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ABBREVIATIONS

AIDS	Acquired immunodeficiency syndrome	MTCT	Mother-to-child transmission
ARV	Antiretroviral	NAA	National AIDS Authority
ART	Antiretroviral therapy	NAC	National AIDS Committee
BCA	Business Coalition on AIDS	NCCA	National Committee for Control of AIDS
CCT	Conditional cash transfer	NGO	Nongovernmental organization
CSW	Commercial sex worker	OVC	Orphans and vulnerable children
DHS	Demographic and Health Survey	PDR	Peoples Democratic Republic (of Lao)
GCE	Global Campagne for Education	PEPFAR	President Emergency Plan for AIDS Relief
GECA	Gestion d'entreprise en culture Africaine	PLHIV	People living with HIV
HAART	Highly active antiretroviral therapy	PMTCT	Prevention of mother-to-child transmission
HIV	Human immunodeficiency virus	RCT	Randomized controlled trials
HRW	Human Rights Watch	SCF	Save the Children Foundation
IDU	Injecting drug user	UK	United Kingdom
IMR	Infant mortality rate	UNAIDS	Joint United Nations Programme on HIV/AIDS
LAC	Latin America and the Caribbean	UNICEF	United Nations Children's Fund
MICS	Multiple indicator cluster surveys	URC/QAP	University Research Co., LLC/ Quality Assurance and Workforce Development Project
MSM	Men who have sex with men	VCT	Voluntary counseling and testing
		NAA	National AIDS Authority

PART 1: INTRODUCTION AND METHODS

Executive Summary

Worldwide, the commitment to protect and support children affected by HIV/AIDS is growing, and countries with low level or concentrated epidemics are increasingly developing and putting in place special programs to support these children. The overall goal of this study¹ is to summarize and weigh the evidence on a number of challenges faced by children affected by HIV/AIDS in low prevalence and concentrated epidemic countries in order to facilitate evidence-based programming.

The specific objectives of this study are to: 1) review, analyze, and document the *situation of children affected by HIV/AIDS* in low prevalence and concentrated epidemic settings related to health, nutrition, education, protection, placement, psychosocial and cognitive development as well as socioeconomic status and experiences with HIV/AIDS-related stigma and discrimination; 2) review, analyze, and document evidence on *interventions* to support children affected by HIV and AIDS in low prevalence and concentrated HIV epidemic areas; 3) summarize the *extent of the evidence base*; and 4) formulate and *prioritize practical recommendations to strengthen the evidence base* for programming on affected children.

Children affected by HIV/AIDS have been defined for the purposes of this study as children aged 0-18 years living in low prevalence and concentrated epidemic countries who are in one or more of the following categories: children infected with HIV, children for whom one or both of their parents have died from HIV-related illnesses, children living in an HIV-affected household, or children at high risk of becoming infected with HIV.

Methods: The literature worldwide on orphans, children, and HIV and AIDS is quite large, with most related to eastern and southern Africa. This review of the evidence base for children affected by HIV/AIDS in low prevalence and concentrated epidemic settings prioritized its search on:

1. Peer-reviewed and published literature related to children affected by HIV/AIDS in low prevalence and concentrated epidemic countries;
2. Grey literature related to children affected by HIV/AIDS in low prevalence and concentrated epidemic countries; and
3. Selected literature related to children affected by HIV/AIDS in high prevalence countries deemed useful to understanding challenges and interventions for such children in low prevalence countries.

Principle sources of literature reviewed included: the UNICEF orphans and vulnerable children (OVC) database (August 2006), internet searches (PubMed, Google, WHO, UNICEF, UNAIDS, and other key organizations), ALADIN shared digital library (HOLLIS, CSA, PsychINFO, Proquest), networking with UNICEF regional offices and other key stakeholders, the Cochrane

¹ This study is the result of collaboration between the United Nations Children's Fund (UNICEF) and University Research Co., LLC/Quality Assurance and Workforce Development Project (URC/QAP) funded through the United States Agency for International Development (USAID).

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Collection, and references cited in reviewed studies. It should be noted that several potential biases may influence the conclusions based on this body of evidence: published and unpublished literature tends to focus on what people think serves their purposes and may tend towards studies that illuminate differences and difficulties and on interventions with positive results; articles reviewed were mainly in English, and the handful of documents reviewed in French and Spanish cannot be considered representative of the non-English literature in those languages; and finally, the difficulty to identify and obtain unpublished or grey literature even with the help of networking.

Four hundred and fourteen (414) studies were judged to be relevant to our objectives and were each read by one or more reviewers who completed a summary checklist for each document they reviewed. The checklist included the judgment of the reviewer of the relevance of the study document to our programmatic review, a summary of the study findings and methodology, and an assessment by the reviewer of the quality of the document and the rigor of its scientific methodology as reported in the document, based on specific criteria. About half of the 414 studies were judged to have good quality documentation, and about half fair or poor. The criteria used to judge quality differed slightly by type of study, depending whether they were about interventions, about the situation of children, or literature reviews. A majority of the studies (62%) focused on the situation of children, 25% looked at interventions only, and 13% discussed both the situation and interventions (most of which had little beyond a description of the interventions). Of these 414 studies, only 3 were systematic reviews of relevant all randomized controlled trials, 16 were single randomized controlled trials, and 64 reported on study designs with control groups or comparative, time series analysis. The majority presented data or findings from cross-sectional quantitative studies without controls, qualitative descriptive studies, literature reviews of varying quality, and other assorted documents (conference reports, policy documents, etc).

Three general conclusions about the evidence base emerged from this review:

1. The current evidence base is too geographically limited with insufficient evidence of the underlying causal relationships to allow for generalizable conclusions about the situation of children affected by HIV/AIDS.
2. Given the diversity of countries in the category "low prevalence and concentrated epidemic countries", it is probably impossible (and unwise) to draw overarching, generalizable conclusions for all low prevalence and concentrated epidemic countries.
3. The evidence base on effectiveness and efficiency of interventions in low prevalence and concentrated epidemic settings is almost non-existent.

The review arrives at a set of findings about the situation of HIV-affected children and the effectiveness of interventions based on the evidence for each of the major challenge areas addressed: health, nutrition, socioeconomic, education, protection, placement, stigma, psychosocial and cognitive development. Specific conclusions based on strong evidence and on moderate evidence are discussed for each challenge area, as well as the notable gaps in evidence in each area. These conclusions are discussed in the individual chapters about each challenge area, and summarized in the Synthesis chapter and listed individually by challenge area in Table 7 in that chapter. In all, there are 44 findings about the *situation* based on strong or moderate evidence and 23 important evidence gaps identified for situational evidence; and

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17 findings about *interventions* based on strong or moderate evidence and 22 important evidence gaps identified for interventions.

In addition, the review discusses how its findings about the evidence base can inform several important issues. First, how much evidence is enough for effective programming? Not only is there insufficient context-specific evidence about the situation of children in many of the low prevalence and concentrated epidemic countries and a dearth of strong evidence about the effectiveness and efficiency of interventions, but a lack of attention on some emerging highly vulnerable groups and on how antiretroviral therapy should alter future programming. Second, should programs target or not? When is targeting efficient? Does it cause additional stigma and discrimination? Is targeting practical given the intertwining of other factors (such as poverty, class, gender, lack of empowerment, etc.) with HIV-infected and affected? Third, how can HIV/AIDS affected children be identified and quantified? This appears to be more difficult in low prevalence and concentrated epidemic countries than in high HIV-prevalence ones for many reasons. The experiences so far in doing this can be useful. Last, how does the current evidence base translate into something useful for programmers.

Chapter 1 Introduction

This report on the evidence base for programming principles for children affected by HIV/AIDS in low prevalence and concentrated epidemic countries is the result of collaboration between the United Nations Children's Fund (UNICEF) and University Research Co., LLC/Quality Assurance and Workforce Development Project (URC/QAP). The report summarizes and weighs the evidence on a number of challenges faced by children affected by HIV/AIDS in low prevalence and concentrated epidemic countries.

1.1 Rationale and objectives of the study

Worldwide, the commitment to protect and support children affected by HIV/AIDS is growing. About two-thirds of all people living with HIV are in sub-Saharan Africa, which also has the most initiatives to support children affected by HIV/AIDS. However, countries with low level or concentrated epidemics are increasingly developing and putting in place special programs to support these children. The overall goal of this study is to document the evidence base for programming principles for children affected by HIV/AIDS in low prevalence and concentrated HIV epidemic areas.

A key principle of developing programs for children affected by HIV/AIDS is consideration of the evidence – what are the needs of these children and what efforts have successfully met them? While the evidence for programming on HIV/AIDS-affected children in high prevalence countries is increasing rapidly, no review exists of the evidence base in low prevalence and concentrated epidemic countries. Thus, the main objective of this study has been to review and synthesize what is currently known from the evidence base in low prevalence settings so as to inform the development of support for affected children.

There are, in fact, several impetuses behind this study. First, while it can be said that a higher percentage of children affected by HIV/AIDS live in high prevalence countries than in lower prevalence countries, in reality, larger absolute numbers of children affected by HIV/AIDS live outside those high prevalence countries (UNICEF et al., 2006b). These children likely also need assistance and should not be overlooked, but the question remains: what are their key challenges and how can we best meet their needs? Secondly, there is debate about whether using information from high prevalence countries is appropriate to guide programming for lower prevalence countries. The extent of the relevance of high prevalence evidence to low prevalence settings has been poorly defined and researched.

As a consequence, this report presents and carefully weighs *evidence* from documents reviewed, rather than their conclusions. The work behind this report additionally seeks to understand the situation of HIV/AIDS-affected children in low prevalence and concentrated epidemic countries and their priority challenges. Key in the review is examining how the situation of affected children may differ from unaffected and/or other vulnerable children and assessing what we know about how these disparities can be effectively addressed.

The specific objectives of this study are:

1. Situational evidence: To review, analyze, and document information describing the situation of children affected by HIV/AIDS in low prevalence settings within priority challenge areas such as health, nutrition, education, protection, placement, psychosocial

and cognitive development as well as socioeconomic status and experiences with HIV/AIDS-related stigma and discrimination.

2. Intervention evidence: To review, analyze, and document evidence on interventions to support children affected by HIV/AIDS in low prevalence and concentrated HIV epidemic areas relative to situational findings across priority challenge areas. The review of the evidence around interventions for affected children included an analysis of the scope and focus, process, and impact of these interventions.
3. Analysis of the evidence: To summarize the extent of the evidence base, describing its strengths and weaknesses for developing programming principles and identifying trends emerging from the evidence base.
4. Strengthening the evidence base: To formulate and prioritize practical recommendations to strengthen the evidence base for programming on affected children.

While the overall goal of this study is to contribute to programming principles for low prevalence and concentrated epidemic countries, the study itself seeks only to present the evidence base and lay out issues that should be considered for program development. In doing so, the report provides an input into the process of developing these principles, but successful development of strategies also requires input from those responsible for implementation in the field. This field is vast in that HIV and AIDS affect children in all parts of the world, and it is nuanced in that children in different regions are not necessarily affected in the same manner. How children are affected depends on many factors, such as:

- *Epidemiological factors* that determine which children are infected, living in HIV-infected households, and/or orphaned by AIDS;
- *Family factors*, which include poverty levels and child care capacity;
- *Cultural factors*, which include child care practices and orphan uptake and care;
- *Community factors*, such as community ability to absorb and care for children affected by HIV/AIDS and community coherence; and
- *Response potential*, such as community, organizational, and government capacity to respond effectively.

Indeed, a reliable and informed evidence base is needed for HIV/AIDS-affected children in all these areas in low prevalence and concentrated epidemic settings.

1.2 Which children are we talking about?

Terms central to the objectives that deserve clarification and definition include “children,” “children affected by HIV and AIDS,” and “low prevalence and concentrated epidemic countries.” Although these terms seem self-explanatory, none has a single and universal definition. The subsections below explain how these terms are used here.

