basic protection to all vulnerable children at a country scale.

In addition to the pressures placed on human and financial resources at the family and household level, which can directly affect children’s care, there are emotional impacts on adults and children (the latter generally mediated by adults) which result from experiencing the illness and death of someone close. Children may also experience

direct and indirect stigma and discrimination from those around them. Again the family can, to some extent, protect children from long-term harm. A supportive and protective family can help children deal with emotional distress and discrimination.

The impacts of HIV and AIDS on children are broader than the impacts on individual children in households directly affected by illness, death and the absorption of affected children. **The failure to prevent adults from being infected, and the failure to treat those infected, have implications also for the provision of services, especially health, education and social assistance.** This affects all children in the community. Health services are particularly hard hit because HIV and AIDS increase the level of illness in societies and more people seek treatment. At the same time, personnel providing services are themselves at risk of infection, as well as resultant illness and death. Children not directly affected by HIV and AIDS in the home may receive less or lower quality health services as a result. The education and social assistance systems are similarly reliant on professional staff, and their absence and loss associated with illness and death may also affect service levels.

### 5.3 Conclusions

1. Mitigating the impacts of HIV and AIDS on children depends on improved prevention for and treatment of the adults on whom they depend for care and services, as well as better prevention for and treatment of children themselves.
2. Everywhere, the major impact of HIV and AIDS at the household level is lower economic capacity, and risk of asset loss and destitution. For this reason, economic assistance to families, through social protection and income transfers is a necessary foundation for other complementary services.
3. In high prevalence countries, HIV and AIDS cluster in households. Family-focused services will support families and expand access to needed services.
4. Universal access to health care and education will help to protect children from family economic stress.

## 5.4. How are Families Changing as a Result of Adult Illness and Death Associated with HIV and AIDS?

How households are changing is approached from two points of view: family structure, and family function, particularly child care.

### Family Structure

There have been radical transformations in family and household forms and structures in sub-Saharan Africa due to colonization, modernization and urbanization, making it **impossible to isolate changes due solely to HIV/AIDS**. The impact of HIV/AIDS is also obscured because many of the anticipated effects of the epidemic on households— such as single motherhood and absent parents— also occur as a result of other factors, including declines in fertility and marriage, and increased urbanization and female labour force participation (*Hosegood, Madhavan & DeRose, Mathambo & Gibbs*).

The most studied aspect of family and household change is adult mortality. Less attention has been paid to determinants of variation in childcare, such as remarriage and subsequent partnering, and mental and physical health of child care providers, and to how childcare may be improved and supported.

Two extremes along a continuum are adopted in the interpretation of the impacts of HIV/AIDS on families. The first, generally held by practitioners, is called the “social rupture thesis”. This holds that extended families cannot cope with the demands placed on them for the care of children whose parents are ill or have died, and that alternatives to family care must be developed. The second approach recognizes the cyclical nature of family life. **Families are a constant feature of human life, and they continually evolve in response to changing external conditions, including the stresses of adult death**. All newly created families, regardless of their form, pass through lifecycle changes — specifically formation, building and eventual dissolution — that significantly alter role relationships amongst members. Examples include the birth of a child, the departure of a child to live or work elsewhere or to start their family in a new household, the death of a spouse, and so on.

The impacts of HIV/AIDS on families must be understood in terms of declines in marriage and fertility that were well underway before the onset of HIV/AIDS. Together with migration in search of work, these trends are resulting in smaller families, more single parent or sequential parent households, separation of children and parents, and care by family members other than biological parents.

Childbearing is central to family and household life in sub-Saharan Africa, and there is no evidence to suggest that this is changing. The majority of couples, whether infected or not, want and will continue to have children and to form families. In the same way, changes in household composition and even dissolution of particular household structures, are intrinsic aspects of the family lifecycle. Although frequently portrayed only in negative terms, household dissolution is a common family lifecycle stage associated with growing to adulthood and leaving one’s parental home, partnering, ageing, widowhood, long-term migration and the like. Little attention has been paid to the positive role that the dissolution of a particular household structure and migration can play for families in coping with adverse events such as death. Demographic studies indicate that household dissolution is more common when the deceased person is older, when the death is sudden (often non-AIDS related), or when households experience multiple deaths. In general, though, **what longitudinal population-based survey data are available, suggest a strong predisposition for the survival of families and households**.

### Child Care

Understanding how care arrangements for children might be changing requires a sense of a “benchmark living arrangement” for children — that is, to know what is usual, in particular circumstances. This enables changes in observed patterns of child care to be attributed to the impact of HIV/AIDS, rather than background social and economic factors that evolved ahead of the epidemic (*Hosegood, Madhavan & DeRose, Mathambo & Gibbs*). From this perspective, it needs to be borne in mind that single and double orphans remain a minority of all children even in countries with high prevalence and, in most countries, the majority of adult deaths are still non-AIDS related. **Eighty percent of children who**

**are defined as orphans by the UNAIDS/UNICEF definition have a surviving parent.**

In some southern African countries only about a quarter of non-orphaned children live with both parents. These patterns of residential separation between children and their parents (irrespective of parental death) emerged long before the HIV epidemic, from well-entrenched patterns of within-family fostering, labour migration and, in southern Africa, some of the lowest rates of marriage on the continent. Children may be sent to “foster parents” in the extended family in order to cement kin relations or friendships, to facilitate access to better educational opportunities, to offer companionship to childless couples or grandparents, to offer additional labour when needed, and to reduce strain on limited household resources.

With HIV/AIDS, there appears to be a shift from purposive to some crisis fostering. Under crisis conditions, children may be sent to particular relatives simply as a matter of convenience. In these circumstances, there may not always be a good fit between the best interest of the fostered child and/or the receiving household. **Pre-existing relationships between the foster family and the family giving up a child for fostering, as well as the reasons why a child is fostered or sent to a particular relative, exert an important influence on the quality of care children receive.**

Data on sibling separation is scarce, but there is some indication that orphans may be separated in efforts by extended families to provide care to affected children. There is little information on the psychological and other effects on children of such separations.

**The vast majority of orphaned children — more than 95 percent — are living with family.** In order to enable families to cope with increased dependency, every effort must be made to support the care and protection provided to children. About one in six households in eastern and southern Africa are caring for at least one orphan. The majority of these households are female-headed, have an older head, have more people and a larger dependency ratio than households without orphans. Country statistics differ as to whether families that care for orphans are better or worse off than other families. Some studies indicate that orphans are sent to wealthier households in the

family network; in other circumstances, family resources may be depleted and orphans end up in extremely poor households

**Few child-headed households are identified in large scale surveys — in the order of less than 1 percent — and most are attributed to data errors,** such as recording or entering age incorrectly. Available information suggests that, while child-headed households may emerge following the death of adult members of a family, they tend to be temporary with adults soon moving in to care for the children, or children moving to join other households. The same applies to so-called skip generation households. Most households with older individuals and children also consist of one or more working age young adults.

## 5.4 Conclusions

1. A large number of changes have been occurring in household and family structure across sub-Saharan Africa for a very long time — most of them in response to colonization, modernization and urbanization. For this reason, it impossible to isolate changes in family structure due solely to HIV/AIDS.
2. Families are not dying out or diminishing. Families are a constant feature of human life, and they continually evolve in response to changing external conditions, including the stresses of adult death.
3. Most children who are called orphans (because they have lost one or both parents) actually have a surviving parent. And the vast majority of orphans (more than 95 percent) live in family care.
4. Households get poorer when they take in and care for dependents from the wider family circle. They need economic and other forms of support to be able to cope.
5. Young adults play important, but as yet unrecognized roles, in family life (as they do in HIV prevention and infection), by both being active in production (income and livelihood activities) and reproduction (bearing and caring for children).

## 5.5. In What Ways are Children's Health, Education and Development Affected by the HIV/AIDS Epidemic?

We report effects on children with respect to domains such as nutrition, education and health care. The evidence reported here is based on exhaustive reviews and interpretations of the available literature (*Sherr*) using the narrow and often problematic UNICEF and UNAIDS definitions of orphans and vulnerable children. **While it is frequently assumed that children affected by HIV/AIDS will have worse indicators of health and wellbeing than others, the evidence is not clear cut.** This is mainly because the background conditions of the vast majority of children in sub-Saharan Africa are very poor, due to destitution, food insecurity, and lack of access to services. Education is the one domain in which the evidence is clear: HIV/AIDS at the household level has a disruptive effect on children's schooling.

