



## LEARNING GROUP 1: STRENGTHENING FAMILIES

CHILD, YOUTH, FAMILY AND  
SOCIAL DEVELOPMENT

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*“The costs of inaction are those impacts felt by children because the response was inadequate to counter the challenge when it could have dampened or negated it.”*

## THE COSTS OF INACTION

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### INTRODUCTION

Very few of the many impacts experienced by children as a result of HIV and AIDS are inevitable. Instead, children suffer as a result of our failure to adequately respond to the challenges posed by the epidemic. To understand the costs of this inaction, it is necessary to examine the path from challenge to child, examining the role of the context in amplifying the challenge, noting all possible points of intervention, and recognizing which potential responses did not occur.

The paper focuses on the costs of inaction by actors external to the family. In order to meaningfully address impacts, it is necessary for external actors to reach out to families and communities. Families and communities play a critical role in mitigating the impacts of the epidemic on children, but in high prevalence, high poverty contexts, they may not be strong enough to do so without assistance.

Six essential components of family care are identified in this paper: intention to care; power relations in the household; human resources including time, child care knowledge and child care skills; financial resources; opportunities for the child to form significant and secure bonds with caregiver(s); and access to appropriate quality services and social support. Each of these components draws attention to pathways by which HIV and AIDS impact children. This allows for the identification of potential mechanisms to prevent or reduce an impact, along with the costs of failing to act.

### METHODS

This paper draws together insights from previous research, based on a thorough literature review of work addressing the impacts of HIV/AIDS on children, and households. It is located in a conceptual framework of family functioning which makes explicit the pathways through which HIV/AIDS impacts on children, and the points at which preventative action could have occurred. The discussion focuses on impacts related to child infection, adult illness and death, the consequences of adult death for care, and death outside the family. The paper concludes with a discussion of aggregate impacts, and a summary and conclusion.

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*“The ill health and death of children as a result of being infected with HIV by their parents is perhaps the clearest example of a cost of inaction.”*

## KEY FINDINGS

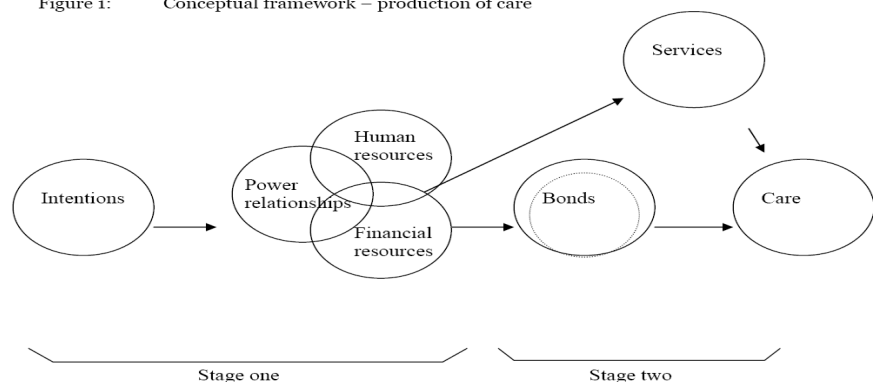
### Child infections

- Context shapes a child’s risk of HIV infection during pregnancy, childbirth and breastfeeding. HIV prevalence levels determine the probability of a mother being HIV positive; poverty and poor maternal health increase risk of transmission, and breastfeeding, while offering many health benefits to a child, increases the risk of infection if it is non-exclusive.
- The largest factor in determining transmission, however, is adequacy and accessibility of prevention of mother-to-child transmission (PMTCT) services. Available interventions can reduce the risk of transmission to 2%, but these are widely available only in wealthy countries. In developing countries, coverage is generally less than 50%, and the most effective interventions are not used. When coverage rates are low, the poorest people are least likely to be served.
- Shortcomings in PMTCT include both failure to provide services, and failure to enable access for the most disadvantaged members of society. Poor PMTCT services also results in the loss of an opportunity to identify affected families and refer them to other services, including treatment.
- The costs of inadequate PMTCT and treatment for infected children is that approximately 420 000 children become infected, and 330 000 die each year. Related costs include suffering, expenditure on health care, and the lost potential of each infected child.
- Inaction around paediatric ARV coverage also harms children; while 28% of eligible adults receive treatment, only 15% of eligible children do.

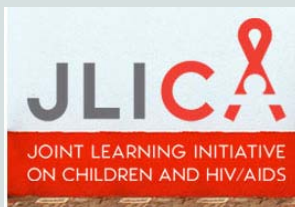
### Adult illness and death

- Adult HIV infection reduces household earnings and productive capacity, while simultaneously increasing demands on available resources, both human and financial. Clustering of HIV infections within households, and among people of productive age, exacerbates this. As a result, the flow of resources to children may be reduced.
- Fewer household resources for children affects their education, nutrition and health care. In addition, increasing demands for household work may be made on them.
- Implications of adult HIV infection vary with the socio-economic starting position of the affected household. Those in a better position, with more productive adults, higher levels of earnings, greater savings, or greater access to external resources, are better placed to deflect impacts of HIV from children.
- Inaction with regard to treatment for sick adults, and provision of social security services including cash transfers give rise to harmful impacts for children.