1.2.1 Children

We use the term “children” to encompass individuals from birth to 18 years,² as defined by UNAIDS et al. (2004). The commonality across the range of situations and developmental stages represented by “children” is that they are not legally considered to be adults, who are

² However, not all countries use this definition, and many define childhood as ending at age 15 or 16.

individuals 18 years and older. However, in considering “children” it is important to recognize that their needs vary significantly as they grow older:

Most policies, programs, information and literature concerning orphans and other children made vulnerable to HIV/AIDS have tended to regard them as an undifferentiated homogeneous group. However, the development level of a child or adolescent will influence how he or she reacts to the death of a mother or father or both, to separation from siblings, and to other possible consequences of a parental death (UNAIDS et al., 2004).

While there are many ways to divide childhood into phases of development, and the studies reviewed in this report are inconsistent in doing that, the phases of childhood can be viewed generally as follows³ (AAP, 2007):

1. **Infancy:** This category includes children up to 12 months. The infancy phase covers a period of rapid development and complete dependency on the parent(s). Vulnerability to physical risk is considered very high during this phase. For some issues, the first few hours, days, or months after birth are significantly different from later in infancy.
2. **Early childhood:** This category accounts for children aged 1 to 5.9 years. Early childhood connotes significantly rapid physical and mental development, with slightly less risk of infection than infancy.
3. **Middle childhood:** Children aged 6 to 10.9 years are in middle childhood with continued development toward adolescence.
4. **Adolescence:** This last stage of childhood includes children aged 11 to 17.9 years. This phase is also noted for rapid development, both physical and mental. It is also an age of increasing risk of psychosocial impact and risk-taking behaviors.

We chose these age groupings because they provide a useful distinction in understanding the various challenges faced by children affected by HIV/AIDS across categories of cognitive, emotional, physical, and psychological development. Each phase likewise has its own age-related needs, risks, and vulnerabilities, as well as opportunities for intervention.

1.2.2 “Children affected by HIV and AIDS”

The term “children affected by HIV and AIDS” also merits definition because any term used to describe the group of children we seek to assist appears to be fraught with complications – and the terminology itself has changed many times over the last decade. In this study, we use

Children affected by HIV and AIDS for the purposes of this study include:

- Children infected with HIV or HIV-positive children;
- Children directly affected because one or both of their parents have died from HIV-related illnesses;
- Children directly affected because one of their parents and/or caretakers is infected with HIV; and/or
- Children indirectly affected by HIV/AIDS because they are living in families that foster children directly affected by HIV/AIDS.
- Children whose situation and/or behavior puts them at high risk of exposure to the virus.

³ While these stages are adapted from the American Academy of Pediatrics (AAP, 2007), many divide middle childhood as 6–11 and 12–17 (PEPFAR, 2006).

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a more theoretical definition of “children affected by HIV/AIDS” that is most relevant for low prevalence and concentrated epidemic countries (see Box). Many of the definitions used to describe these same children were developed for high prevalence settings and often more for the needs of monitoring or programming purposes. In this study, we are seeking to understand how much we can know about these children and their needs, and how to reach them, based on evidence from research. The findings can then be translated into information useful to programmers.

Historically, the first group to gain attention was “orphans due to AIDS”: children who had lost one or both parents to AIDS. However, those children who were living in households with HIV were also facing unusually difficult challenges, so vulnerable children were added – “orphans and vulnerable children due to HIV/AIDS.” Yet, the stigma associated with HIV/AIDS led many to remove the reference to AIDS – “orphans and vulnerable children.” This last classification served as a proxy for children affected by HIV/AIDS in high prevalence settings.⁴

In low prevalence settings, the term “orphans and vulnerable children” could easily encompass a group of children for which “children affected by HIV/AIDS” would be only a small subset: children may be orphaned or made vulnerable as a result of other factors that are not related to HIV and AIDS. In this report, we focus on the evidence base related to those children who are affected by HIV/AIDS in general, recognizing that HIV/AIDS-affected children are not the only vulnerable children and that factors such as poverty or inequalities may increase their vulnerabilities, and furthermore these factors tend to overlap.

The literature offers several definitions for “children affected by HIV/AIDS” (UNICEF, 2002; Sherr, 2005a; Richter et al., 2006, PEPFAR, 2006). In addition to the definition in the box above, other categories often cited in high prevalence settings include:

- Children indirectly affected by HIV/AIDS because they are living in communities greatly affected by HIV/AIDS (e.g., losing teachers, health personnel, etc., to HIV and AIDS);
- Children especially vulnerable to exposure to HIV due to their circumstances (living outside of family care, early marriage, sex work, living in the street, etc.).

We have not explicitly included the first category because it is generally less relevant in low prevalence and concentrated epidemic countries. We have included the latter category, although it is often not explicitly included among “children affected by HIV/AIDS.” It includes children who exhibit high-risk behaviors and those whose situation puts them at risk because they are not in a position where they can control their exposure to the virus, such as street children, girls in early marriage, girls living away from their families, etc. Children who are

⁴ This is reflected in the official definition of orphans and children made vulnerable by HIV/AIDS outlined in the *Guide to Monitoring and Evaluation of the National Response for Children Orphaned and Made Vulnerable by HIV/AIDS* (UNICEF et al., 2005), which encompasses children below 18 years who have at least one of the following characteristics:

- Have lost one or both parents;
- Have a chronically ill parent (regardless of whether the child is living with that parent);
- Live in a household where, in the past 12 months, at least one adult has died and had been sick for 3 of the 12 months before dying;
- Live in a household where at least one adult was seriously ill for at least 3 of the last 12 months;
- Lives outside of family care (in an institution or on the streets).

especially vulnerable to becoming infected by HIV may also be directly or indirectly affected by the disease; and conversely, children directly affected by the disease may or may not be especially vulnerable to HIV infection. We have not systematically reviewed the literature around “increased vulnerability to exposure to HIV” but have cited some documents where the issue is discussed.

Even the definition of “orphan” is not standardized, since international norms hold that orphans are children who have lost either or both parents (UNAIDS et al., 2004), while many countries still hold that only children who have lost both parents are orphans, and Bangladesh legally defines an orphan as a child whose father has died (UNICEF, 2005c). Most countries do not distinguish between causes of orphanhood due to unreliable data on causes of death.⁵

These definitions try not only to carve up a complex situation into its components, but also define what is in reality a very dynamic situation where a child can pass from one state to another, and then another, in a short period, and where the categories are not mutually exclusive. For example, a child who is living in a household with adults infected with HIV may become a single orphan and then a double orphan. A child may quite easily fit into more than one subset, possibly leading to increased vulnerability and need for protection.

1.2.3 Low prevalence and concentrated epidemic countries

Another area requiring definition is the countries of focus in this review. “Low- and concentrated-level HIV areas” refers to:

Countries or parts thereof with a low-level HIV epidemic stage or a concentrated HIV epidemic stage. A low-level HIV epidemic stage is one where the HIV prevalence in defined sub-populations is not consistently >5% and a concentrated HIV epidemic stage is one where HIV is not well established in the general population but HIV prevalence is consistently >5% in at least one sub-population and/or consistently >1% in pregnant women (UNAIDS, 2006b).

Countries with low prevalence can include those with specific sub-populations being affected (such as sex workers or injecting drug users) or a more generalized pattern of infection. It should be recognized that categorization is not always easy, particularly since valid and reliable data on HIV and AIDS prevalence are not always available. In addition, although we have limited ourselves mostly to data from low prevalence countries, there are instances where the data from high prevalence countries inform the evidence base in a relevant way, an issue explained in the methodology section.

1.3 Report outline

This report has four parts: The first provides an introduction to the issues relating to the evidence base regarding affected children in the target countries and describes the methods used to examine the evidence base for development of programming strategies. Parts 2 and 3 review the evidence related to two intertwined aspects of programming: quantity and quality. Part 2 focuses on the quantity issue: what do we need to know about *who* are the children affected by HIV/AIDS and how much information currently exists to help identify and quantify programming needs. Part 3 examines specific challenge areas for these children, such as health, nutrition, education, protection, psychosocial support, placement, socio-economic

⁵ India, however, has now specifically identified “orphans due to AIDS.”

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issues, and stigma. It seeks to outline what we know about the challenges children in these countries face and to provide evidence (where available) on what works to address these challenges. Part 4 draws conclusions and outlines implications of the evidence base for programming.

Chapter 2 Methods

Developing evidence-based programming principles requires, first and foremost, accessing and analyzing the evidence. This section describes how documents that might contribute to the evidence base for HIV/AIDS-affected children in low prevalence and concentrated epidemic countries were identified, reviewed, and categorized, as well as the methodology used for analysis and summary.

2.1 Methods for document search

The literature worldwide on orphans, children, and HIV/AIDS is quite large, with most related to eastern and southern Africa, so a first step was to prioritize the literature to be reviewed to guide our search. This step resulted in a prioritization of documents as follows:

1. Peer-reviewed and published literature related to children affected by HIV/AIDS in low prevalence and concentrated epidemic countries,
2. Other literature related to children affected by HIV/AIDS in low prevalence and concentrated epidemic countries produced by academia, governments, international and development organizations, and other non-commercially published sources, and
3. Selected literature related to children affected by HIV/AIDS in high prevalence countries deemed useful to understanding challenges and interventions for such children in low prevalence countries.

Several document sources were used to develop the list of documents for review (in Box 1). The process of identifying and reviewing was on-going, with the list of documents growing as additional literature was located.

UNICEF orphans and vulnerable children

(OVC) database: The first source reviewed was the UNICEF's OVC Division database, comprising 556 documents (August 2006) covering all world

regions: journal articles, reports produced by international and non-governmental organizations, government documents, conference reports, presentations, grey literature, and others. A significant portion focused on high prevalence countries; we found only 25 journal articles and 23 reports (with data) relevant to low prevalence and concentrated epidemic countries. However, we reviewed other documents from the database due to their relevance to the broader topics.

Internet searches: An online internet search began with Google and then expanded to major organizations dealing with orphans and vulnerable children and children affected by HIV/AIDS: other international organizations, major partners, and the Better Care Network. While there are numerous documents available on these websites, most focus on east and southern Africa, and many lack data or reports of data.

Box 1: Document sources
<ul style="list-style-type: none">• UNICEF OVC database (August 2006)• Internet searches: PubMed, Google, WHO, UNICEF, UNAIDS, and other key organizations involved with OVCs and HIV/AIDS• ALADIN shared digital library: HOLLIS, CSA, PsychINFO, Proquest• Networking: with UNICEF regional offices and other key stakeholders• Cochrane Collection• References cited in reviewed studies

Published literature search engines: Published literature searches accessed, using English language and publications after 1996⁶ as criteria, included:

- PubMed (a service from the [U.S.] National Library of Medicine): using keywords “orphans and AIDS” (379 hits) and “children AIDS” (13,244 hits) for which most related to treatment and PMTCT; “children, commercial sex workers, HIV” (42 hits); “children, domestic workers, HIV” (5 hits); “children, IDUs, HIV” (53 hits); “children, migrant workers, HIV” (41 hits); and “street kids, HIV” (13 hits).
- ALADIN (a shared digital library system from the Washington Research Library Consortium), which accesses:
 - ✓ HOLLIS Catalog: using keywords “children & AIDS” (15 hits)
 - ✓ CSA: Social sciences: using keywords “orphans & AIDS” (240 hits) and “social services and targeting” (66 hits)
 - ✓ PsycINFO & PsycARTICLES: using keywords “orphans & AIDS” (89 hits), “children & HIV/AIDS” (459 hits), “children & AIDS” (992 hits), and “HIV and stigma” (31 hits)
 - ✓ Proquest: Social Sciences: using keywords “orphans & AIDS” (10 hits), “children & AIDS” (129 hits), “HIV and stigma” (36 hits), “orphans and social services” (7 hits), and “social services and targeting” (7 hits)
- Cochrane Collaboration:⁷ Cochrane reviews and protocols related to HIV/AIDS (7 hits).

Networking: Because much of what is written on children affected by HIV/AIDS is not published in peer-reviewed journals, several key organizations and individuals, including UNICEF regional orphans and vulnerable children (OVC) advisors and members of the InterAgency Task Team Orphans and Vulnerable Children group, were contacted to identify additional grey literature. A few documents are in French and Spanish.

References cited in documents reviewed: Additional documents were identified through references and bibliographies in the documents reviewed.

2.2 Selecting and summarizing relevant studies by type

Selecting relevant studies: All documents identified by the literature search were scanned for relevance to our objectives. Most were judged not relevant, particularly those found by search engines, because they either address issues in high HIV prevalence countries or clinical management of HIV and AIDS (Table 1). Overall, 414 documents were found relevant to our objectives and reviewed. (Three references (Kafulafula et al. 2007; Kourtis et al. 2007; Thomas et al. 2007) from a single poster session were reported as one document.)