### Survival and Health

**Young children whose mothers are living with HIV have poorer health and survival than those whose mothers are HIV-negative.** Thus, even when mothers survive, children with HIV-positive mothers are exposed to more challenges than children born into environments free of HIV and AIDS. It is important to note, though, that the mortality of children improves when the health of HIV-positive mothers is maintained through appropriate treatment and support.

**There are few detectable differences in the health status of non-infected children in HIV/AIDS-affected households compared to other children.** There is, however, some indication that children affected by HIV/AIDS may have less access to health care, although the evidence is not strong.

Institutional (residential group or orphanage) care has negative effects on children's health in comparison to other care environments, and extremely adverse effects on the mental development and adjustment of young children.

### Nutrition

Nutritional requirements of children are very much influenced by their age and stage of development—for example, breastfeeding among infants, weaning and complementary foods among toddlers, and food security among older children.

Malnutrition interacts with infection among children living with HIV/AIDS. With respect to infants, mixed breast and bottle feeding result in higher rates of transmission than exclusive breastfeeding or exclusive replacement feeding. **Where food insecurity is as pervasive as it is in much of sub-Saharan Africa, nutritional challenges exist for children regardless of their exposure to HIV and AIDS.** As a general finding in both low and high prevalence settings, HIV/AIDS-affected children tend to reside in food insecure households more often than unaffected children. However, in sub-Saharan countries where undernutrition is widespread, the bulk of studies (11 of 14 identified) indicate that orphaned children are not worse off in measured growth than non-orphaned children (see *Sherr*).

### Education

LG1 identified 15 studies with acceptable methodology that examined the impact of orphaning and vulnerability due to HIV/AIDS on one or other aspect of schooling in southern and eastern Africa. Despite the variability in definitions of children affected, **13 of the 15 studies identified a negative effect of orphanhood on some aspect of education — enrolment, attendance, and/or performance. Poverty, age and gender all mediated these impacts on children.**

In low prevalence countries, younger children are not likely to be removed from school because of HIV/AIDS, whereas older children are. The role of orphanhood in this is not clear cut, as poor children are often withdrawn from school to help with household subsistence (*Franco et al*). In all settings, household structure and family relationships of care affect the probability of orphans attending school. There is also some indication that children and families affected by HIV and AIDS fear discrimination at school (*Franco et al, Sherr*).



## Cognitive Development and Performance

HIV permeates the blood-brain barrier and this raises concern about the neurological and cognitive development of children living with HIV. From the beginning of the epidemic, neurological problems in infected children have been noted, but the mechanisms of effect, including interactions with environmental conditions, are not yet clear. Few studies control for low birth weight, premature delivery and adverse caregiving, all of which may be associated with HIV infection and with relatively poorer neurological and cognitive development. Of 54 studies identified, 10 did not include a control group. A wide variety of assessment instruments were used — some standardized and some not — making it difficult to compare studies. **The vast majority of studies with a control group found some kind of detrimental cognitive effect among children infected with HIV, regardless of child gender and age, or measure used.** All families, including those affected by HIV and AIDS, need assistance in caring for children with cognitive and/or neurological problems. The outcome of antiretroviral treatment on limiting or reversing HIV/AIDS-related cognitive and neurological problems has not yet been adequately studied (*Sherr*).



## Psychological Effects

**In conditions where many children spend a major portion of their lives living with caregivers other than parents, the impact of parental death on children is likely to vary, as is the impact of the death of a child's customary caregiver.** Bereavement is core to many psychosocial interventions and programmes to assist children affected by HIV/AIDS. However, only 16 studies of children, bereavement and HIV were identified in the literature, most of which were qualitative in nature. Despite the interest in the impact of AIDS-related bereavement on children — particularly the bereavement caused by sometimes repeated losses of their caregiving adults — there remains a paucity of understanding about the mental health ramifications and the effectiveness of efforts to support the survivors.

Ideally, families, friends and communities meet the needs of children for security and affection. Children affected by HIV/AIDS are exposed to distress through their experience of illness, death, increasing destitution, stigma, discrimination and isolation. **Family functioning, including stability and warmth, have been found to predict which children affected by HIV/AIDS experience distress and psychological symptoms in both high and low prevalence settings** (*Franco et al, Sherr*).

## Stigma and Discrimination

Although not extensively studied in high prevalence settings, research from low prevalence and concentrated epidemic countries suggests that stigma and discrimination is prevalent against children. It may come from community members, public services and school staff, and arise in caretaking situations and foster families. Children are also affected by stigma aimed at their parents and guardians. **Stigmatization goes beyond individuals and families infected with HIV/AIDS to include other parameters for exclusion, such as poverty; for example, families who can't afford to send their children to school, or who ask for help with basic foods.**

## Out-of-Home Care

The vast majority of orphans and other children dislocated as a result of HIV/AIDS and other factors live with surviving parents or are cared for within extended families in informal, culturally appropriate fostering arrangements. As a result of increasing dependency, households that take in children without additional assistance, experience reductions in consumption, expenditure and long-term capital accumulation.

**Orphanages, institutions and other forms of non-family residential group care cost up to ten times as much as family care, and there is strong historical and contemporary research evidence that children in these forms of care fare worse than children in families, including foster families. These facts make orphanages, institutions and other forms of residential group care choices of last resort.** Even in resource rich countries, such as the United States and the United Kingdom, orphanages often provide too little and poor quality care, and children suffer physical and psychological deprivation.

The focus on “orphaning” was originally the metric for monitoring the stage of an HIV/AIDS epidemic in terms of parental death and the need for care. But this *orphan focus* tended to create the impression that huge numbers of children in sub-Saharan Africa were in need of replacement care, including in orphanages and other forms of group residential settings. It has been argued that poor children affected by HIV/AIDS receive better food, clothing and other material care in orphanages than is available in the homes of kin. But this is deceptive; if families were provided with the funds, training and supervision invested in orphanages, they would be able to more than adequately care for children. The tragedy is that, even under conditions of high HIV and AIDS prevalence, most children in orphanages are not orphans, but very poor children whose parents have given them up for care. **Efforts need to be directed at helping destitute families acquire greater resources in order to provide better for children themselves, rather than at facilitating or increasing orphanage care for affected children.**

In addition to their expense and adverse impact on children in the short and longer term, orphanages are seldom maintained at the level of quality at

which they were initially established. For example, funding for orphanages in Mozambique, created during the liberation war, has dried up, leaving most of the centres in extremely poor condition, resulting in inevitable neglect and abuse of children. Community re-integration programmes, which have been initiated in every country with high numbers of children in institutions, are expensive and difficult to effect. While these programmes are preferable to, and more cost-effective than maintaining children in residential institutions, they may come too late to reverse the negative effects of residential group care for many children.

## Legal Protection

**Children affected by HIV/AIDS, like other vulnerable children, may experience violence, exploitation, abuse and neglect.** While information on this subject is extremely limited, it is clear that legal and social welfare systems in the most affected countries are often inadequate and fail to provide children with protection and support. The support children require includes birth registration and other proof of citizenship, financial aid, protection from abuse and discrimination, enforcement of inheritance rights, and the like.

Access to justice is an area rarely explored or studied in relation to children. Unlike health care and treatment access, fewer formal pathways and provision to legal protection and legal services are available generally. Within this vacuum, children are least likely to be represented and defended. However, there are many legal frameworks to guide the protection of children and to ensure their rights, including the Convention on the Rights of the Child, and the African Charter on the Rights and Welfare of the Child. Protection of these rights for children rarely involves action through the courts.

Parallel to social protection, social justice and legal protection for children and families affected by HIV and AIDS must be actively pursued.

## 5.5 Conclusions

1. Due to the generally adverse physical and social conditions in which many children live in the poorest parts of the world, it is difficult to isolate the specific effects of HIV and AIDS on children. If untreated, children living with HIV tend to have neurological and other developmental difficulties, and HIV-negative children living with HIV-positive mothers have also been reported to show a number of development and adjustment problems.
2. Where food insecurity is as pervasive as it is in much of sub-Saharan Africa, nutritional challenges exist for children regardless of their exposure to HIV and AIDS.
3. Orphanhood, broadly defined, has been found to affect children's education, but whether the underlying cause is poverty or other factors is not yet clear.
4. The impact of parental death on children is likely to vary, especially given the large number of children partially reared by relatives. Strengthening and supporting families to provide comfort and security to affected children is likely to be the most effective way of addressing children's distress due to loss and stigmatization.
5. Orphanages and the institutionalization of children in non-family residential care should be strongly opposed. The health, social and psychological damage caused by orphanage care compounds the problems of poor children affected by HIV and AIDS, and their families. The high cost of residential care draws funds away from much-needed family support. Where children have to be placed in institutional care because all efforts at family placement have failed, the state and providers of institutional care must put in place strong monitoring and protection systems to avert potential abuse and neglect and to facilitate speedy alternative family placement.
6. As social protection mechanisms are adopted to support children and families, attention needs to turn also to strengthening social justice systems to prevent abuse and neglect, and to assist children and families affected by abuse and neglect.

