



**LEARNING GROUP 1: STRENGTHENING FAMILIES**

CHILD, YOUTH, FAMILY AND  
SOCIAL DEVELOPMENT

**INSIDE THIS ISSUE:**

<i>Introduction and methods</i>	1
<i>Key findings</i>	2
<i>Key findings</i>	3
<i>Recommendations</i>	4

*“The family approach is based on a system where there is established secure and stable individual focus on a child by an identified individual or set of adults.”*

**STRENGTHENING FAMILIES THROUGH HIV/AIDS PREVENTION, TREATMENT, CARE AND SUPPORT: A REVIEW OF THE LITERATURE**

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The entire cultural milieu in which family structures develop and evolve provide a rich tapestry within which childbirth and child care flourishes. This review provides a family-focused analysis of HIV/AIDS programmes and policies. It examines the strengths that families have to offer children in the era of AIDS, and provides insight into the challenges families face, and ways in which policies and strategy may be realigned to provide a holistic family approach to HIV prevention treatment and care. The working definition of family for this review is broad and includes extended family and home-based care provision. This definition links children to carer(s) through kith and/or kin ties, and residence in the family or community.

Although HIV and AIDS has had a dramatic effect on family structures, resources and capacity worldwide, it is also clear that families still provide a rich resource to combat negative effects of the HIV epidemic. They are also a unit of analysis and provision that has been greatly neglected in international strategy, for many reasons. Early Western responses to HIV, which formed the basis for HIV strategy in the developing world, were largely individualist. Young children didn't really fit within this scenario, limiting knowledge about and support for their needs. This neglect stands in sharp contrast to media attention and calls for rights and equality.

This paper explores the needs of children, and reviews strands of knowledge that feed into a family focus. Families provide a social context that has evolved for the protection and rearing of children, and children thrive in families. Strengthening families as a global strategy will provide an invaluable resource and a new pathway to child wellbeing, but the continued neglect of families may result in short sighted, misdirected approaches with harmful long term consequences that may be difficult to reverse.

**METHODS**

Three papers focus on three broad areas: HIV prevention in pregnancy; Family approaches to childcare; and Gender considerations in programmes. These areas are used as examples in an assessment of how programmatic features can either handicap or strengthen family capacity. The paper also explores how the oversight or understudy of family has meant that the issues are lost or under-funded in the response to HIV/AIDS. The paper is based on the results of a series of systematic literature searches and reviews. This process generated an evidence base around the relevant themes, on a number of relevant themes in order to generate a “state of the art” understanding of the findings.

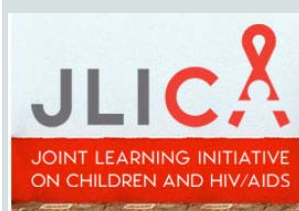
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*“Family care can enhance individual, family & community capital. Orphan programmes must support, not supplant, parenting, to reach those in greatest need.”*

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## KEY FINDINGS

### HIV prevention in pregnancy

- Children should be studied from conception rather than from birth.
- Maternal and paternal physical and mental health shape a child's family and caregiving environment.
- Sustaining intact families benefits children. Parents, grandparents, siblings and extended family are rich resources for the new infant.
- HIV prevention in pregnancy benefits children.

### HIV Testing

- Quality of testing is often menu driven, lay provided and not optimum.
- Couple testing and the inclusion of fathers is rare, despite good evidence of cost-effectiveness.
- Repeat testing and HIV prevention in pregnancy are rare.
- Although HIV testing and treatment is the most effective intervention, the reach remains low (34% in 2008).

### Treatment

- Treating parents is of enormous benefit to the child. The MTCT+ programme has proven efficacy and should be expanded.
- Research on treatment resistance, compound choice and impact on uninfected but exposed children is urgently needed.
- Infant feeding remains challenging, and ongoing evaluations of interventions are required.
- Treatment roll out to children has been slow with delayed attention to child specific compounds, and little data on child adherence.

### Orphan definition

A systematic review of all studies mentioning AIDS and Orphans generated 383 papers, but only 17 reported a control group. The majority (n=273, 71.3%) did not differentiate or clearly define orphan. Those that did, used a variety of definitions, including: one or both parents died (n=64, 16.7%); both parents died (n=13, 3.4%); mother died (n=23, 6.0%); father died (n=3, 0.8%); and multiple definitions including death of primary caregiver (n=7, 1.9%). Few papers gave the age ranges used to define a child. When ages were given, they varied between under 19 years and under 15 years. Few studies reported or controlled for the HIV status of the child. Over 80% of children coded as “orphans” had a surviving parent. For further information, see Sherr et al (2008). Full reference details are in the full paper, which is available on the JLICA websites.