⁶ We excluded earlier literature in the belief that given the evolution of the epidemic and especially access to treatment, more recent literature would provide better guidance to current programming.

⁷ The Cochrane Collaboration is an international not-for-profit organization that produces and disseminates systematic reviews of health care interventions and promotes the search for evidence in the form of clinical trials and other studies of interventions.

Table 1: Results of searches and review selection

Source	Total documents /hits	Reviewed
UNICEF	556	120
URC/QAP, internet, networking finds, citations	157	157
Publication search engines	13,623	131
Cochrane Collaboration	7	6
TOTAL	14,343	414

Study types: situational analyses, intervention evaluations, reviews: Strong evidence describing the situation of children affected by HIV/AIDS is required to understand how these children differ from others. Interventions should have a research design that allows conclusions about causality as well as improvement, and their evaluations should include a clear description of both the intervention and the population it serves. Some documents are comprehensive reviews of studies on a particular topic, but the review itself can be done with more or less quality. Most of the reviewed documents analyzed the situation of children affected by HIV/AIDS (72%), of which 16% also provided some discussion of interventions. Only 25% focused exclusively on interventions.

Summarizing relevant studies: The studies judged to be relevant to our objectives were each read by one or more project staff who completed a summary or checksheet (see Appendix 2), which includes scores on relevance and quality for the summarized document as well as identifying data, a summary of the study findings and methodology, and its relevance to our review.

2.3 Quality of Evidence

Each document was judged according to two indicators of quality: one assessed the quality (or “rigor”) of the study documentation as manifested in an article or report, and the other assessed the quality of the evidence the study produced, as best as we could determine from the document.

2.3.1 Quality of documentation

Definition and measurement of documentation quality: Our definition of documentation quality uses criteria applicable to a variety of study methods, from randomized controlled trials to qualitative anthropological studies. It thus allows examination of the quality of the literature and evidence describing the challenges that children affected by HIV/AIDS face, the effectiveness of interventions to address these challenges, and formal literature reviews of portions of this literature. To judge the quality of the documentation for different types of studies, we developed a checksheet (Appendix 1) and applied it in summarizing each document. The resulting documentation quality score is referred to as the “rigor” of the study. This score reflects how well the study was conducted, analyzed, and documented within the scope of its design. Most of the evidence of interest was observational and descriptive in nature, rather than experimental and thus subject to biases inherent in such design. The checksheet helped us consider these limitations as it was designed primarily to measure the study’s quality relative to studies with a similar design. For example, a qualitative study that used methods appropriate for qualitative research with well-substantiated conclusions would earn a high rigor score. The criteria differed somewhat depending on whether the study was a situational

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analysis, an intervention evaluation, or a literature review. Many documents addressed both a situation and an intervention, in which case its rigor score reflected the documentation quality for both. Modified criteria were used to devise a rigor score for literature reviews (discussed below).

The checklist has a 16-point additive series of standards comprising four main standards:

- *Focused issue:* The extent to which the study had adequate information on the population studied, the intervention or situation under observation, previous studies or theory, and the outcomes to be considered.
- *Methodology:* The extent to which the study had appropriate research methods for the question being asked: this would include purposefully selected sample participants, adequate sample size, response or participation rates, and appropriate methods to minimize bias.
- *Analysis:* The extent to which the study explored different sources of knowledge and understanding about the research topic; it applied appropriate qualitative or quantitative analytical tools; its analysis accounted for potential biases; and its results and key findings were thoroughly presented.
- *Review of the evidence:* The extent to which sufficient original evidence was provided to justify the relationship between the evidence and the conclusion; the discussion of findings included study implications for policy or programming, limitations relating to interpretability or generalizability, and areas for further research.

For the literature reviews we also assessed the thoroughness of the literature search, use of an analytical framework, and consideration of the strength of the evidence.

Based on the rigor score, all three types of studies were categorized as having “good” (12 to 16 points), “fair” (8 to 11 points), or “poor” rigor (less than 8 points). The rigor score was estimated based on attributes of the study related to the topic of this review.

Rigor of situational analyses and intervention evaluations: Table 2 presents the level of rigor of documentation found in the different types of studies reviewed. One study addressed methodologies for defining rigor and is not included in the Table.

Table 2: Types of studies and relative rigor categories

RIGOR	Situation	Intervention	Situation + intervention*	Total
Good	54% (137)	52% (54)	43% (23)	52% (214)
Fair	22% (56)	29% (30)	37% (20)	26% (106)
Poor	25% (63)	18% (19)	20% (11)	23% (93)
TOTAL	62% (256)	25% (103)	13% (54)	100% (413)

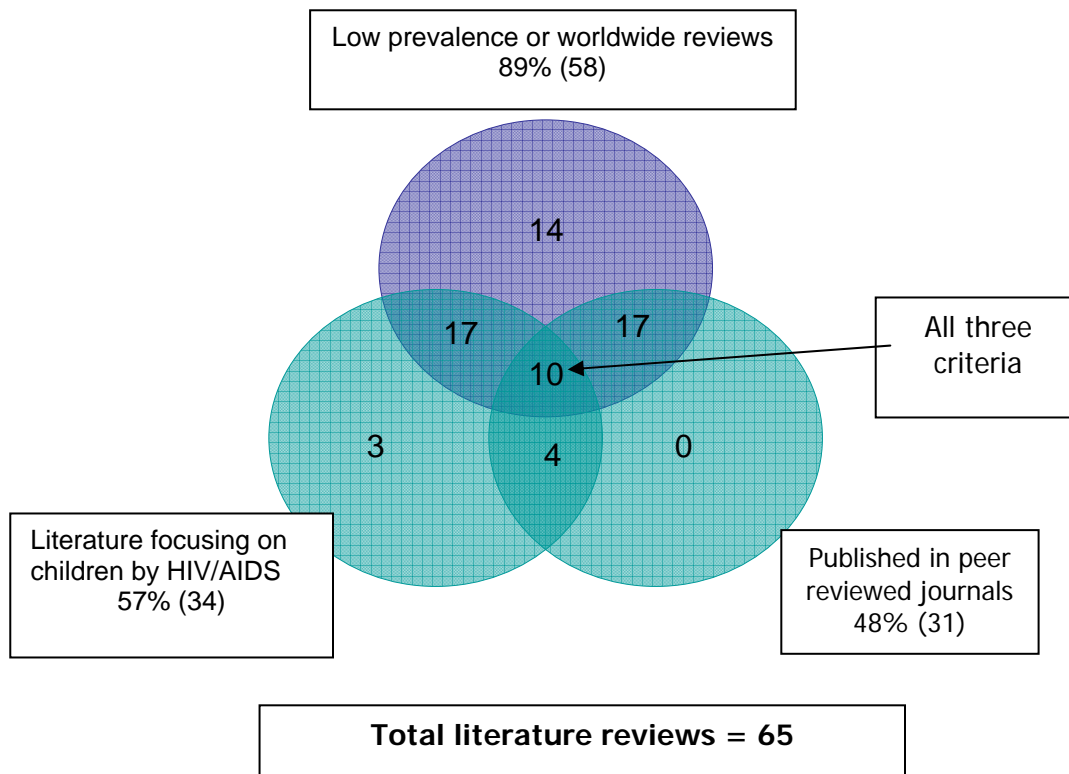
* Most combined studies had little beyond a description of the intervention(s).

The most common weaknesses were inadequate description of the methodology, insufficient analysis, or limited report of findings. Some studies also had insufficient evidence to support conclusions or failed to discuss study limitations, including information on magnitude or sample size. Several studies with strong designs lacked statistical analysis of results. Many articles that

covered both the situation and an intervention(s) had strong evidence on the situation but weak evidence on the intervention.

Rigor of literature reviews: We reviewed 65 literature reviews, including documents with some analysis but that we judged to be primarily reviews. Thirty-one were published in peer-reviewed journals: most focusing on issues concerning children affected by HIV/AIDS, such as stigma, but not directly on the impact these issues have on children. Sixty percent of the literature reviews focusing on children affected by HIV/AIDS were published by organizations, rather than published commercially or in peer-reviewed journals. Almost all literature reviews had some discussion of the rigor and levels of evidence in their methodology sections, but most, with the exception of the six Cochrane reviews, reported conclusions without weighing the strength of the evidence. Figure 1 presents an assessment of the literature reviews identified in our search and indicates only 15% of reviews had all three relevant criteria.

Figure 1: Assessment of literature reviews



2.3.1 Quality of study methodology or level of evidence produced by it

We judged the quality of each study's *methodology* according to generally accepted standards for "level of evidence." Table 3 presents our categorization of the 414 documents reviewed. The five levels of methodological evidence were defined by the Royal Australian College of General Practitioners (2002); we added a sixth level to accommodate documents not considered by the College. The highest levels of evidence were reserved for studies that included controls, thus enabling comparison of HIV affected children to non-affected and the assessment of the marginal impact of interventions; these studies are listed in Appendix 3. The right-hand column shows how we judged study methodologies. While we considered using other methodological

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issues, such as actual sample size and retention rate per study arm, exposure to intervention (“dose effect”), sufficient “up-to-speed” duration for the intervention, and conservative assumptions when calculating statistical significance, as further accepted standards for judging the quality of evidence (Lyles et al., 2007; Des Jarlais et al., 2004), few of the intervention studies reviewed used methodologies that would have merited such detailed analysis.

It should be noted, however, that standards of evidence were designed for evaluating evidence related to interventions. Yet, strong evidence describing the situations of children affected by HIV/AIDS is needed, including studies over time and controlled cross-sectional studies (Level III). Such evidence can help us understand how these children differ from others and which interventions are most likely to transfer to similar situations. Therefore, all situational analyses, as well as intervention evaluations, were categorized by this quality of methodology definition.

When these levels of evidence (or quality of the methodology) were applied to the reviewed studies, the results indicated that strong evidence is very thin with regard to programming for children affected by HIV/AIDS in low prevalence and concentrated epidemic countries: only 20% of the studies categorized for methodological quality were in the top three levels.

Table 3: Levels of methodological evidence for documents reviewed *

Levels of Evidence			
Level	Percent of documents reviewed	Generally accepted categories of evidence	Types of studies reviewed for this document
I	1% (3)	Evidence from a systematic review of <i>all</i> relevant randomized controlled trials	Cochrane reviews
II	4% (16)	Evidence from at least one properly designed randomized controlled trial	Randomized controlled trials
III	15% (64)	Evidence from any of the following: <ul style="list-style-type: none"> • well designed pseudo-randomized controlled trials • comparative studies with concurrent controls and allocation not randomized (cohort studies), case-control studies or integrated time series with control group • comparative studies with historical control, two or more single arm studies, or interrupted time series without a parallel control group 	Studies with controls over time, cross-sectional studies with controls, cohort studies Quasi-experimental design
IV	5% (21)	Evidence obtained from case series, either post-test or pre-test and post-test	Time series without control group, modeling
V	67% (278)	Opinions of respected authorities, based on experience, descriptive studies, or reports of expert committees	Descriptive qualitative and quantitative studies (situation analyses), non-experimental direct or indirect analysis (intervention evaluations), case studies, most lit reviews
OTHER	8% (32)	Added category	Policy documents, conceptual frameworks, conference and meeting notes, assessment of methods, etc.