## 5.6. What Does Knowledge and Experience of Other Crises Teach Us About the AIDS Response for Children and Families?

**Children and families in eastern and southern Africa have been exposed to HIV/AIDS for more than two decades.** Of the children first exposed to the risk of HIV through mother-to-child transmission in the 1980s, those who survived are now part of the next generation of families with their own children — again facing the risk of their own infection and possible vertical transmission to their children. HIV can no longer be seen as an external shock. Given the long duration of the epidemic, it has become part of the context (*Hosegood, Madhavan & DeRose*).

The epidemic is unlikely to be brought under control within three to four decades into the future. Yet many HIV/AIDS responses, including those aimed at children, are based on the perception of the epidemic as a crisis. Even from this vantage point of crisis, **we have generally failed to learn from previous crises.** The fact that HIV/AIDS is not entirely unique in its effects on age structure, fertility, marriage, migration, labour and education should offer us both models to adapt, and lessons on mistakes to be avoided (*Madhavan & DeRose*).

An examination of 35 20<sup>th</sup> century crises of a processual nature (that is, crises that are extended rather than instantaneous — such as a sudden immediate natural disaster — and which usually have periods of incubation before the effects are fully felt) indicates predictable impacts of crises on mortality, marriage, fertility, migration, childcare arrangements and child labour (*Madhavan & DeRose*). High levels of mortality as well as concentrated effects among productive and reproductive age groups have occurred before; for example, during the Khmer Rouge regime and the collapse of the Soviet Union, respectively. It is common for marriage to be delayed under conditions of hardship but, on the other hand, early marriage may secure safety nets during crises. It is well recognized that crisis tends to reduce fertility and that fertility typically rebounds to a higher level after the crisis before returning to a hypothetical normal.

As indicated previously, **children are regularly fostered between families in sub-Saharan**

**Africa, including in response to crises.** Migration rises during crises, in order to increase access to greater and more diversified income, but it also escalates HIV risk. Migration may also lead to a loss of household and livelihood labour, which might not be sufficiently compensated by remittances, resulting in greater demands for children's labour. With respect to HIV/AIDS, a unique feature of migration is the large numbers of people who return home to their families for care at advanced stages of illness and to die. These once productive people, on whom families relied for economic support, no longer contribute to the resources of the household. Rather, household expenditures increase in the face of their illness and death (*Haour-Knipe*).

Crisis usually intensifies households' need for labour. Children may be withdrawn from school to supplement labour, especially when households lack reserves to offset income shocks. Children are also drawn in because the types of labour shortages experienced by very poor people cannot usually be compensated for by technology. **HIV/AIDS may be more detrimental to human capital accumulation than other crises because of its impact on education and educational systems.**

There are few alternatives to child labour when adult mortality is high. This is compounded by the fact that HIV/AIDS is a long-run crisis and parents cannot expect conditions to get better before their children finish school. Many sub-Saharan countries also do not offer schooling, or prospects following education, of high enough quality to be worth releasing children from productive tasks. In addition, as a result of HIV, it seems less likely that children who have left school will be motivated to return when the time horizons for returns on investments are more variable and shorter. Lastly, the epidemic seems to motivate early marriage for girls from the poorest households. This adversely affects their education, making them more vulnerable to HIV infection and thus contributing to a vicious cycle of HIV and AIDS.

**There is a great deal that HIV/AIDS shares with other crises, such as the withdrawal of children from school and increased child labour, and this could have been better anticipated. However, HIV/AIDS is different from other crises in two important respects. First, it clusters within intimate family relationships (partners, parents**

**and children).** In addition to concentrating stresses in the household, children often watch their parents get ill and die of a stigmatized disease, and they may also have to care for their parents and other sick adults. **Second, it is of an unprecedentedly long duration, and will continue to have lasting effects on families in sub-Saharan Africa through its impact on their regenerative capacities, and its degradation of human capital. It also compromises the educational and health systems necessary to restore human capital in the future.**

## 5.6 Conclusions

1. Children and families in eastern and southern Africa have been exposed to HIV/AIDS for more than two decades. It is no longer a crisis, but part of the broad social context influencing family and personal life.
2. Nonetheless, there is much to be learnt from responses to previous crises of a similar nature, for example, the fostering of children within extended family networks, the withdrawal of children from school to conserve resources, and an increase in child labour to compensate for lost adult work.
3. Because of its long-term nature, and the fact that it clusters within families and households, HIV and AIDS is likely to have an unprecedented impact on the regenerative capacities of families and human capital. This is especially probably because HIV and AIDS also compromise the educational and health systems necessary to restore human capital in the future.

## 5.7. What Can We Learn from Carefully Evaluated Family Strengthening Efforts in Fields Other Than HIV and AIDS That Can be Usefully Applied in Hard-Hit Countries Such as in Eastern and Southern Africa?

It has long been recognized that strengthening the capacity of families through systematic, large-scale, public sector initiatives is one of the most critical strategies for the care and protection of children, especially children in families affected by poverty. In order to understand how this might be done, a review was undertaken of well evaluated family strengthening programmes in the Western world. While very few programmes specifically define themselves as “family strengthening”, there are a number of large scale efforts to improve family functioning and/or outcomes for children and youth through family-level interventions.

Home visiting, parent education and parent behaviour skills training, two-generational (child development and parental wellbeing)<sup>2</sup> and combined early child development and youth development programmes all aim in some way to improve the family care environment (*Chandan & Richter*).

**Parenting and family support programmes include a range of services** including skill building, home visiting, social support, and counseling. These programmes are **generally targeted to children less than five years of age because early intervention is more efficacious and cost-effective than attempts at remediation implemented later**. To date, the evidence on their effectiveness is modest to promising. Effects are improved when services are provided to parents *and* children, when trained professional staff are employed and when beneficiaries are networked to provide each other with social support. Home visiting programmes, in particular, have been well evaluated and, while the evidence of their effectiveness is mixed, their impact is enhanced when combined with centre-based early childhood programmes, when trained professional staff are employed, and when the programme is implemented at a high level of quality for a long duration.

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<sup>2</sup> Many two-generational programmes aim to improve the health, development and educational achievement of children, as well as the labour market participation of parents.

The best evidence for scaled-up interventions are **early child development programmes with parental involvement and training, and home visiting**. There is good evidence that, across a range of interventions, the economic return to interventions in early childhood are higher than at any other time in life. Two-generation or combination programmes also aim to address family poverty through parent education, job skills and income generation. Combined centre- and home-based services, such as Early Head Start in the United States, for example, have shown a range of child and family benefits. **In all programmes evaluated, quality is critical, as are well trained staff and intensive services over an extended period of time.**

In examining the evidence on family strengthening from high-income contexts and considering its applicability to high prevalence, resource-constrained settings, **two key areas, home visiting for pregnant mothers and follow up with young children, as well as early childhood development programmes, emerge as areas of appropriate and promising intervention**. Importantly, both intervention modalities speak to the need to strengthen caregiving. Given broad scale impacts in high prevalence countries, **there is general consensus that enhancing protection for children affected by HIV and AIDS necessitates large scale systematic interventions that enhance international, national, and community level responses for all vulnerable children. This means refocusing institutional capacity and delivery systems to provide services such as home visiting and early childhood development programmes.**

While home visiting programmes and early childhood development programmes can provide important services to families, it is difficult for families facing multiple stressors to benefit from interventions if they are struggling to meet very basic needs such as food, shelter, access to water, etc. It is clear then that implementation of **family strengthening programmatic activities must unfold alongside or build upon efforts to strengthen families economically**. Services and income transfers are complementary, aiming to achieve the same goals.