Figure 1: Conceptual framework – production of care



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## KEY FINDINGS

### Consequences of adult death for children's care

- The impact of an adult death on children is often determined by who died, the capacity and willingness of the household to manage this loss, and the response of those around children. Particularly important is the extent to which the adult was previously involved, financially or emotionally, in caring for the child. Even the death of an adult not living in the household may have serious impacts.
- Adult death may result in the need to change care arrangements. New caregivers may lack the intention to care for children, and may also lack childcare skills and knowledge. Household power relations may also change, impacting children's access to resources. When household resources are limited, the need to find new care arrangements may result in household collapse.
- The lack of social security payments for childcare in the developing world means that incoming children generally increase household costs without increasing household income. This could result in negative impacts when affected children are taken in by kin. Children who move into residential group care are also faced with documented negative impacts.
- Children may also suffer due to a failure to provide adequate support through traumatic experiences such as parental illness and death. When experienced by young children without support, such stresses may result in long-term neurological damage and reduced life chances.
- Quantifying the forms and costs of inaction is very challenging, particularly insofar as they relate to human resources within and outside of families.

### Death outside the family

- The most critical impacts of death outside the family on children are through the systemic deterioration of health and education services. HIV and AIDS increases demands on health care services, while simultaneously causing illness and death among those with the necessary skills to provide health care. Similarly, capacity for the provision of education is also harmed. Therefore, even children who are not directly affected by HIV and AIDS are harmed by inaction in the prevention and treatment of adults outside of the family.

### Aggregate impacts

- Huge numbers of children will experience impacts due to HIV/AIDS, both directly and indirectly. Millions of children will experience parental illness and death, which may lead to increased poverty and decreased access to health care and education. In some high prevalence contexts these impacts are so widespread that they may be observable in national statistics.
- Impacts are being felt on child health as health systems suffer, resulting in increases in infant and child mortality, or at least a slow down in progress on these indicators.
- Parental deaths have led to large increases in the numbers of biological orphans in high prevalence areas, as well as in the movement of children between households.
- Decreases in school enrolment may be observed, due to increased child mortality, but they may also be due to decreased fertility, higher rates of drop out and absenteeism, and delays in enrolment due to socio-economic pressures.
- These negative impacts on children are likely to have long-term macro-economic implications, which may well be cumulative and could affect the health and well-being of future generations.

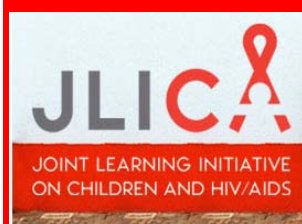
• *“...even children who are not directly affected by HIV and AIDS are harmed by our failure to prevent and treat infections of adults outside of the family”*

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*“The impacts felt by children are not simply unfortunate, inevitable consequences of the epidemic ... the bulk of the impacts observed are costs of inaction.”*

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## RECOMMENDATIONS

The review suggests that most impacts felt by children as a result of the HIV/AIDS epidemic can be classed as the results of a failure to take action.

Several high prevalence countries have now demonstrated that treatment services can be effectively rolled out, and that high levels of coverage can be attained. Family-based service provision provides a clear opportunity to further expand coverage and reduce impacts on children. While universal service provision remains a challenge, it can be done.

Resources to respond to HIV-related challenges are indeed limited, but it must be borne in mind that the impacts of HIV and AIDS experienced by children violate their basic rights. Directing resources towards the protection of these basic rights, which countries have committed to upholding, should be a priority. Not acting not only violates these rights, it is also likely to result in greater costs in the long term.

This paper makes a strong argument for immediate and significant action to prevent children from experiencing further negative impacts due to the HIV/AIDS epidemic.

Critical action includes:

- Widespread rollout of effective PMTCT interventions, to prevent further paediatric HIV/AIDS infections;
- Effective use of PMTCT interventions as a conduit to direct affected families to other relevant services;
- Increased support of affected families to enable them to access PMTCT interventions and ARV treatment;
- Increase in family based HIV care and interventions;
- Increased availability of paediatric ARV treatment;
- Increased prevention and treatment of adult HIV infection;
- Urgent implementation of child support grants and stronger social security and social protection;
- Attention to the protection of skills in the health and education sectors, as well as the generation of new skills.

The impacts of HIV/AIDS on children in highly affected areas occur because of a failure to address the root causes of the epidemic: failed prevention, poor quality and low coverage PMTCT services, inadequate adult treatment, and strained and unsupported families. None of these impacts are inevitable, but they do occur. The cost of the inaction which allows them to be felt are serious. The short term effects on children are evident, but the impact on children's developmental potential will continue over the long term, as results of infection, increased poverty, emotional strain and, in some cases, a neglectful or abusive environment.