* Based on categories defined in Royal Australian College of General Practitioners (2002)

2.4 Reporting findings according to the strength of evidence

- **Strength of the evidence (strong, moderate, gaps):** Parts 2 and 3 of this report (Who are the children affected by HIV/AIDS? and What challenges do they face?) consider the strength of the evidence in the analysis and review of findings. Each section begins with an introduction of the kind of information needed to inform programming, generally focused on the magnitude of the problem and of the disparities between children affected by HIV/AIDS and other children, and on the barriers that prevent the former from receiving necessary services. This section is followed by three sections of reported findings based on the strength of evidence, both for the situation and for interventions: 1) findings with strong evidence, 2) recurrent themes for which evidence is moderate, and 3) gaps in knowledge for which evidence is weak or inexistent. Of course, programmers also need information on the efficiency, efficaciousness, and efficacy of interventions.
- “Findings with strong evidence” indicates evidence that is relevant to the kind of information needed for programming and that has been carried out rigorously and in accordance with widely accepted research practices. This includes appropriate control of biases that are specific to the issue under research. For example, some research areas may require randomized, clinical study over time, while others may require in-depth qualitative study across groups. Reported findings in this section predominately include studies with a “good” rating and required studies within the standards of evidence mentioned in Table 3, Levels I–IV and usually multiple studies confirming similar findings. Note that with regard to an intervention, evidence may strongly support or strongly negate its cost-effectiveness.
- “Recurrent themes for which evidence is moderate” refers to program-relevant findings commonly asserted in the literature lacking sufficient empirical data to rule out competing explanations for attribution and causality. This includes studies with a small sample size(s), limited measurement, lack of comparison groups, or lack of observations over time. Studies with “good” and “fair” rigor scores are included in this section since, by design, some study methods are subject to biases but were nonetheless well conducted. As much as possible, we have highlighted on a case-by-case basis aspects of studies that strengthen the evidence base for the priority area under review, as well as studies’ weaknesses that limit our ability to draw strong conclusions. An emphasis is placed not only on the aggregate rating for an individual study, but the consistency of findings across contexts. As with strong evidence, moderate evidence may be either positive or negative with regard to an intervention.
- “Gaps in knowledge for which evidence is weak or inexistent” refers to either claims made by authors for which they provided little or no evidence (but which may have important implications for programming) or to information needs for which no data were obtained during this review. In this section, studies with “poor” rigor ratings were useful for highlighting areas for further research, although recommendations from higher quality articles are also discussed.

2.5 Potential biases in findings

There are several potential biases in the conclusions we are drawing in this report, due to the nature of both publication and documentation. The literature itself has biases, and there are biases related to the body of literature (available) that was selected for review:

- *Publication bias:* Published and unpublished literature tends to focus on what people think serves their purposes. Published or circulated literature on the situation of children tends to focus on those children's differences and difficulties, and literature on interventions tends to focus on interventions that were shown to be effective. Thus, it is possible that negative results, even for interventions found to be effective elsewhere, are not circulated or published.
- *Language bias:* Documents reviewed were mainly in English. We reviewed a handful in French and Spanish, but these could not be considered representative of the literature in those languages, and other languages were not reviewed at all. Thus, this review may not adequately cover Latin America, Francophone Africa, or other regions where evidence may be reported in local languages.
- *Availability bias:* It is difficult to identify and obtain unpublished or grey literature even with the help of networking. In our experience, literature published by regional or country offices under the auspices of international organizations or international NGOs was often not available on web sites.

PART 2: WHO ARE THE CHILDREN AFFECTED BY HIV/AIDS?

Orphans and vulnerable children (OVC) include a wide range of children, some whose vulnerability is due to HIV/AIDS-related factors – such as HIV/AIDS-related stigma, discrimination, abandonment, illness, or death – while others experience increased vulnerability due to non-HIV/AIDS-related factors such as poverty, violence, substance abuse, or illness and death due to other diseases. Although section 1.2.1 defines “children affected by HIV/AIDS,” no single definition is always used in the documents reviewed, and the definition used has significant effect on who is counted. For example, children affected by HIV/AIDS in south Asia have been defined as children who are infected, whose parents are HIV-positive, or who have been orphaned by AIDS (UNICEF, 2007b); whereas some countries, such as Bangladesh and Nepal, also include children at risk of infection, and UNICEF et al. (2005) includes children living in households with HIV-positive adults and children living outside of family care. In addition to official definitions, communities may interpret the term “orphan” differently than officials (Skinner et al., 2006), and children themselves have a perspective on what makes them at risk or vulnerable (SCF/UK, 2006a).

Chapter 3 Evidence on the situation of children

“Who are the children” affected by HIV/AIDS is one of the primary questions that must be answered to develop good programming strategies to support some of the world’s most vulnerable populations. This section aims to provide an overview of the magnitude of the situation in low prevalence and concentrated epidemic settings – what sub-categories of children are affected by or vulnerable to infection, and what data concerning the prevalence of affected children are still lacking.⁸

Effective and efficient programming and resource allocation decisions about affected children in low prevalence settings require information on who these children are. Such data for many countries are available, although several gaps exist, both at the national level and across categories of children. Evidence reviewed in this chapter comes mainly from official statistics.

Evidence reviewed to describe “Who are the children affected by HIV/AIDS?” (n = 43)

Authors	Rigor	Type (Location)
Akwara et al. 2005	Good	Descriptive quantitative (Ghana)
Bruce & Chong 2003	Good	Descriptive quantitative (worldwide)
Carswell et al. 2005	Fair	Descriptive qualitative (Cambodia)
Cornia et al. 2002	Fair	Descriptive qualitative (China)
de Lind van Wijngaarden 2007a	Good	Descriptive qualitative/quantitative (Vietnam)
Dutt et al. 2007	Good	Cochrane research protocol (worldwide)
Gulaid 2006	Fair	Descriptive qualitative (East Asia, Pacific)
Hong et al. 2007	Good	Descriptive quantitative (Ghana)
Hunter & Williamson 2000	Good	Descriptive quantitative (worldwide)

⁸ While our intent was to examine the evidence only within the context of low prevalence and concentrated epidemic communities, some of the available data are intermingled with information on children living in high prevalence countries, especially in the regional characterizations of many of the documents tracking global trends.

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Knodel & Saengtienchai 2005	Good	Descriptive qualitative (Thailand)
Lambert et al. 2005	Good	Descriptive quantitative (Bolivia)
Loudon et al. 2007	Fair	Descriptive qualitative/quantitative (India)
Monasch & Boerma 2004	Good	Descriptive quantitative (worldwide)
Nostlinger et al. 2006	Good	Controlled cross-sectional quantitative (western Europe)
Pelton & Forehand 2005	Good	Descriptive qualitative (US)
Pisani et al. 2003	Good	Descriptive qualitative (worldwide)
Pivnick & Villegas 2000	Good	Cohort intervention study (US)
Population Council 2003a–e	Good	Descriptive quantitative (Mozambique, Mali, Cameroon, Nigeria, Nicaragua)
Sanigest 2006	Good	Descriptive qualitative (Central America)
SCF/UK 2006a	Fair	Descriptive qualitative (China)
SCF/UK 2006c	Fair	Descriptive qualitative (Indonesia)
SCF/UK 2006e	Fair	Descriptive qualitative (Southeast Asia)
Skinner et al. 2006	Good	Descriptive qualitative (Botswana, South Africa, Zimbabwe)
UNAIDS et al. 2004	Good	Descriptive quantitative (worldwide)
UNAIDS 2006a	Good	Descriptive qualitative/quantitative (worldwide)
UNAIDS & WHO 2006	Good	Descriptive quantitative (worldwide)
UNAIDS & UNICEF estimates 2006	--	(See UNICEF & UNAIDS 2006)
UNAIDS et al. 2007	Good	Descriptive quantitative (worldwide)
UNFPA 2003	Good	Descriptive quantitative (worldwide)
UNFPA 2006	Good	Descriptive qualitative (worldwide)
UNICEF 2002	Good	Descriptive qualitative (Nepal)
UNICEF/Belize 2004a	Fair	Descriptive quantitative/qualitative (Belize)
UNICEF 2005c	Good	Descriptive quantitative (Bangladesh)
UNICEF 2005d	Good	Descriptive quantitative/qualitative (LAC)
UNICEF 2005g	Fair	Literature review (Papua New Guinea)
UNICEF & UNAIDS 2006	Fair	Descriptive qual/quant Ppt (Thailand)
UNICEF et al. 2005	Good	Descriptive qualitative/quantitative (worldwide)
UNICEF et al. 2006	Good	Descriptive qual/quant (sub-Saharan Africa)
UNICEF 2007b	Fair	Literature Review (South Asia)
UNICEF & SCF 2007	Good	Descriptive quantitative (Lao PDR)
USAID-AED 2004	Fair	Literature review (Africa)
Verma et al. 2002	Fair	Descriptive quantitative (India)
WHO et al. 2007	Good	Descriptive quantitative (worldwide)
Zaba et al. 2005	Good	Descriptive quantitative (Uganda, Tanzania, Malawi)

3.1 Information needed on “Who are the children affected by HIV/AIDS?”

We have outlined six key information areas that are critical in determining “*Who are the children affected by HIV/AIDS?*” (Dutt et al., 2007). These include:

HIV status of children: We consider it important to programming to distinguish between children who are infected with HIV and those who are not infected but are directly or indirectly affected by HIV/AIDS. HIV-positive children have specialized care and treatment needs that do

not pertain to uninfected children. Also, information on predominant sources of infection, such as among adolescents, is relevant for programming for uninfected youth who are particularly vulnerable to HIV infection.

Orphanhood status of children: Knowledge of the orphanhood status of children is important in designing programming strategies to support children who are without parental guardianship or care. Orphaned children may be maternal (i.e., deceased mother), paternal orphans (i.e., deceased father), or double orphans (i.e., deceased mother and father), which has implications for where children reside and their access to and need for additional support services.

Caretaking situation of children: A detailed review of challenges related to the caretaking situation of affected children is examined in Chapter 10 on placement. Important questions include: What proportion of children is living with HIV-infected parents, grandparents, or other extended family? Are affected children residing in foster care or long-term institutions? How many children are living on the street and without care? Information on children's caretaking situation also considers whether households are female-, male-, or child-headed.

Vulnerability to HIV infection: In addition to the needs of children infected with HIV and/or living in households with HIV-infected individuals, there is a glaring need for more systematic information about children at-risk for HIV infection; and they are sometimes considered "vulnerable" to HIV and sometimes not. These are children who, because of their participation in high-risk behaviors, are at increased risk for HIV infection compared to children not engaging in these behaviors. Children at-risk also include those whose placement, HIV-compromised parental protection, or age group (e.g., early adolescent girls) increases their vulnerability through financial or sexual exploitation, lack of supervision, rape, abuse, early marriage, and/or substance abuse.

Geographic concentration or dispersion: Where do children affected by HIV/AIDS live: in rural or urban areas? Which communities or regions? There is abundant evidence that programs often need to be tailored to the location of residence. However, in concentrated epidemic countries, the location of children may be difficult to know if parents do not fall into an identifiable population category or are difficult to reach due to stigma/discrimination or mobility.

Stage of development: To develop effective strategies to support HIV/AIDS-affected children, it is imperative to systematically gather data on affected children by age group and gender, since a child's phase of development will substantially influence the challenges he or she faces and what interventions will be appropriate for mitigating those challenges.

These categories are not mutually exclusive. In fact, they are often additive, and in some cases the needs of affected children overlap. Yet, programming for particular groups of HIV/AIDS-affected children requires information on the magnitude of the problem and distribution of relative vulnerability across categories.

3.2 Information available on "Who are the children affected by HIV/AIDS?"

While both UNAIDS and PEPFAR have sets of indicators for children affected by HIV/AIDS, surveillance and data collection systems at the country level lag behind, creating severe data

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limitations, especially in countries less hard hit by HIV/AIDS, at least in the short term. Merely identifying children affected by HIV/AIDS is very difficult, complicated by inadequate, often incomplete data upon which programming decisions must be made (Sanigest, 2006; Gulaid, 2006; UNICEF, 2002).

Table 4 summarizes the number of countries from which definitive data are available at the international level on selected indicators relevant to programming for children affected by HIV/AIDS (by region).

Table 4: Number of countries with data on children affected by HIV/AIDS

Low prevalence and concentrated epidemic countries: Indicators for HIV/AIDS-affected children						
		Estimated adult HIV prevalence*	Estimated # of children who have lost one or both parents due to all causes**	Estimated # children 0–17 orphaned by AIDS*	Estimated # HIV-positive children 0–14*	Estimated # children < 15 living with HIV-positive parent(s)
	Total # countries	# countries with data	# countries with data	# countries with data	# countries with data	# countries with data
Africa	36	32	30	25	27	0
Asia	21	19	0	0	1	0
LAC	27	27	0	0	10	0

Estimates are 2005 unless otherwise noted.

* Source: UNAIDS & WHO, 2006.