## 5.7 Conclusions

1. There is general consensus that enhancing protection for children affected by HIV and AIDS necessitates large scale systematic interventions that strengthen international, national, and community level responses for all vulnerable children.
2. Parenting and family support programmes need to include a range of services generally targeted to children under five years of age because early intervention is more efficacious and cost-effective than attempts at remediation implemented later.
3. The best evidence for scaled-up interventions come from early child development programmes with parental involvement and training, and home visiting, implemented in the West. In all programmes that have been rigorously evaluated, quality is critical, as are well trained staff and intensive services provided over an extended period of time.
4. To be effective, family strengthening programmatic activities must unfold alongside or build upon efforts to strengthen families economically.

## 5.8. What Programmatic Experience in the HIV/AIDS Field Has Been Gained in Strengthening Families?

Interventions attempting to provide support to children affected by HIV and AIDS have evolved generally without reference to, or benefit from, programmes implemented to support children affected by war and violence, children affected by natural disaster, street and working children, and children with disabilities, amongst others.

**Families and communities provide by far the major share of care and support for children affected by HIV/AIDS. Very few families receive any form of external assistance additional to that provided by kith and kin.**

In a comprehensive review of the literature and informal documents, 52 articles were found which described some form of family strengthening approach to assist children and households affected by HIV and AIDS. To supplement these sources,

interviews were also conducted with seventeen key informants from USA-based implementing agencies, and thirteen key informants from field-based programmes in southern and eastern Africa (*Wakhweya et al*).

**Very little of the literature and few respondents defined family-centred care, a strategy for providing family-centred services, or offered a model of a family-centred approach.** There were a few descriptions of mechanisms through which a family's capacity to protect and care for affected children could be strengthened — by prolonging the lives of parents and providing economic, psychosocial and other support (such as education, food security and nutrition, health care, shelter, legal support, child protection and/or spiritual support), according to assessed need and capacity.

However, there were exceptions, with **considerable effort being made by some field programmes to provide comprehensive services using a family-centred approach.** These include: linking children and caregivers to primary health care and HIV/AIDS services; assisting families to apply for social assistance grants; providing educational support to children and vocational support to youth; linking children and families to psychosocial support groups; providing nutritional assistance; and providing child protection services while working to enable families to stay intact.

**Family-centred approaches could also help to provide support for the elderly and for young adults, who, together, have assumed the major responsibility of care for children affected by HIV and AIDS** (*Drimie & Casales, Hosegood, Sherr*). These two groups have stepped in to fill the gap caused by adult deaths and increased migration for reasons of income and livelihood activities (*Haour-Knipe*). There remains a need to explore how services can be extended to all family members, including a specific focus on young adults and the elderly.

It is difficult to estimate accurately the numbers of children, and specifically children affected by HIV and AIDS, being cared for by grandparents because there are only a handful of studies which explore this, and the sample sizes are generally small. However, demographic data from 24 sub-Saharan countries show that 46 percent of adults over the age of 60 live with at least one grandchild, and

14 percent of households contain grandparents and at least one grandchild, but no parent (this does not exclude the possibility of other adults being present in the home). The most common reason for this is that the grandchild's parent/s are alive but living elsewhere (*Sherr*).

## 5.8 Conclusions

1. Families and communities provide by far the major share of care and support for children affected by HIV/AIDS, but very few families receive any form of assistance additional to that provided by kith and kin.
2. Although considerable effort is being made by some field programmes to provide comprehensive services using a family-centred approach, these are generally not widespread and need to be expanded. Very few programmes have been subject to systematic evaluation, and none to evaluation using scientifically rigorous methods.
3. Family-centred approaches could also help to provide support for the elderly and for young adults, who, together, have assumed the major responsibility of care for children affected by HIV and AIDS.

## 5.9. What Promising Directions Are There for the Future and What Do They Suggest?

Apart from the family-centred policy and programming explored in the previous sections, several other promising directions are suggested by the comprehensive literature and programmatic reviews undertaken in Learning Group 1: Strengthening Families. The two main ones are **family-based HIV/AIDS approaches and income transfers for the poorest families in communities hard hit by HIV/AIDS**.

### **Family-Based Approaches to HIV/AIDS Prevention, Treatment and Care**

**Extending HIV/AIDS platforms to families is an extremely important new direction**, as adduced from a number of lines of evidence. As indicated earlier, HIV and AIDS cluster in families and households. Secondly, the expansion of prevention,

treatment and care for adults involved in the care of children is a critical and strong intervention for improving the care of children, and preventing them from becoming infected with HIV. Ensuring that parents and caregivers remain uninfected, that infected caregiving adults receive and adhere to their treatment, and that families receive the financial and social support they need to maintain their care of children and provide for children's basic needs are the fundamental first steps in the response to children affected by HIV and AIDS.

In addition, treatment and care for infected children needs to be prioritized, and programmes designed to assist families in coping with multiple members on ARV treatments. Successes in treatment will bring their own challenges. **Earlier detection, longer survival, issues of disclosure, adherence, family stresses associated with treatment regimens, and the desire of infected and discordantly infected couples to bear and raise children all make it imperative to adopt family-centred approaches to prevention, treatment and care.** Couples- and home-based voluntary counseling and testing are first steps in such a direction. Services should be guided by integrated family provision rather than vertical stand-alone programmes. One study, for example, showed that ART adherence improved when parents and children were treated together, rather than, as is typical, through different services directed at adults and children.<sup>3</sup>

Several studies attest to the microeconomic benefit at the household level of ARV treatment for adults and children. Besides reducing the financial and care burden on families of ill-health, **ARV treatment improves the propensity of adults to return to work. This increases household income and food security, improves child nutrition, reduces the need for children to work and increases their probability of returning to school.** The improvement in the health status of the individual on ARV also reduces the burden of care and household work on other family members. This frees up time for the care of children.

Lastly, **ARV treatment helps to reduce stigma and discrimination.** When infected children and adults look and act well, they are less likely to be isolated. In addition, when they are able to re-engage in routine

<sup>3</sup> Reddi, A. et al (2008). Antiretroviral therapy adherence in children: Outcomes in Africa. *AIDS*, 22 906-907

activities, such as returning to work and school, they are more likely to reintegrate into their social groups.

Similar thinking, using family-focused and family-centred approaches, must be applied to prevention, as well as care and support.

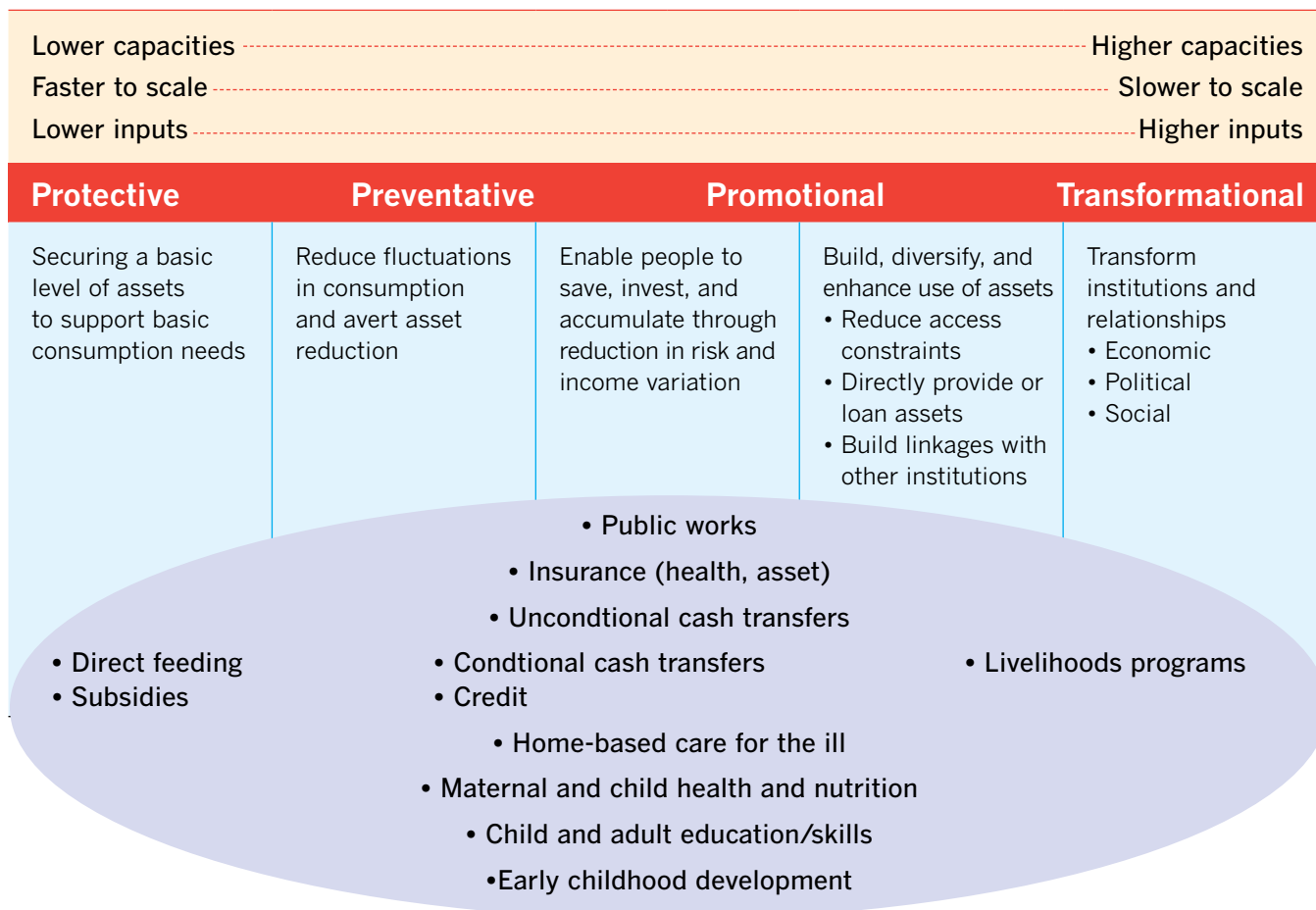
### **Income Transfers for the Poorest Families in Communities Hard Hit by HIV/AIDS**