### Institutional Care

- Institutions are bad for child development, but some negative effects are reversible. The literature on institutional care should be consulted in developing child care policies in the face of HIV/AIDS.
- Policy must focus on keeping families intact.

## KEY FINDINGS

### Schooling

- 15 controlled studies on schooling, children and HIV/AIDS were found. 13 of these identified a negative effect of orphanhood on some aspect of schooling.
- Control and comparison groups varied, and the HIV status of the child was rarely recorded or controlled for.
- Poverty was an overriding issue. Age was a factor, but this may be mediated by age cut off for free school provision and age-related caring duties within a household.

### Nutrition

- 14 controlled, empirical studies on nutrition, HIV and children were identified. 10 recorded no nutritional effects of orphanhood.
- Most of the studies did not control for child or parental HIV status.

### Bereavement

- The systematic review of HIV, children and bereavement generated 16 studies and only one fully evaluated intervention.
- There was a complete lack of consistency in measurement, data recording population definition.
- Despite the high profile presence of AIDS related bereavement for young children, there is very little research on the mental health ramifications of this bereavement, or on needs in this area.

### Cognitive development

- 54 studies were identified which had at least one systematic measure of cognitive functioning, and reported on place of study, sample size, age and outcome measures. 13 (24%) of these had no control groups.
- 3 studies found no effect of HIV on cognitive outcomes, 4 reported mixed effects, and the remaining 81% all showed a detrimental effect.
- There is an urgent need for systematic and routinely used measures to understand, prevent and provide for cognitive development challenges for children in the presence of HIV.

### Gender considerations in programmes

- Gender concerns permeate much thinking on children and families, but are not sufficiently highlighted in the AIDS response.
- All previous systematic reviews were re-evaluated to note whether gender was recorded, data was analysed by gender, or gender specific findings were recorded. 1 of 12 studies on treatment resistance, 12 of 15 studies on schooling, 9 of 14 studies on nutrition, 4 of 54 studies on cognitive development, and 7 of 15 studies on bereavement analysed data by gender.
- Major international data sets do not provide information on gender for children under 15 years of age.
- Data on gender variation and outcome is urgently needed to inform policy and research on children and HIV.

*“The evidence base for children is sorely lacking. Good quality, evidence based policy can only emerge if sound evaluation, with sufficiently powered studies utilizing adequate methodologies and control groups are available.”*

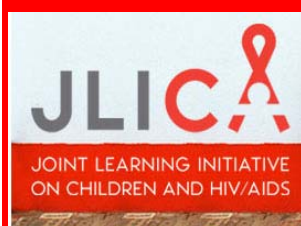
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JOINT LEARNING INITIATIVE  
ON CHILDREN AND HIV/AIDS

*“Policies that do not consider the family do a disservice to those they aim to help. A dramatic rethink is needed.”*

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## RECOMMENDATIONS

### Policy

- Evidence based policies and provision are the gold standard. This means resourcing studies to gather the evidence.
- Policy makers must also look beyond HIV/AIDS to other areas of child provision, to learn research and adapt findings and policies. Attention must also be paid to HIV-negative children who are nonetheless affected by HIV.
- Families continue to provide the major response to HIV/AIDS for young children. Understanding family resilience is critical to supporting families.
- HIV/AIDS affects children's schooling, nutrition, mobility, bereavement, cognitive development and care.

### Prevention and treatment

- Prevention of infant infection is possible, but is inadequate in resource poor countries. This must be improved.
- Protection of maternal and paternal health, physical and mental, is essential as a means to improve quality parenting for young children.
- Treatment for children is inadequate, especially when compared to adult treatment provision in a particular setting. This must be addressed. When children receive treatment, monitoring is inadequate and excludes psychosocial parameters. This must be improved.
- Barriers to child treatment, such as development of child appropriate medications, are finally on the agenda.

### Bereavement and psychosocial support

- The family situation of young children experiencing bereavement is not clearly defined. Surviving parents are discounted when "Orphan" labels include children with a surviving parent.
- There are negative effects of parental death and multiple bereavement on child development outcomes. These effects are gendered.
- Attention to emotional health in programmes and provision at the family level is lacking and must be improved.
- Psychosocial wellbeing measures are difficult and complex. Standardized indicators that allow for cross comparisons of findings, or integration of psychosocial measures into broader biomedical studies must be developed.
- Quality, family care is important for optimum child development, and institutionalization must be avoided.

### Gender

- Data on fathers is urgently needed.
- Data on HIV and children must be disaggregated by gender, and research on young children and HIV must pay greater attention to this variable.
- Gender data should be routinely collected on all interventions and trials, and results need to be analysed by gender.