** Source: UNAIDS et al., 2007.

The data gaps on even a modest number of basic indicators are significant and much larger in some regions than others. According to the 2006 *Report on the Global AIDS Epidemic* (UNAIDS, 2006a), over half of African countries had official data on the estimated number of HIV-positive children (ages 0–14) but only one Asian country (Thailand) had such data. No countries had official data on the number of children living with HIV-positive parent(s) or, in the Latin American/Caribbean and Asia regions, definitive data on the number of children orphaned by all causes or AIDS within countries.

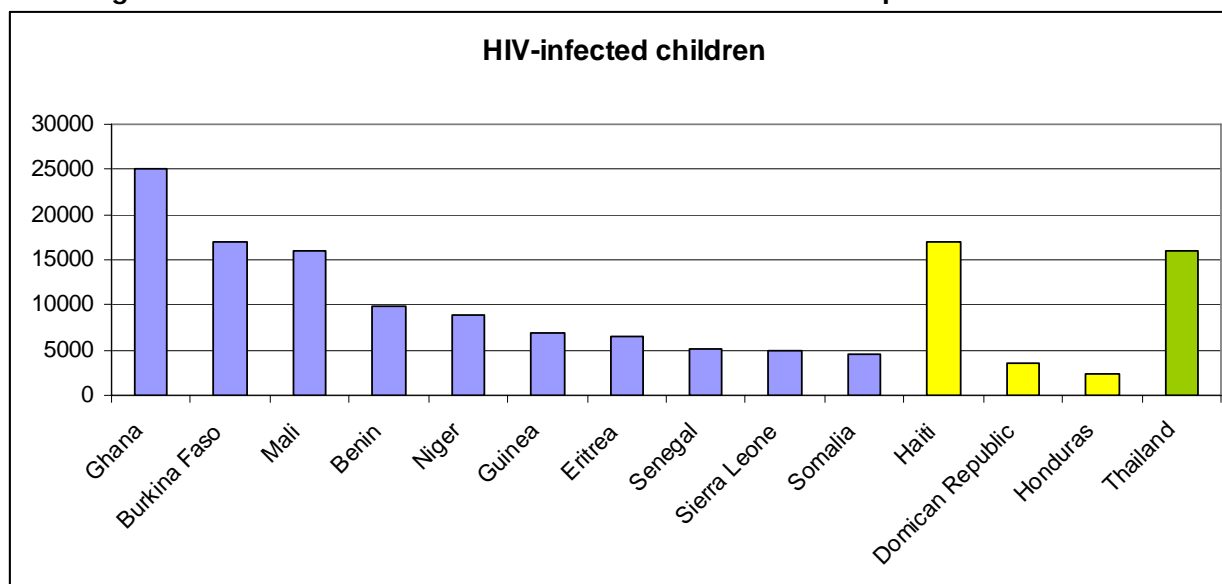
Nonetheless, our search identified several documents with unofficial estimates or “educated guesses” of the number of children orphaned by AIDS, living with HIV infection or other categories of vulnerability for countries not included in Table 1. Estimates were based on the reported numbers of HIV-positive adults who are living with or who have died from AIDS and who had children and/or sero-prevalence among adults in high-risk groups (Loudon et al., 2007; UNICEF/Belize, 2004a; UNICEF, 2005g). For instance, in Belize, national stakeholders estimated that AIDS caused nearly 600 maternal orphans and approximately 2000 paternal orphans by assuming that women of child-bearing age who had died of AIDS had on average 2.5 children and that men who had died of AIDS had fathered on average five children (UNICEF/Belize, 2004a).

In India, although there is little agreement on exact numbers, estimates on the number of HIV-infected children fall between 50,000 and 300,000 (Loudon et al., 2007). As much as possible, these numbers try to account for under-reporting of AIDS-related deaths and double-counting of orphaned children who may have two deceased parents. Similar processes were used to estimate the number of children living with HIV-positive parents and, for very young children, those at risk for vertically transmitted HIV infection.

3.2.1 Children living with HIV

National data are reported to UNAIDS on the numbers of children infected with HIV, although in reality only a small number of children are actually tested. In 2006, the number of children worldwide under 15 estimated to be infected was 2.3 million. Approximately 530,000 children under 15 were newly infected in 2006, and 380,000 died of AIDS in 2006. Figure 2 presents the numbers of infected children in selected low prevalence countries in the Africa, Asia, and LAC regions in 2005 (UNAIDS, 2006a). In the Africa region, Ghana and Burkina Faso had the highest number of HIV-infected children among low prevalence countries with official data on infected children, in addition to Haiti in the LAC region and Thailand in the Asia region. There are also unofficial estimates as mentioned above.

Figure 2: Numbers of HIV-infected children in selected low prevalence countries



Source: UNAIDS, 2006a.

Of the estimated 2.3 million infected children, more than 90% are thought to have become infected through mother-to-child transmission (MTCT) (WHO et al., 2007). Young children who become infected likely did so through blood transfusion, non-sterile needles and syringes, and sexual abuse, while older children may do so through high-risk behaviors such as sex work, drug abuse, or unprotected sex. Because a large proportion of children have not been tested for HIV infection, reliable estimates of the number of HIV-infected children are generally not available.

New HIV infections worldwide are increasingly concentrated among youth (15–24 years), accounting for 40% of all new infections among people 15 years and older in 2006 (UNAIDS, 2006a). The percentage who are newly infected aged 15–18 years is unknown.

Importantly, in countries with very low HIV prevalence and low implementation of prevention of mother-to-child transmission, the proportion of children living with HIV may be relatively small in comparison to other categories of children affected by HIV/AIDS. In South Asia, HIV-positive children accounted for less than 15% of all HIV/AIDS-affected children (UNICEF, 2007b). In many Latin American countries, unofficial estimates of children who are HIV-positive are also

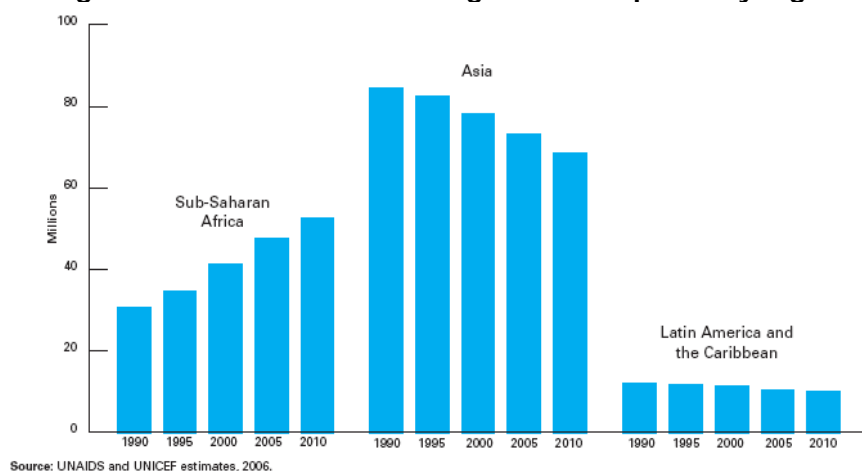
small (UNICEF, 2005d). However, poor monitoring and surveillance systems may result in significant under-reporting of HIV-positive children.

3.2.2. Children orphaned by AIDS

As shown in Table 4 from the 2006 *Report on the Global AIDS Epidemic* (UNAIDS & WHO, 2006), all low prevalence countries with official data on the numbers of children who have lost one or both parents to AIDS are in the Africa region: no countries in Asia or LAC had official, national level data on the orphanhood status of children due to parental deaths from all causes or AIDS.

Figure 3 shows the relative number and growth of orphans across regions, based on UNICEF and UNAIDS estimates. Although Africa is the only region with an increasing number of orphans, Asia still houses the largest number.

Figure 3: Relative number and growth of orphans by region



Source: UNAIDS and UNICEF estimates, 2006.

* Unless otherwise indicated, the figures on orphans in this document include orphans from all causes.

Source: UNICEF & UNAIDS, 2006.

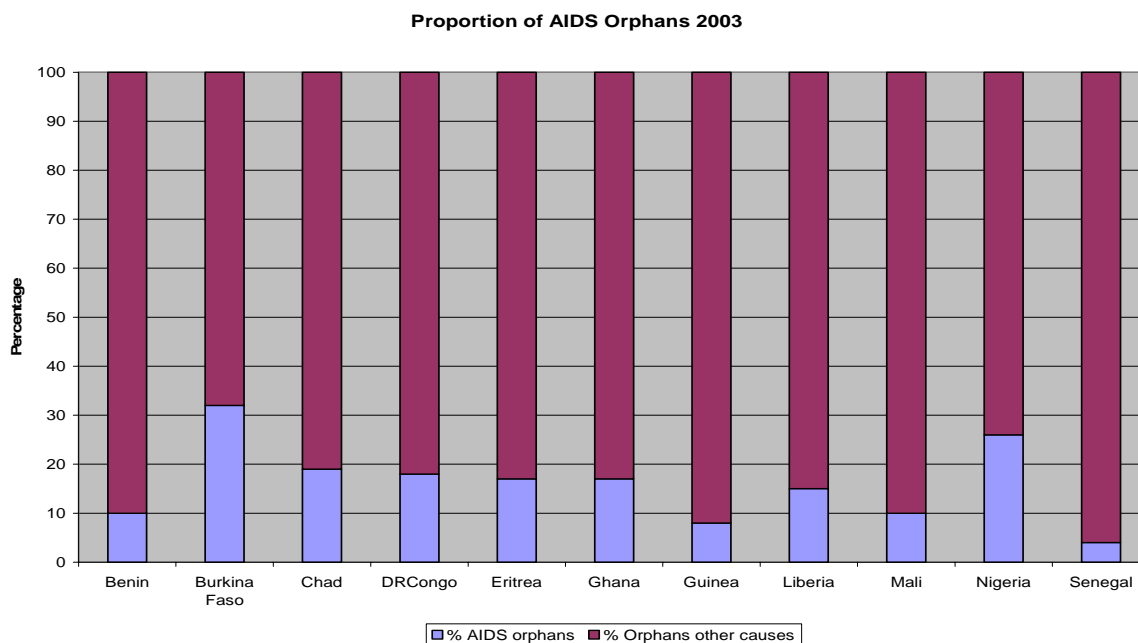
According to one major review (UNAIDS et al., 2004), the number of orphans due to AIDS is expected to continue rising for at least the next decade. Data from three Latin American countries showed substantial increases in the percentage of orphans due to AIDS among all orphans between 2001 and 2005 (Sanigest, 2006):⁹ during that time, the percentage of orphans due to AIDS as a percentage of all orphans rose from 8–9% to 11–14% in Guatemala, El Salvador, and Cost Rica. This trend is also perceptible in other regions, although in many low prevalence settings, children orphaned due to AIDS still account for a relatively small portion of all orphans.

Figure 4 shows UNAIDS estimates of the proportion of orphans due to AIDS to all orphans in several low prevalence countries in sub-Saharan Africa. Here, orphans due to AIDS are less than 35% of the orphan population and in many countries even lower than 10% (compared to estimates of 50–80% in high prevalence countries) (UNICEF & UNAIDS, 2006).

Figure 4: Children orphaned by AIDS in selected low prevalence African countries

⁹ The author notes that the causal factor for this trend could be better reporting of children orphaned by AIDS.

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Source: UNAIDS et al., 2004.

3.2.3 Children living with HIV-positive parents or other adults

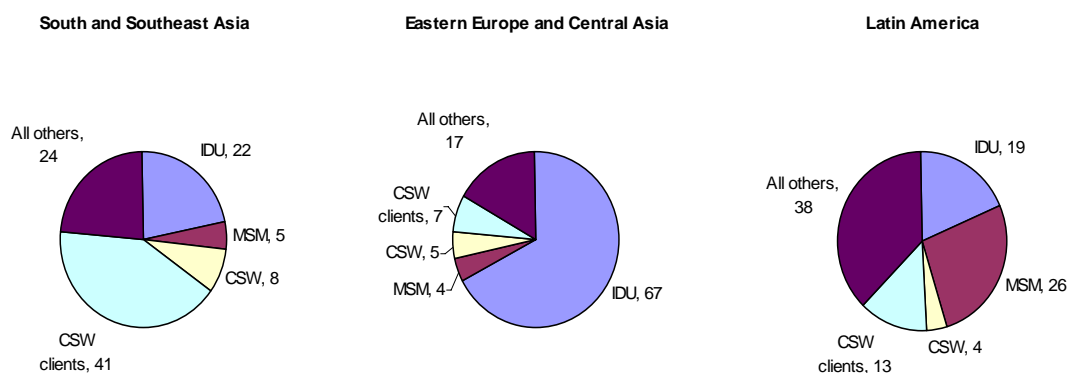
The number of children living with HIV-positive parents is not officially reported, and countries make estimates based on numbers of HIV-positive adults and assumptions of 1–3 children per adult. The caretaking situation of HIV/AIDS-affected children is not routinely collected, but effectively programming for them requires understanding the households where they live and who is taking care of them, both of which mediate many of the challenges these children face.