The upsurge in interest among governments, as well as development and donor agencies, in social protection in poor countries has reached sub-Saharan Africa. This issue is taking on a new urgency as **HIV and AIDS interact with other drivers of poverty to simultaneously destabilize livelihoods systems and family and community safety nets.** A new focus on the vulnerability of families, and threats to the human capital of children, with lifelong and intergenerational consequences, has **accelerated international, regional, and national commitments to social protection programs in heavily AIDS-affected countries.**

**Among different forms of social protection, a momentum is gathering around direct income (or cash) transfers to the poorest households.** Such programmes are now found from El Salvador to Kenya, Bangladesh and Cambodia. In sub-Saharan Africa, national governments, donors, multilateral agencies, and international and national non-governmental organizations (NGOs), are cooperating to pilot and roll out programs intended to reach hundreds of thousands of people within a few years. **More than a dozen countries in sub-Saharan Africa currently have income transfers programs, most at early stages, and more countries are planning or considering them.**

Income transfer programs can take many forms. Transfers can be given to households as a unit because they meet poverty or vulnerability criteria, to an individual such as an elderly or disabled person, or to families based on the presence of individuals such as children, girls, or fostered orphans. Cash transfers may be unconditional (given without obligations), or they may be conditional; tied to obligations of recipients in

**Figure 1: An Asset-Based Social Protection Framework (Adato)**





work, training, children's education, health, nutrition, or other services or activities. Income transfers provide for current basic needs of adults and children such as food and clothing. They can also enable and encourage investment in assets that increase people's chances of breaking out of poverty in the long-term. Depending on their design and people's ability to take advantage of them, income transfers have also been shown to have additional benefits such as increasing women's autonomy and capacities, and strengthening capacities of local organizations.<sup>4</sup>

Based on an exhaustive review of over 300 documents describing and evaluating income transfer programmes, including evidence from: (1) studies of several large-scale, well-established transfer programs in eastern and southern Africa; (2) studies from newer pilot income transfer programs in southern and eastern Africa; (3) modeling of impacts of income transfers in sub-Saharan Africa; and (4) studies of conditional cash transfers in Latin America and Asia (*Adato*), **income transfers are the recommended form of social protection to be implemented immediately in countries severely affected by HIV and AIDS. Income transfers have demonstrated a strong potential to reduce poverty and strengthen the human capital of children through improved health and education, and thus can form a central part of a social protection strategy for families affected by HIV and AIDS.**

Income transfers as part of social protection can be visualized in the framework depicted in Figure 1 on page 32.

The framework illustrates that income is more appropriate than livelihood or credit approaches for low capacity HIV- and AIDS-affected families. Income transfers require fewer managerial and other inputs than other approaches, including the disbursement of food, and can be scaled up relatively quickly, especially with the assistance of international donors and local and international civil society organizations.

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<sup>4</sup> Many income transfers are paid to women, and local organizations frequently assist in the identification of recipient families, the distribution of benefits and the monitoring of beneficiaries.

As indicated in Figure 1, starting from the left, the most basic benefit of income transfers is to relieve distress and protect consumption and other basic needs. Progressively, moving to the right — and with increasing capacity of beneficiaries — income transfers can prevent asset selling, promote savings and, at the level of the state and community, help to reduce inequalities. Low capacity families, for example those that are labour constrained due to illness or disability, are frequently unable to participate in public works programmes, skills training and micro-credit.

## 5.9 Conclusions

1. HIV and AIDS cluster in families. Therefore, providing prevention, treatment and care to, and through, families will help both to support families and expand access to needed services. Earlier detection, longer survival, issues of disclosure, adherence, family stresses associated with treatment regimens, and the desire of infected and discordantly infected couples to bear and raise children all make it imperative to adopt family-centred approaches to prevention, treatment and care.
2. HIV and AIDS interact with other drivers of poverty to simultaneously destabilize livelihoods systems and family and community safety nets. This has accelerated international, regional, and national commitments to social protection programs in heavily AIDS-affected countries.
3. Among different forms of social protection, a momentum is gathering around direct income transfers to the poorest households. Income transfers have demonstrated a strong potential to reduce poverty and strengthen the human capital of children through improved health and education. Income transfers should therefore form a central part of a social protection strategy for families affected by HIV and AIDS.
4. Income transfers can be implemented immediately by governments in countries severely affected by HIV and AIDS, with technical assistance and support from donors.

## 6. What Now Needs to be Done?

### 6.1 What Now Needs to be Done?

Seven specific recommendations are made based on the combined work of Learning Group 1: Strengthening Families. These are: 1. Improve prevention of HIV infection among adults and children; 2. Expand the treatment of adults and children living with HIV; 3. Focus on families to support children affected by HIV and AIDS; 4. Support extended families; 5. Adopt family-focused approaches to HIV/AIDS prevention, treatment and care; 6. Implement income transfer programmes; and 7. Build relationships between the state and civil society that build on their comparative advantages.

#### *Improve the Prevention of HIV Infection Among Adults and Children*

**Attention has been drawn to the importance of preventing adult infections for the wellbeing of children.** Most children are infected with HIV during pregnancy, delivery or breastfeeding. Interventions available in well-resourced settings include antiretroviral treatment in pregnancy, Caesarian section delivery and avoidance of, or breastfeeding with improved safety. The feasibility of some of these preventive approaches diminishes in resource-poor settings.

**Administration of effective antiretrovirals in pregnancy (beyond monotherapy), delivery, and to the child (PMTCT) holds the promise of being the single most effective intervention to prevent children from being infected with HIV.** It is also a critical entry point for mothers, fathers, siblings and other family members into HIV and AIDS prevention, treatment, and support programmes. However, the promise remains far from fulfilled. Excluding Botswana, implementation of PMTCT in southern Africa was as low as 10 percent in 2006, and is currently estimated to be around 34 percent. The poor quality of most PMTCT programmes means that transmissions are only reduced to about 15 percent among women reached. This is still a very long way off the 2 percent vertical transmission rate which is now technically possible with effective drug regimens. In addition, monotherapy treatment, which is the norm in the majority of high prevalence

countries in eastern and southern Africa, runs the risk of generating resistance in the mother and, as yet, unknown resistance in the infant. This means that the mother and child may become resistant to HIV treatment as it becomes available, and it may also contribute to the transmission of resistant strains of virus.

HIV testing only in pregnancy misses opportunities to reach partners and mothers' other children, or other potentially affected adults and children in the household. HIV and AIDS cluster in families, and entry points such as PMTCT are ideal platforms for reaching related or co-residential individuals for prevention, treatment and care. Parental treatment should be incorporated into the prevention paradigm for children. **Keeping families intact, well, and functional is in the best interest of children.**

#### *Expand Treatment of Adults and Children Living with HIV*

The introduction of highly active antiretroviral treatment (HAART) has revolutionized the impact and prognosis of HIV infection. The benefits of ARVs are seen in extended life expectancy, reduced opportunistic infections, reduced infectivity and recovered functioning. But treatment is complicated by challenges of access, adherence, resistance, side effects, and long-term care.