Children living with HIV-positive parents: In many settings, uninfected children living with HIV-positive parents make up the largest proportion of HIV/AIDS-affected children (UNICEF, 2007b). This is true particularly as improvement in the prevention of vertical transmission results in decreases in the number of children infected at birth and during infancy and as improvements in access and effectiveness of antiretroviral therapy leads to a greater number of HIV-positive adults who survive and care for their children. Anecdotal and moderate evidence from several countries indicates that HIV-infected parents tend to be in poorer socioeconomic strata and are additionally members of high risk adult populations such as sex workers and/or injecting drug users who may live near ports or other “transition areas” (SCF/UK, 2006e). More details are available in Chapter 6 on Socioeconomic Situation.

In addition, because of the feminization of the HIV epidemic in some settings, children living with HIV-positive parents are more likely to be living with women. “Globally, more adult women (15 years and older) than ever before are now living with HIV. In sub-Saharan Africa, for every ten adult men living with HIV, there are 14 women infected with HIV,” and this ratio holds equally for both high and low prevalence countries in sub-Saharan Africa (UNAIDS, 2006a). On the other hand, in many Asian countries, it is still men who are predominately infected and who are also parents, with implications for children living in male-HIV-infected caretaking situations (UNICEF, 2007b).

Children living with high risk adults: The socio-demographic characteristics of the guardians of HIV/AIDS-affected children, including the distribution of children among adults within specific high risk groups, vary substantially by geographic region. Thus, the proportion of children living within specific categories of risk among adult caretakers is context-specific. For example, as shown in Figure 5, in south and southeast Asia in 2005, 41% of HIV infections in adults are among clients of sex workers, and 22% are among injecting drug users, while in eastern Europe and central Asia, 67% of HIV infections in adults are among injecting drug users compared to 7% of sex worker clients and 5% of sex workers. In Latin America, 26% of adult infections occur in men having sex with men compared to 19% in injecting drug users, 13% in sex worker clients, and 4% in sex workers (UNAIDS, 2006a).

Figure 5: Proportion of HIV infections in adults by population group & region, 2005



Note: IDU – Injecting drug users; MSM – Men having sex with men; CSW – Commercial sex workers

Note: India was omitted from this analysis because the scale of its epidemic (largely heterosexual) masks the extent to which other at-risk populations figure in the region's epidemics.

Source: UNAIDS, 2006a.

High-risk adults may also include migrants whose “spatial mobility” is a major risk factor for HIV infection. For example, migrant laborers account for 35% of the HIV-infected population in Lao People’s Democratic Republic (Lao PDR) (UNICEF-SCF, 2007), and in some provinces in China, migrants accounted for up to 50% of those found to be HIV-positive (Cornia et al., 2002).

Children living with extended families: Most children orphaned by AIDS live with their extended families, usually grandparents, especially grandmothers. Data from DHS surveys in Burkina Faso, Cameroon, Ethiopia, Ghana, Kenya, Malawi, Mozambique, Nigeria, and Uganda, presented in UNICEF et al. (2006), can be examined to assess the impact of AIDS on the prevalence of orphanhood and care patterns in high and low prevalence countries in sub-Saharan Africa: while over 85% of orphans not living with the surviving parent¹⁰ were living with extended family, data indicate that grandparents are more likely to be caretakers in high prevalence countries (in more than 50% of cases), whereas in low prevalence countries grandparents were caring for 20–40%. It should be noted that the parent’s cause of death is not available in these datasets. The second most important caretaker group was “other relatives,” such as aunts or siblings. Data from a comparison of 40 African countries with older DHS data (Monasch & Boerma, 2004) indicate that orphans more frequently live in households that are female-headed, larger, and have a less favorable dependency ratio – that is, the

¹⁰ Double orphans or single orphans not living with surviving parent.

number children (under age 18) and senior-aged adults (over age 60) divided by the of number of working-class adults aged 18–59 – and that these patterns are similar across west, central, eastern, and southern Africa.

Nationally representative qualitative findings from Thailand reiterate the role of grandparents in the care of orphans, but also in the care of their adult children with HIV/AIDS (60% of terminally ill parents lived with their own parents, the grandparents of the children, at the time of their death). In most cases, grandparents “inherit” their grandchildren when their adult children become ill with AIDS, when the parent is still living but too ill to care for the children and when only one parent dies from AIDS (Monasch & Boerma, 2004). Grandparents were the main caretakers for 55% of all orphans due to AIDS and 67% of double orphans due to AIDS, although siblings, especially sisters, also become caretakers for their HIV-infected brothers and sisters, as well as for their children (Knodel & Saengthienchai, 2005). A descriptive qualitative survey in Cambodia found that orphans were significantly more likely relative to non-orphans to live with a guardian over the age of 60 and that a significantly higher proportion of orphaned children were living with guardians in poor health than non-orphaned children (Carswell et al., 2005).

Other caretaking situations: Not all HIV/AIDS-affected children are living with adults or with their family. Some are heads of households themselves, particularly where the care capacity of a community is saturated by AIDS-related orphans. Other affected children may live in institutions or on the street, such as abandoned children and those displaced by war.

Non-orphaned youth separated from parents: A surprising number of young adolescents – orphaned and not orphaned – do not live with their parents and, depending on the society, may be especially vulnerable to HIV infection. Table 5 shows the percentage of 10–14 year olds who live with neither parent in a number of low prevalence countries (UNFPA, 2006), although it does not mention whether the parents are living or not.

Table 5: Percentage of children 10–14 not living with parents, selected countries

Country	DHS survey year	% who live with neither parent (girls/boys)
Benin	1996	32/18
Burkina Faso	1998–99	21/15
Ghana	1998	29/21
Mali	2001	19/14
Nigeria	1999	21/17
Senegal	1997	22/21
Colombia	2000	14/11
Dominican Republic	1996	25/20
Peru	2000	11/9
Indonesia	1997	7/7
Egypt	2000	2/1

In almost all countries, girls were more likely to be separated from parents than boys. In Benin, the percentage of girls not living with parents is nearly 2-fold higher than boys, and in

other countries, girls have a significantly higher percentage of separation than boys. This may be due in part to early marriage of girls or when girls perform caretaking roles in other related households. However, the data highlight an important phenomenon regarding the orphanhood status of affected children: youth who are not effectively orphaned but are separated from parents may have similar challenges to those whose parents have died from AIDS.

3.2.4 Children vulnerable to HIV infection

Youth engaging in high risk behaviors: New HIV infections worldwide are increasingly concentrated among youth (15–24 years), accounting for 40% of all new infections among people 15 years and older in 2006 (UNAIDS, 2006a). Older adolescents contract HIV through risky behavior (unprotected sex, drug use, etc.) and often lack the information or skills to protect themselves (UNFPA, 2003; Dutt et al., 2007). In HIV sero-prevalence surveys of 2440 persons in high risk groups in Bolivia, street youth were the most at risk for transmission of HIV and had a higher HIV prevalence than sex workers. Older street youth also had the highest sero-prevalence (no case found in children <15 years), the majority of whom in Latin America were males. Most engage in a panoply of risky behaviors, including “survival sex” to obtain money or food; have multiple sexual partners (including same sex partners); and suffer from frequent sexually transmitted infections (STIs) (Lambert et al., 2005).

Adolescent girls: There is evidence also that adolescent girls are vulnerable to HIV infection as a result of early sexual debut or marriage. The 2003 Ghana DHS analysis showed that women who have been sexually active by age 15 are 2.4 times more likely to be HIV-positive (even after controlling for age, socio-demographic characteristics, and knowledge and attitude variables) than women who experience sexual debut at a later age (Akwarwa et al., 2005). In many sub-Saharan African countries, the percentage of adolescent girls having sex before age 15 is significant: 20% in Cameroon, 28% in Mali and Mozambique, and 21% in Nigeria. In Nicaragua, 12% of girls have sex before age 15 (Population Council, 2003a-e).

For a vast majority of young adolescent girls, sexual activity during early adolescence occurs within marriage. In Niger, more than 25% of girls are married by their 15th birthday. In other countries, between 6% and 15% are married before turning 15, although this percentage is declining in all countries. Young girls may also have difficulty negotiating “safer” sex with husbands than older women. For example, 81% of women in Cameroon say they can negotiate safer sex with their husbands, but only 52% of women 15–19 so indicate. Figures are similar in Uzbekistan and Vietnam, although in several countries worldwide, this distinction was not pronounced (Bruce & Chong, 2003).

Other categories of vulnerability: Other children with increased vulnerability to HIV infection include orphans working as household servants or in other menial labor (vulnerable to sexual abuse), street children who are often orphans (USAID-AED, 2004), children of sex workers (Verma et al., 2002), or teenage sex workers, who are paid more in Indonesia, for example, than older sex workers (SCF/UK, 2006c), as well as teenage injecting drug users. Not much evidence was found on the number of vulnerable children in these different sub-groups. Data from HIV Prevention Project surveys in Bangladesh (cited in UNICEF, 2005c) indicate that the rate of childlessness among sex workers is very high (only 1.5 children per sex worker compared to 2.6 as the national average), probably related to work factors of the mothers such as infertility caused by abortions and sexually transmitted diseases, rather than to non-work factors such as age. A study by CARE found that in Bangladesh 52% of drug users are married and 72% of those have children (cited in UNICEF, 2005c).

3.2.5 Geographic location

We reserved this section for evidence on the location of children affected by HIV/AIDS within countries and/or regions. Identifying who are the children affected by HIV/AIDS requires information on where they are located, whether they are living predominately within urban or rural settings, in specific high-risk locales, or whether they are geographically interspersed across countries. These data are limited to information available on the magnitude and proportion of children affected by HIV/AIDS – which in many countries is limited. However, several unofficial estimates were identified. For example, in Papua New Guinea where the adult HIV prevalence is estimated to be 1%, approximately 70% of infections are among the rural population where most Papua New Guineans reside, suggesting likewise that this is where most of HIV/AIDS-affected children are (UNICEF, 2005g).

3.2.6 Stage of development

Data on children affected by HIV/AIDS are not, as a rule, collected by age group, with the occasional exception of “youth” (15–24 years) because of their other needs related to reproductive health, which is systematically collected and reported, for example, in demographic and health surveys. Data that were identified that disaggregated HIV/AIDS-affected children by age category indicate that children are affected across all childhood age categories. In low and high prevalence countries in sub-Saharan Africa, age distribution of orphans (both AIDS and non-AIDS), for instance, was fairly consistent across countries: 0–4 years = 15%, 5–9 = 35%, 10–14 = 50% (Monasch & Boerma, 2004). Although these data show that most orphans are of school going age, it is important to recall that children are affected by AIDS several years before they become orphaned.

3.3 Information gaps about “Who are children affected by HIV/AIDS?”

Identification of AIDS-orphans and infected children: Household data collection on HIV status has not historically facilitated the task of identifying children infected or affected by HIV/AIDS, their age groups, their caretaking status, etc. Sentinel HIV surveillance of pregnant women visiting prenatal clinics, for example, can provide an effective alternative or complement to population-based studies, but it does not elucidate the situation of the children already born to these mothers.

Gaps appear in knowledge of the number of children infected by HIV, those orphaned by AIDS, their geographic location, age categories, etc. In reality, the percentage of children infected but whose HIV status is unknown is probably very high, and data collection on orphans due to AIDS particularly is inadequate in most world region of the world. Older orphans especially are excluded: household surveys do not currently collect data on orphaned children aged 15–17.

Identification of highly vulnerable children: There is also an apparent under-reporting of children living outside family care, such as street children and institutionalized children (UNICEF et al., 2006; Monasch & Boerma, 2004). Groups like street children and sex workers are excluded from household surveys and are not always covered by sentinel surveillance systems. In addition, groups like adolescent girls living away from their parents or given in early marriage who are at high risk for HIV infection are often invisible in the data. Accurately identifying these different groups remains a large challenge, especially in low prevalence countries.

Extent of layered vulnerabilities: Populations of children affected by HIV/AIDS overlap. That is, orphans may be HIV-infected, and HIV-infected children may be living with HIV-

infected adults. In cases where affected children have increased needs for programming over unaffected children, identifying layers of vulnerability will be crucial for providing comprehensive strategies to meet their needs – strategies that consider not only HIV status, but also orphanhood status, age category, vulnerability to HIV infection, etc. (Hunter & Williamson, 2000). However, information on the extent of overlap remains scarce, such as, What percentage of orphans are also HIV-positive or what percentage of infected children are also living with HIV-infected caretakers?

Data across world regions: As Table 4 shows, in some regions virtually no official data are available on the numbers of children affected by HIV/AIDS, much less systematic information about living arrangements, guardianship, etc. An important challenge will be to construct comprehensive country-level data systems for HIV/AIDS programming for affected children.

3.4 Conclusion

Patterns of HIV infection in adults and through MTCT are increasingly well understood and documented. However, it is virtually impossible, to date, to systematically identify what is probably the largest group of children affected by HIV/AIDS – those with HIV-positive parents. Evidence on the patterns of HIV infection in children beyond MTCT is relatively thin. Even where overall numbers of orphans are available, many low prevalence or concentrated epidemic countries do not estimate the number of children orphaned by AIDS. Even less evidence is available on the living and caretaking situations of children affected by HIV/AIDS. Consequently, it is difficult to find reliable data about the growing number of children currently affected by HIV/AIDS worldwide for use in programming decision-making. As we wait for more advanced HIV surveillance systems that will make the evidence base on HIV/AIDS-affected children stronger, it is possible at a programmatic level to track HIV-positive parents and their children through integrated programming – enabling better services to families and more complete data.

The dynamic nature of the epidemic makes it nearly impossible to strictly assign children affected by HIV/AIDS to any one category of exposure. Their risks and situations will change, requiring additional information over time regarding vulnerability, placement, and HIV and orphanhood status. The myriad of interrelated and dynamic factors has implications not only for programming, but also for how data are collected and used to address specific challenges.

The evidence on “who are the children affected by HIV/AIDS” demonstrates the difficulty of drawing conclusions across countries and regions: comparable data are not always available and patterns of infection (and those of children affected) also vary.

Chapter 4 Health

Children affected by HIV/AIDS may face a series of challenges related to health and health care. Although HIV-positive children can have substantial health issues related to their infection, this chapter will not cover the evidence base related to case management of HIV infection or to programs for the prevention of mother-to-child transmission (PMTCT).¹¹ Instead, it will focus on the evidence base for health challenges for affected children that relate to differential health status (beyond that due to infection) and to barriers to services that affect their health.¹² However effective PMTCT and antiretroviral (ARV) treatment programs and treatment of opportunistic infections are essential to addressing a large portion of the issues faced by children affected by HIV/AIDS, in terms of preventing infections in children, improving their own health issues, and maintaining the health and ensuring the survival of their parents.

Evidence on health disparities in low prevalence or concentrated epidemic countries examines primarily orphans in institutions (worldwide) or the self-reported health status of children living in HIV/AIDS-affected households (mostly in Asia, but some in west Africa). Evidence on disparities in mortality (beyond that due to HIV infection in children) is more limited in low prevalence countries, but some data are available from west Africa. As to the barriers, the evidence base on health and HIV prevention services for children of different ages affected by HIV is less consistently strong (more qualitative and not investigating the specificity of factors preventing use of health services), but more geographically representative. Additional information on barriers to health care access is in other programming areas such as socioeconomic situation (Chapter 6) and stigma (Chapter 11).

Evidence cited on health and children affected by HIV/AIDS (n = 14)

Authors	Rigor	Type (Location)
Alkenbrack et al. 2004	Good	Controlled cross-sectional qualitative (Cambodia)
Brahmbhatt et al. 2006	Good	Descriptive quantitative (Uganda)
Deininger et al. 2001	Good	Panel study (Uganda)
Dutt et al. 2007	Good	Cochrane research protocol (worldwide)
GECA et al. 2005	Fair	Cross-sectional with controls (Benin)
Jianhua et al. 2006	Fair	Descriptive quantitative (China)
Lambert et al. 2005	Good	Descriptive qualitative (Bolivia)
Loudon et al. 2007	Good	Descriptive qualitative (India)
Newell et al. 2004	Good	Descriptive quantitative (sub-Saharan Africa)
Pradhan et al. 2006	Good	Cross-sectional with controls (India)
SCF/UK 2006e	Fair	Descriptive qualitative (Southeast Asia)
Taha et al. 2000	Good	Longitudinal with controls (Malawi)
Verma et al. 2002	Fair	Descriptive quantitative (India)
WHO et al. 2007	Good	Descriptive quantitative (worldwide)

4.1 Information needed for programming around health challenges

Disparities in health status among HIV/AIDS-affected versus unaffected children: It is important to know whether children affected by HIV/AIDS face additional challenges to their

¹¹ A substantial evidence base related to clinical case management of HIV/AIDS and PMTCT exists but is not reviewed in this document.

¹² Not all "health" services are necessarily conducted through the health sector: prevention programs can be carried out by education, youth, and other sectors as well.

health (beyond those related to their infection status) due to family-related or caretaking factors that would require additional focus on health care services beyond treatment with ARVs. Also, are affected children more at risk for (non-vertical) HIV infection?

Differences in barriers to health care access among children affected by HIV/AIDS compared to other children: While many children in low prevalence countries face barriers to accessing health care, it is important to know whether HIV/AIDS in the household creates additional barriers. How do problems of such access differ among children living in households with (declared or undeclared) HIV infection, those orphaned by AIDS, and those infected with HIV? Do the barriers vary by age group? How does health care coverage differ among these groups?

4.2 The situational findings on health

4.2.1 Findings with strong evidence

Healthy HIV-positive mothers reduce risk of child mortality: There is strong evidence from high prevalence countries that keeping HIV-infected mothers alive and healthy leads to decreases in child mortality, although few studies include low prevalence countries. However, a pooled study (Newell et al., 2004) of longitudinal data on 3468 children of HIV-positive mothers in west (Burkina Faso, Ivory Coast), east (Kenya, Tanzania, Uganda), and South Africa found that all children born when their mothers were at an advanced disease stage or whose mothers died during follow-up were at a considerably increased risk of death than those whose mothers survived or were at a less advanced disease stage. While it can be expected that infected children would be more likely to die, even uninfected children were almost four times as likely to die if the mother died ($P < 0.0001$), controlling for geography, sex, maternal CD4, and breastfeeding. Stratified analysis by geographical region showed similar effects in east, west, and South Africa.

Although with data solely from a high prevalence country, a recent prospective study (birth through 24 months) in rural Uganda (Brahmbhatt et al., 2006) is one of few studies that included a non-HIV/AIDS-affected control group: 69 infected children of infected mothers, 267 uninfected children of infected mothers, and 3128 uninfected children of uninfected mothers. Results demonstrate additional effects of HIV-positive mothers on child mortality: at 18 months cumulative mortality rates of uninfected children born to infected mothers was 1.16 times higher ($p < 0.05$) than for uninfected children born to uninfected mothers (and 4.01 times higher for infected children: $p < 0.001$), and at 24 months cumulative mortality rates of uninfected children born to infected mothers was 1.29 times higher than children born to uninfected mothers (and 4.22 times higher for infected children). In other words, children born to infected mothers and who remained uninfected still faced a much higher risk of dying before 24 months than children born to uninfected mothers

4.2.2 Recurrent themes for which the evidence is moderate

Non-infected children in HIV/AIDS households have about the same level of health problems as children in non-infected households: A large cross-sectional household survey in India comparing 2068 HIV households and 6224 non-HIV households found no differences in prevalence of non-hospitalized illnesses or hospitalizations in children 0–14 years (Pradhan et al., 2006). A cross-sectional study with controls in Cambodia that interviewed 718 children 6–18 years old living in HIV/AIDS-affected households and 725 control children found no significant difference in self-reported health status (98% of children in both groups self-

reported good health) (Alkenbrack et al., 2004). While not from a low prevalence or concentrated epidemic country, data from a strong longitudinal study with controls in Malawi (Taha et al., 2000) followed 808 children over 18 months broken down into three groups (190 HIV-positive children of HIV-positive mothers, 499 HIV-negative children of HIV-positive mothers, and 119 HIV-negative children of HIV-negative mothers) and found no significant differences in how often a child gets ill or in specific morbidities among non-infected children, regardless of mother's HIV status.

In some countries, children living in HIV/AIDS households make fewer health care visits: Mixed results were found relative to frequency of care-seeking behavior. A large qualitative study of barriers in India (Loudon et al., 2007) showed consistent examples (across 65 focus groups with children affected by HIV/AIDS and 90 focus groups with caregivers and household heads) of being humiliated, being refused examination and treatment, being served last, and being incorrectly labeled as HIV positive. In a parallel set of 85 key informant interviews in the health sector, only 41% of health professionals interviewed were aware of these exclusions. This study did not address how much of this behavior was due to membership in groups at high risk of HIV rather than to HIV infection itself. Another study in India (Verma et al., 2002) examined the impact of adult AIDS death on children by comparing three types of households: those with an AIDS-related death (256 children), those with a non-AIDS-related death (214 children), and those where no death had occurred (230 children). While the prevalence of disease among the three types of households was similar, the percentage of child members being "unable to visit a health care center when in need of essential health care services" was 25% in households that had experienced an AIDS death, compared to 18% in households with a non-AIDS death and 9% in households with no death.¹³ As in the Loudon et al. report, this study did not analyze the effect of AIDS versus the impact of membership in groups at high risk of HIV infection. In another cross-sectional study in rural China, children who were living in affected households with both parents and orphans reported visiting a doctor when last ill less than children who were unaffected by HIV/AIDS, but the results were not statistically significant (Jianhua et al., 2006). In Benin (GECA et al., 2005), a cross-sectional study of 1155 orphans and vulnerable children (including HIV/AIDS-affected children) and 1155 who were neither orphans nor vulnerable (control group), the former were more likely to resort to self-treatment (60%) than other children (53%).¹⁴

Data from a high prevalence country (Uganda) provide evidence that where health sector policies are inadequate (where general access to good quality health care is poor), orphans may suffer greater health and nutrition consequences: children living with their own family were more likely than fostered children to have received measles vaccine (69% compared to 62%; $p < 0.01$) and to have taken vitamin A (59% compared to 50%; $p < 0.01$) (Deininger et al., 2001).

4.2.3 Gaps in information on the situation

Better information on children at highest risk for infection: Data are emerging on age groups and sub-populations that are at higher risk of becoming infected with HIV. A study of specific high risk groups in Bolivia found street children (15 years or older) having the highest prevalence of HIV infection – greater than sex workers (Lambert et al., 2005). There is as yet little evidence on whether adolescents (11–18 years) affected by HIV/AIDS and living in low

¹³ No statistics reported.

¹⁴ No statistics reported.

prevalence or concentrated epidemic countries are at greater risk of infection than other children and whether these risks are due to self-initiated behaviors or to having their HIV/AIDS situation increase their risk of becoming street children, being forced to marry early, or taking employment where they are likely to be abused.

More systematic information is needed about the relative importance of specific barriers to access and effective follow-up: The evidence base we compiled is insufficient to clearly identify barriers to health that result from worsening household economic status versus those that result from provider behavior, fear of stigma, and/or lack of child-friendly services. Moreover, documentation is lacking on synergies and collaboration between the health system and social services to ensure adequate follow-up of HIV-affected families or to better reach vulnerable groups for prevention, testing, and counseling.

4.3 Interventions to address health challenges

The evidence base is quite thin on specific interventions that have proven effective in overcoming the barriers experienced by these children to HIV prevention and health care services or in targeting groups of children at high risk for HIV infection.