**Treatment for adults benefits children directly.** Parents on ARVs are able to return to work and resume other livelihood activities. This reduces pressures on household consumption, and in turn children's nutrition improves, they return to school, and there is an observed reduction in child labour.

**Positive treatment outcomes have been demonstrated in children.** However, in resource poor settings, **treatment for children lags substantially behind treatment for adults.** Paediatric formulations are only gradually being improved. Only 4 percent of children who need cotrimoxazole prophylaxis receive it. Fewer than 10 percent of children who need ARVs are currently receiving them, compared to about 28 percent of adults in the same settings. There are few palliative care resources for chronically and terminally ill children, and little has been done to develop feasible and effective mental health interventions for children who need them.

Little attention is currently being given to HIV infection in children after infancy, and there is a gap in data between 2 and 15 years of age. Where HIV prevalence data from children is available from household surveys, such as in South Africa, Botswana and Swaziland, **prevalence among children 5 to 9 years of age is estimated at around 4–6 percent, constituting very large numbers of children** (about 192, 000 in South Africa alone).

While the bulk of HIV infection in children under 15 years of age is due to vertical transmission, **the data suggest either that HIV-positive children are living longer than was previously thought or that there are other possible routes of later transmission.**

An unknown proportion of child infection may be due to sexual abuse, wet nursing, unprotected care of infected people in the home, and nosocomial infections (infections resulting from treatment in a health facility). It is shocking that, at this stage of the HIV and AIDS epidemic, so little is known about the vulnerability of children to infection, let alone how such infection may be prevented.

**Children and young people who are affected by HIV and AIDS in their family might be at higher risk for HIV infection.** Preliminary findings from cross-sectional studies show correlations between orphanhood and risky sexual behaviour in adolescence, including earlier age of sexual debut and multiple partnerships. None of the studies distinguish children orphaned as a result of AIDS or other causes. Causal pathways have not yet been explicated, but include the possibilities of sexual abuse and sexual exploitation, mental health problems, poverty and reduced access to services, and stigmatization of AIDS-affected children (*Cluver & Obadario*).

### **Focus on Families to Support Children Affected by HIV and AIDS**

**HIV/AIDS is, in one sense, a family epidemic. The disease is spread within families and its impacts cluster in families and households.** In sub-Saharan Africa, the majority of infections are transmitted in long-term heterosexual relationships. In turn, parents inadvertently transmit the virus to their children. The impacts of HIV and AIDS on children cannot be divorced from impacts of the epidemic on families.

There is a large and long-standing body of **evidence attesting to the importance of functional families for children’s care and protection, health, development, and wellbeing.** **Nurturing family environments are associated with** higher rates of school attendance and better school performance; higher levels of self-esteem, self-confidence and future orientation among children and youth; and a reduction in behaviour problems, including aggression, substance use and crime, among other benefits. Families are where children spend the majority of their time, derive their emotional and social support, have their most formative experiences, and learn values and views of the future.

The health, development and social needs of children are met primarily within the social and financial context of the family. The capacity of families to care for children is dependent on their family capital. This is the combination of their resources (income and livelihoods, land, tools, skills), relationships (family and community networks) and resilience (security, social integration).

We need a dramatic rethink in policy. **Both now and over the medium- and long-term, we will make greater advances in responding to children by strengthening and supporting families to provide for children,** than by targeting children alone. Families affected by HIV and AIDS are often presumed to “fail” children — by not meeting their basic needs, including for protection. In fact, though, public services fail families more often than families fail children.

It is known that some families exploit orphans and vulnerable children in the context of inadequate social and legal protections. In general, though, the network of family relationships has proved to be extremely supportive of children affected by HIV and AIDS.<sup>5</sup> **The majority of children affected by HIV/AIDS in sub-Saharan Africa continue to live with or be supported by their parent/s, and parents and other family caregivers are the most appropriate and sustainable sources of family and household stability and wellbeing for children.**

<sup>5</sup> As noted earlier, LG1 did not succeed in commissioning a review paper on child abuse and protection. At this stage, little is known, beyond anecdotes, about abuse of affected children in foster family conditions. Even less is known about how to prevent and manage neglect and abuse in communities with little, if any, capacity for case management approaches usually employed in social work, and fewer resources for judicial protection and subsequent supervised placement in alternative family care.

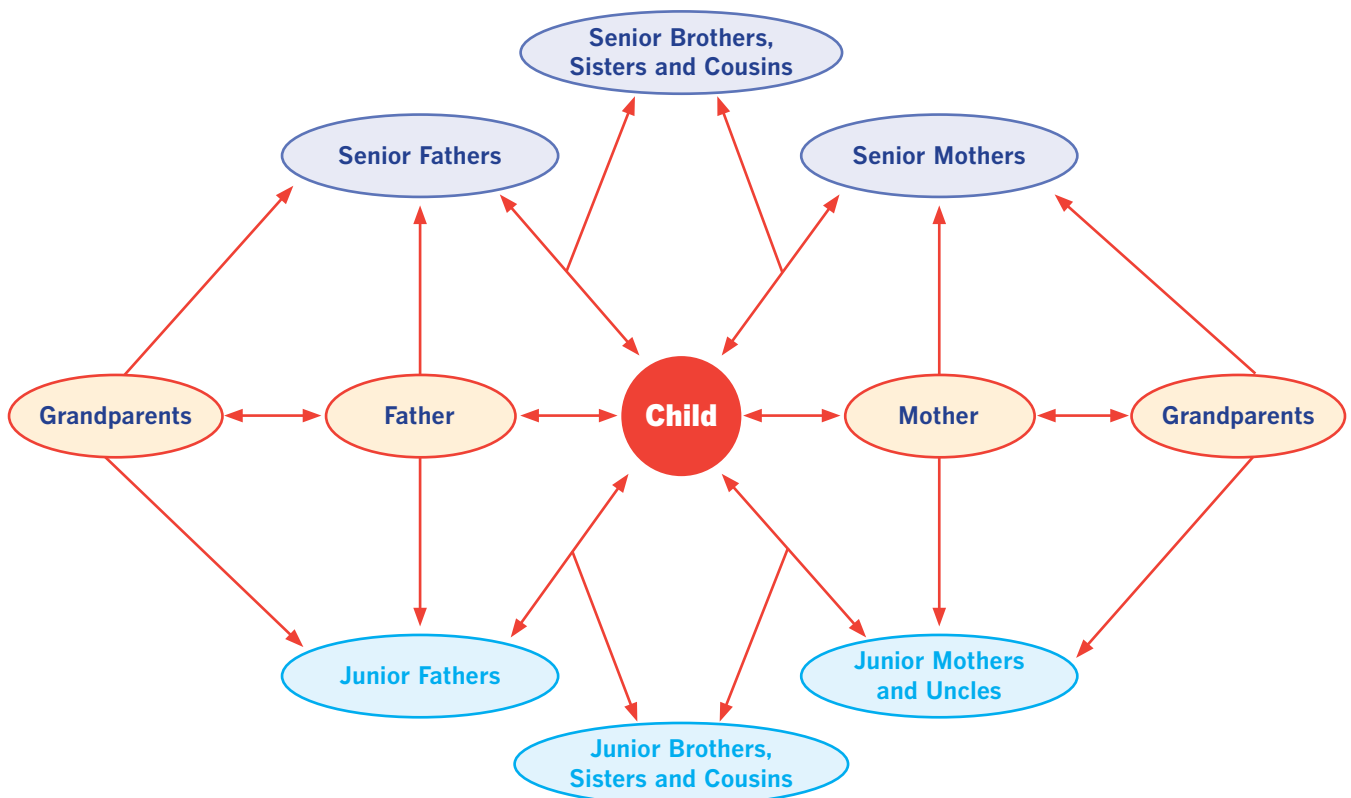
The importance of family care is true for older as well as younger children, adults as well as children. However, it is especially important for young children. The functionality and nurturance of families becomes more important in the face of external stresses, including those occasioned by HIV and AIDS. The foundational strategy to ensure children’s care and protection in the face of the epidemic is to strengthen the functionality of families, however they are defined. **Actions to strengthen families include keeping parents alive and healthy for longer; helping families to stay together; preventing the separation of children from each other and from extended kin; facilitating family access to essential services; decreasing isolation arising from stigmatization and discrimination; increasing support for coping; and ensuring economic security for the most destitute households.**

### Support Extended Families

**In most of sub-Saharan Africa, family is more than biological parents and their offspring.** For example, a father’s brothers or a mother’s sisters are classified as “senior” and “junior” fathers or as “senior” and “junior” mothers, depending on whether they are older or younger than a child’s parents. Grandparents, in particular, are accorded the status of parents. In this context, a child grows up amongst many fathers, mothers, brothers and sisters who are obligated to support and protect one another. This characterisation of a family denotes kinship, long-term commitment and security, despite the fact that urbanization, demeaning poverty, stress, and lack of state support reduce the capacity of kin to meet commitments adequately. Figure 2 below is a characterisation of typical family structure in sub-Saharan Africa.

These relationships contribute to resilience in the sub-Saharan African context where, in principle, “no child can be an orphan”, because **biological parenthood is not regarded as the only basis of parental responsibility.** Social parents, such as senior and junior mothers and fathers, grandparents, and older siblings are recognized,

**Figure 2: Characterization of a Southern African Family (Mathambo & Gibbs)**



and must be supported as legitimate, stable and secure caregivers for children separated from parents by migrant labour or death.

Programmes and services need to work with families as they actually function in Africa, rather than approach them as if they were the same as the predominantly nuclear families found in the North. One implication of this is to focus on young adults. **The majority of young adults are HIV negative. They are the drivers of family and household life as they are in the process of forming relationships, bearing and raising children. They are also the main role-players in households for earning income, providing labour and care, and ensuring social networks are fostered and maintained.**

**Orphanages and other forms of non-family institutional residential care for children should be strongly opposed.** They eat up resources, are up to tenfold more costly than family-based care, and have been shown to adversely affect the health, development and adjustment of children in the long-term. Resources earmarked for better care of children should be directed to family reunification, family integration and family support to ensure long-term benefits for children, as well as inter-generational benefits for their own children when they grow up.

### ***Adopt Family-Focused Approaches to HIV/AIDS Prevention, Treatment and Care***

The structure of current HIV and AIDS prevention, treatment and care platforms is individually-oriented — most effort is adult- and female-biased. Entry points, such as voluntary counseling and testing, PMTCT, ARV treatment and home-based care take the form of a one-by-one approach, despite the fact that **we know that HIV and AIDS clusters in families. Individualistic approaches miss the opportunity of extending prevention, treatment, and care and support to related people.**

Family-focused and family-centred approaches would be more efficient than most current efforts, and would address family concerns. For example, we know that disclosure to family members is associated with better support and coping. Studies also show that women often neglect their own care and put their child's treatment first if choices have

to be made between the timing, treatment priority and the like of their care and the care of their child.

Family-based approaches must respond to family and household dynamics in sub-Saharan Africa. Extended families have commitments and obligations across households, making it necessary to work with families rather than only with households. Children can be responsibly and responsively cared for by extended kin, although economic and other assistance may be necessary for this to happen without prejudicing children's health and development. Families need to be freed from having to make impossible choices with respect to the wellbeing of one child in comparison to another.

### ***Implement Income Transfer Programmes***

**Most children in communities affected by HIV and AIDS are being taken care of by extended families and communities. Many of these families were already very poor, and are now in even greater need of support.** Increasing poverty and illness in families and communities undermine livelihoods systems, human capital, and physical and psychological well-being.

HIV and AIDS pose extremely grave threats to the human capital of families, including through the health, nutrition, and education of children. These threats result from a vicious downward spiral involving illness; loss of income and assets; decreased food security; the necessity of children having to care for ill adults and do livelihood work; the inability of households to afford health care and school expenses; and stigma and emotional distress that reduce children's participation or performance in school. There is strong evidence of the compounding effects of early childhood nutrition, health and education, and the effect of these interactions on long-term human potential, including education and income. Many children and families who are not protected now from the impacts of HIV and AIDS may never recover.

Income transfers help to preserve basic levels of comfort and human dignity, but are also essential to prevent destitution of entire households, and irreversible health, nutrition and education deprivation among children, with lifelong consequences. **Although income transfers are currently being thought of as part of broader**

**social protection systems, they can also be viewed as family reimbursement allowances, because the largest expenditure in response to the AIDS epidemic comes from the out-of-pocket expenses of families and extended kin.**

As food shortages and food prices increase, there is an even more urgent need to improve people's access to food, especially children. Where markets exist and are accessible, income is a more efficient transfer to families than food, because families often have to sell the food they're given for money to pay for soap, transport, cooking fuel and the like. Income transfers are also easier to scale up than food disbursement at a regional or national level.

**Regular income transfers to the poorest households can be afforded, and can be implemented immediately, with technical and donor assistance, and the outreach capacity of community-based organizations.** Ministries responsible for social welfare and social grants will have to be strengthened. Large sums of money are currently tied up in the poverty-reduction activities of international and local non-governmental organizations. This money is often inefficiently used because infrastructural and salary costs frequently outweigh funds allocated to beneficiaries, and the funds could be better used if they were dispersed directly to destitute households. At the same time, civil society organizations would be freed to use their capacity to provide individualized social welfare and support services for needy children and families. Targeting identifiably AIDS-affected families is not recommended. However, targeting of income assistance based on functional incapacity — such as extreme poverty, labour constraints and the like — has been found to be highly AIDS-sensitive.

**It is likely that the approach taken to direct income assistance to households will vary across countries, and even communities. Some may take the form of universal social security entitlements, such as old-age pensions and child support grants; others may be implemented as programmatic interventions of varying duration, targeted geographically to vulnerable communities and households; others may comprise treatment allowances, or small amounts of money to cover the transport and opportunity costs of accessing HIV/AIDS prevention, treatment and care services.**

**But it is essential to immediately initiate income assistance to the neediest households.** Learning can take place in the course of action, as part of efforts to introduce transfer programs and in the midst of political processes underway to motivate for social protection as an essential part of the response to HIV and AIDS. Income assistance is a critical entry point and basic platform for HIV/AIDS prevention, treatment and care in high and low prevalence settings. Income transfers may also avert the institutionalization of children in orphanages for reasons of poverty.

### ***Build Partnerships between the State and Civil Society for Comparative Advantages***

**The scale of the HIV and AIDS epidemic, particularly when considered against the backdrop of widespread poverty, calls for large scale responses. The strengthening and expansion of health and education services to children is an obvious area for increased state action. Income transfers provide another important avenue for the support of children and families.** These systemic responses can be designed so as to improve the well being of all children while simultaneously providing additional support to the most vulnerable children, as a result of HIV/AIDS, poverty or a combination of both.

Civil society organizations (CSOs) have, to date, played a major role in supporting children, especially in the absence of substantial state intervention. There is now a strong call for systemic state-led responses, making it essential to form robust collaborations between the state and CSOs. Each have a number of comparative advantages in relation to one another, suggesting that considered collaboration will lead to the best outcomes for children.

**The state has a number of advantages over CSOs. Foremost among these is its size and coverage for children, mainly through health and education.** The state also has continuity and longevity. The state can commit to providing services into the future and is not dependent on external budget decisions to the same extent as CSOs. Although a number of states are heavily dependent on donor support, the funding is generally more secure and committed over longer periods of time than CSO funding. The state also has the opportunity to use redistributive taxes



as a means of funding, which is a more just strategy. Redistributive taxation spreads the cost burden more broadly than is currently the case, where costs are largely met by families and the immediate community.

Apart from national infrastructure, albeit limited in poor countries, **the state also has authority. It has the ability to implement legislation, enforce compliance, and create policy environments.** To some extent, the state's advantages are also its weaknesses. As a result of its size, it is slow moving, lacks flexibility and adapts with difficulty to specific local contexts. It is in these respects that the comparative advantages of csos become clearer.

**Free of the bureaucracy, responsibility and the size of the state, csos can be far more flexible.** They can see a problem and adapt their services promptly. Not only can they be flexible, but they can also be creative. Seeing the possibility that something might work, they have the freedom to try it and find out. They can develop services and responses which are only relevant in one particular context and adapt them for another. They do not have the same pressure to provide uniform services or to provide basic services to everyone in their catchment areas. csos can respond to individual distress on a case-by-case basis, which can be difficult and inefficient for the state to do. This flexibility and independence of csos, while at once a strength, is also one of their weaknesses in terms of accountability, collaboration and comprehensiveness of responses.<sup>6</sup>

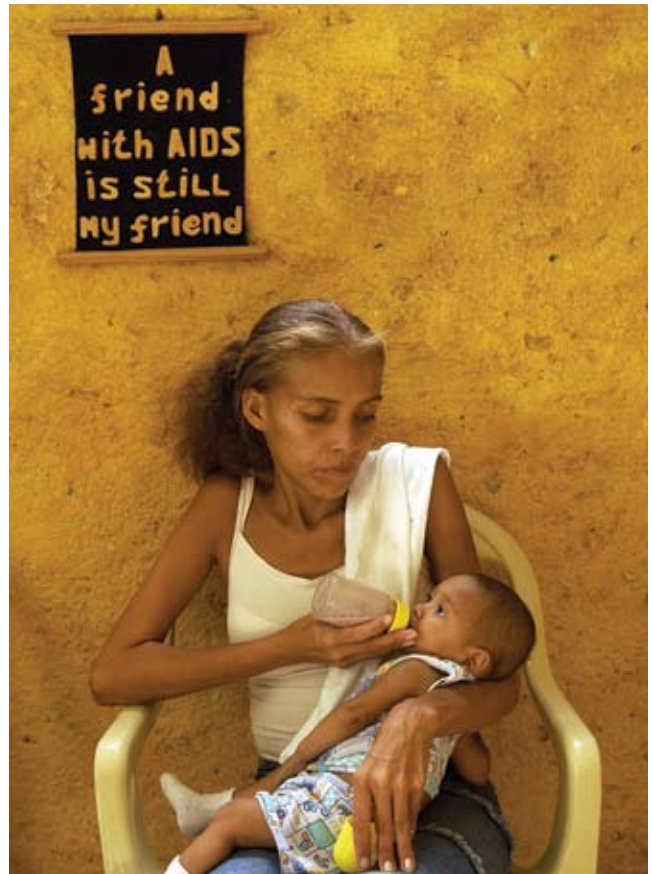
**Given the different advantages of the state and civil society organizations, there is obvious scope for cooperation** to maximize impact. As the state moves towards a systemic response, csos can fulfil a variety of roles, some of which are more suited to their relative advantages than others. Examples are:

- Provision of state services such as health and education, when state facilities are inadequate. This is best done by ensuring that such services coordinate with state provision so that they can be taken on, wholly or partly, by the state as its capacity improves;
- Facilitation of service receipt by families and individuals when state services exist but access is a problem. Income transfers provide an important example of the potential of such projects, as access typically requires documentation and physical access to service providers. Very poor families may lack these resources and, without assistance by csos may well end up being overlooked.
- Amplification of benefits received from state services. The challenges faced by families are generally complex, and access to a single service may not be sufficient to address them, but the provision of complementary services may make a large difference. Health care, for example, works better when the person receiving the care is well fed. Supporting children and adults on ARVs to acquire quality and appropriate food is an example of how a cso project can amplify the benefits of a state provided service.
- Linking services within government, and between government and csos, to create a continuum of care for children and families affected by HIV/AIDS. Ideally, various government systems, such as education, health and social welfare need to work together, as well as with community and other civil society groups and resources, for effective service provision. csos can play a critical role in facilitating and maintaining linkages, enabling beneficiaries to move between different services and sources of support.
- Providing context-specific and non-scalable services in which the state is unlikely to ever have significant involvement, beyond providing

<sup>6</sup> See, for example, work in LG2 on the faith sector.

a supportive legislative, policy, and funding environment. These include, for example, individualised interventions with child sex workers or other groups who require very specific psychosocial, and material support, and assistance. The state, however, remains the ultimate duty bearer, and recognizing the comparative advantage of csos does not absolve state inaction.

- Conducting demonstration projects, especially when it is not yet clear what services the state should be expected to provide, or how they should or can be provided. Given this situation, three important possibilities present themselves for csos — the chance to try new things, the opportunity to experiment with how to do them, and the chance to break down state resistance. For example, not many African countries are in a position to implement cash transfer programmes, and there are many programmatic and logistic choices to make. csos can experiment with these on a small scale and document what is needed to expand them.
- Leveraging activism and empowerment, especially when csos and others working close to communities see problems before the state does, or before the state is willing to acknowledge them. csos have a role to play in increasing the participation of beneficiaries in decisions concerning them, and in empowering recipients to demand services.



## 7. Conclusions

To date, children have been very severely neglected in HIV/AIDS prevention, treatment and care. There was a delayed response to children with respect to prevention and treatment, and it continues to lag significantly in technology, support, access and roll out, in comparison to adult services. Support for affected children has been left largely to families, extended kin and communities. While child-focused civil society organizations, local and international, have attempted to assist children and families, neither governments nor the global HIV/AIDS communities (including UNAIDS, UNICEF and WHO) have formulated, resourced, or implemented large scale interventions, nor yet begun to monitor the national and global impact on children and families.

With the work of the JLICA, UNICEF, the Inter-Agency Task Team on Children Affected by HIV/AIDS (IATT), and the Global Partners Forum (GPF), and vigorous advocacy by a number of child-oriented agencies, the spotlight is slowly moving to children. The current response is composed of small, localised, and largely serendipitous projects reaching at the most a few thousand children with services of questionable



impact. By and large, these services provide psychosocial support in the form of visiting and companionship, and poverty alleviation through the distribution of food, uniforms, and the payment of school fees. These efforts undoubtedly alleviate some of the distress experienced by children and families. But projects can only take us so far. It is clear that having a greater impact requires larger and more systemic responses. This highlights the need for concerted, well-targeted and effective government intervention, supported by international and national technical expertise and financial resources.

Much more is now known, and we are in a better position than five or even two years ago, to know how best to construct effective national responses. Given the background of poverty and destitution in high prevalence countries in sub-Saharan Africa, it does not make sense, nor is it efficient, to target AIDS-affected children specifically. The diffusion of livelihoods, community inter-dependence, family kin networks, and the pervasiveness of poverty and hardship mean that relief and assistance directed to the poorest and most distressed families will be highly AIDS-sensitive. Available models demonstrate that orphans in need of care are covered by such an approach.

Research in the field of children and HIV/AIDS is, in general, limited and not a lot of it is of a high standard. The methods used to date in most studies do not allow unambiguous conclusions to be drawn. Well-constructed large-scale intervention studies are almost entirely absent. However, increasingly, use is being made of literature beyond HIV/AIDS, which indicates some clear and promising new directions. Learning Group 1 lead authors have covered the most important of these areas, drawing on psychology, paediatrics, economics, anthropology, sociology, demography and other studies.

It is clear that the impacts of HIV/AIDS on children are mediated by families, as are the prospects of providing sustainable assistance for children over the long-term. The capacities of families to protect children, and to compensate for their loss of caregivers, security, possessions and the like, is highly dependent on the social context, most especially, pervasive poverty and labour migration. This makes a developmental approach to poverty an essential aspect of responses to protect children and safeguard their human capital. For this reason, access to essential services, such as health and

education, as well as basic income security, must be at the heart of national strategic approaches.

The composite knowledge and experience of LG1 leads to strong recommendations with respect to family-oriented services, income transfers, and better coordination between government and civil society responses. A primary message is to re-orient the support being garnered for children to families, so that they can support children. In the highest-prevalence countries, HIV and AIDS cluster in families. It is through families that children are adversely affected, and in families where they will find the emotional and material resources to withstand and recover from the effects of the epidemic. Children will be parents in their own families within one to two decades. Given the long time scale of the epidemic, unless we adopt a family-oriented approach, we will not be in a position to interrupt the cycle of infection, provide treatment to all who need it, and enable affected individuals to be cared for by those who love and feel responsible for them. Attempting to provide prevention, treatment and care services for one individual at a time is not possible in high-prevalence situations where up to two-thirds of all households are directly affected by the epidemic.

Income transfers, in a variety of forms, are desperately needed, and are indicated by available research. Basic economic security will relieve the worst distress experienced by families, enable them to continue to invest in the health care and education of their children, and to pay for their share of the costs involved in receiving treatment and care, such as transport to health facilities and additional food. Income transfers are not the *solution* to problems surrounding children and HIV/AIDS, and we should prevent resistance to transfers based on such a perception. Rather, income transfers are the entry point to a large scale integrated national response to problems experienced by children and families affected by HIV and AIDS. Money has benefits in and of itself, but it can also facilitate access to other services and, in turn, amplify their benefits.

The recommendations of LG1 are set out in seven key recommendations. Implementing family supportive services, including income transfers, will make a real difference to children. There is evidence that income relief can help to empower recipients to use, request, and demand more and better quality services. Making this work requires the commitment and cooperation of state and civil society resources.

## 8. Appendices

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