Findings with strong evidence

No strong evidence was found on interventions to reduce disparities or barriers to health service utilization for children affected by HIV/AIDS in low prevalence or concentrated epidemic countries, beyond those related to expanding VCT, PMTCT, and ARV services for parents and children (not covered in this review).

Recurrent themes for which the evidence is moderate

No studies with moderate evidence were found on interventions to reduce disparities or barriers to health service utilization.

Gaps in information on health interventions

Effective prevention education for vulnerable children: Children at greatest risk of infection, such as street children, are not being reached by prevention activities, which are largely carried out in schools. Moreover, materials used in these campaigns are often not designed specifically for children, are perceived as unfriendly to children, and may therefore be ineffective (WHO et al., 2007; SCF/UK, 2006e).

Documentation is lacking on effective ways to reach at-risk children: Little documented evidence exists on effective interventions to reach some of the most at-risk groups of children, such as street children. The protocol for a Cochrane Review (updated in August 2005) says that the review will “evaluate and summarize the effectiveness of interventions for changing risky sexual behavior, and consequently prevent transmission of HIV, among street children and young people associated with the streets in low and middle income countries” (Dutt et al., 2007), but the review is not yet available.

Effectiveness of interventions to remove financial barriers: While there is some evidence about programs intended to provide financial protection against the *costs of health care* for children affected by HIV/AIDS, it is not clear how well these programs actually increase access. For example, in Benin (GECA et al., 2005), arrangements exist for subsidized care for children affected by HIV/AIDS, but only under specific and narrow circumstances.

4.4 Conclusions about health

Evidence for health challenges of children affected by HIV/AIDS in low prevalence and concentrated epidemic countries is not extensive, but growing, particularly in Asia. No evidence was found related to health disparities or barriers to health care from Latin America. However, there are several areas where specific health challenges stand out, including information on which children are at highest risk of infection, how to reach the high risk children, whether prevention education is effective for vulnerable children, and the specific barriers to effective follow-up services including financial barriers. While this section did not examine the extensive literature on effectiveness of PMTCT and treatment for AIDS and opportunistic infections that directly affect health status of HIV-positive children and their parents, access to PMTCT and ARVs for infected children and their parents will have a direct effect on the health, need for care, and survival of uninfected children in the family. Strong evidence of the positive effect of healthy mothers on child survival from both low and high prevalence countries indicates that treatment of AIDS and opportunistic infections in ill parents will also have a positive effect on all affected children. While the evidence is somewhat mixed on whether uninfected children living in HIV/AIDS-affected households will have more health problems, there is moderate evidence of important barriers to care-seeking related to either financial issues or stigma (both covered in other chapters of this report). Although not valid for every case of institutionalized care or foster care, orphans in institutions appear to have more negative health effects than children in foster care or other situations. Evidence on effective interventions for overcoming challenges to health status and access to health care among children affected by AIDS is limited in low prevalence countries, particularly in reaching children most at risk of infection.

Chapter 5 Nutrition

Undernutrition is a leading cause of morbidity and mortality among children in low and middle income countries (Sguassero et al., 2007). The food situation and nutritional status of HIV/AIDS-affected children are interrelated and often mutually reinforcing. Affected children are at risk for poor nutrition in several ways, through HIV infection and/or through declines in food security due to being orphaned or living in an HIV/AIDS-affected household.

The important issues surrounding nutrition for HIV/AIDS-affected children often relate to their age. For infants, breastfeeding is the key nutritional issue, while for toddlers, complementary feeding and growth monitoring are key. Once children reach school-age, food security becomes the focus.

The evidence base on nutrition as it relates to HIV/AIDS-affected children, especially orphans, is moderately good and comes from both low and high prevalence countries. Rigorous evidence on effective interventions is limited and usually from high prevalence countries in sub-Saharan Africa. Strong evidence includes the relationship between HIV and malnutrition as well as transmission and mortality risks associated with breast- and replacement feeding. Recurrent themes examine issues in food security in orphans and the nutritional status of other affected children. Gaps remain regarding nutritional measures for older children, including leading socio-behavioral factors relevant to malnutrition.

Evidence cited on nutrition and children affected by HIV/AIDS (n = 55)

Authors	Rigor	Type (Location)
Alkenbrack et al. 2004	Good	Controlled cross-sectional qualitative (Cambodia)
Arpadi 2005	Fair	Descriptive qualitative review (sub-Saharan Africa)
Arpadi et al. 2000	Good	Controlled cross-sectional quantitative (U.S.A.)
Becquet et al. 2006	Fair	Descriptive quantitative (Cote d'Ivoire)
Centeville et al. 2005	Good	Controlled longitudinal study (Brazil)
Cooper et al. 2002	Good	Controlled trial (Puerto Rico, U.S.A.)
Coovadia et al. 2007	Good	Descriptive quantitative (South Africa)
Cornia 2002	Fair	Descriptive quantitative/qualitative (multi-country)
Creek et al. 2007	---	Descriptive quantitative abstract (Botswana)
Dabis et al. 2001	Good	Randomized controlled trial (Burkina Faso, Cote d'Ivoire)
Dabis et al. 2003	Good	Randomized controlled trial (Burkina Faso, Cote d'Ivoire)
DeCock et al. 2003	Good	Literature review (worldwide)
Dorenbaum et al. 2002	Good	Randomized controlled trial (Bahamas, Brazil, Europe, U.S.A.)
Edmond et al. 2006	Good	Controlled longitudinal study (Ghana)
European Collaborative Study 2003	Good	Prospective controlled quantitative (Europe)
Gaillard et al. 2004	Good	Literature review (worldwide)
Iliff et al. 2005	Good	Descriptive quantitative (Zimbabwe)
Irlam et al. 2005	Good	Cochrane review, randomized controlled trials (worldwide)
Jackson et al. 2003	Good	Randomized controlled trail (Uganda)

*The evidence base for programming for children affected by HIV/AIDS
in low prevalence and concentrated epidemic countries*

Jianhua et al. 2006	Fair	Controlled cross-sectional quantitative (China)
Kadio et al. 2005	Good	Descriptive quantitative (Guinea)
Kafulafula et al. 2007	Fair	Abstract of poster session (Africa)
Kourtis et al. 2007	Fair	Abstract of poster session (Africa)
Kruzich et al. 2004	Good	Controlled cross-sectional quantitative (U.S.A.)
Lallemant et al. 2004	Good	Controlled quantitative trial (Thailand)
Lauer et al. 2006	Good	Descriptive quantitative (worldwide)
Leroy et al. 2002	Good	Randomized controlled trial (Burkina Faso, Cote d'Ivoire)
Leshabari et al. 2007	Fair	Controlled quantitative (Tanzania)
Ndehka 2005	Fair	Descriptive quantitative (Malawi)
Nduati et al. 2000	Good	Randomized controlled trial, quantitative (Kenya)
Niang & van Ufford 2002	Good	Descriptive quantitative (Senegal)
Onyango et al. 2007	Fair	Abstract of poster session (Uganda)
PETRA Study Team	Good	Randomized controlled trial (Tanzania, South Africa, Uganda)
Phiril et al. 2006	Good	Quantitative analysis (Zambia)
Piwoz & Preble 2000	Good	Literature review (Africa)
Piwoz & Ross 2005	Good	Descriptive quantitative (worldwide)
Piwoz et al. 2007	Good	Descriptive quantitative (Zimbabwe)
Quinn 2007	Fair	Controlled quantitative trials – Conference reports (Rwanda, Tanzania, Zambia)
Rivers et al. 2004	Good	Descriptive quantitative (sub-Saharan Africa)
Rollins et al. 2007	Good	Randomized controlled trial (South Africa)
Semba & Tang 1999	Good	Descriptive quantitative (worldwide)
Sguassero et al. 2007	Good	Cochrane review, randomized controlled trials (worldwide)
Shapiro et al. 2006	Good	Randomized controlled trial (Botswana)
Sibailly et al. 2000	Good	Randomized controlled trial (Cote d'Ivoire)
Sussman 2006	Good	Descriptive qual/quant review (worldwide)
Thior et al. 2006	Good	Randomized controlled trial (Botswana)
Thomas et al. 2007	Fair	Abstract of poster session (Kenya)
UNICEF et al. 2006	Good	Descriptive qualitative (sub-Saharan Africa)
USAID-AED 2004	Fair	Literature review (sub-Saharan Africa)
Volmink et al. 2007	Good	Cochrane review, randomized controlled trials (worldwide)
WHO Collaborative Study Team 2000	Good	Meta-analysis (Brazil, Pakistan, Philippines)
WHO 2006	---	Consensus statement of Inter-Agency Task Team
Wiktor et al. 1999	Good	Randomized controlled trial (Cote d'Ivoire)
Wilson & Findley 2006	Fair	Descriptive qualitative (worldwide)

5.1 Information needed for programming around nutrition/food security challenges

Disparities in prevalence and consequences of under-nutrition for HIV/AIDS-affected versus unaffected children: In settings wrought by severe food shortages, challenges relating to malnutrition may exist for children regardless of their exposure to HIV.

For programming, information is needed not only on the magnitude of under-nutrition, but also on who is most affected and whether (and to what extent) under-nutrition is exacerbated by HIV/AIDS. Are HIV/AIDS-affected children more vulnerable to nutritional challenges than unaffected children? Are certain sub-groups of HIV/AIDS-affected children at increased risk for malnutrition? What are the consequences when nutritional status is not considered or targeted? Is hunger associated with increases in risky behavior or risk of infection?

Information on direct causes of malnutrition: Because malnutrition itself is a manifestation of a myriad of deficiencies, evidence is needed that outlines the nature of malnutrition experienced by affected versus unaffected children, such as deficiencies in vitamin A, zinc, or other nutritional requirements. Should efforts focus on one or two food components or is a more comprehensive approach required?

Information on socio-behavioral factors contributing to undernutrition, including increased morbidity and mortality: Socio-behavioral causes of malnutrition that lead to increased morbidity and mortality should also be identified for effective programming. These include factors such as home-care feeding practices, health-related knowledge of caretakers, financial constraints for food acquisition, etc. Evidence is needed that outlines the strategies caretakers use to feed children and what barriers exist in providing adequate nutritional support.

Determining the kind of information needed will largely depend on the age and/or infection status of the children being targeted. For instance, information on breastfeeding and replacement feeding (i.e., home-care feeding practices) will be highly relevant for newborns and infants, while information on food security, use of local foods, and dietary intake will be more relevant for older children. To date, the bulk of data available on nutritional status of children is weight-for-age measures for children under the age of five years: more routine data are needed to inform programming strategies for older children, whose nutritional status may be better measured by assessment of other factors.

5.2 The situational findings on nutrition

The evidence base on the nutritional situation of HIV/AIDS-affected children covers a wide-range of challenges. On the one hand, an emphasis on orphans versus non-orphans dominates much of the literature from low and middle income countries, while numerous studies from developed countries examine nutritional differences between HIV-infected and uninfected children. The term “nutrition” itself encompasses aspects of dietary intake, as well as feeding practices and consequences relating to morbidity and mortality – which the evidence base includes. The most rigorous studies document an association between HIV and malnutrition, as measured by growth impairment and decreased dietary intake. There is also strong evidence regarding the nutritional impact of feeding practices on newborns and infants. Recurrent themes for which the evidence base is moderate note that children affected by HIV/AIDS often live in households with more food insecurity than unaffected children, but there are significant gaps regarding factors leading to malnutrition across contexts, including the relationship between household food security and the nutritional status of children living in the household. Nutritional status of adolescents or changes in status over time are also largely undocumented.

5.2.1 Findings with strong situational evidence about nutrition

HIV and malnutrition are mutually reinforcing in HIV-infected children: Evidence indicates that both protein-energy malnutrition and micronutrient deficiency can hasten disease progression and that HIV worsens malnutrition by its impairment of the immune system and impact on nutrient intake, absorption, metabolism, and storage. These processes have important implications for overall growth and development of infected children (Irlam et al., 2005; Piwoz & Preble, 2000; Semba & Tang, 1999). In a careful study of 42 prepubescent children in the U.S., the anthropometric growth (height, weight) of HIV-infected children was significantly less than that of uninfected children, and in addition growth impairment and dietary intake were associated with increased viral load in the infected children (Arpadi et al., 2000). A multi-country study in Europe found that vertically HIV-infected children had significantly lower height and weight measures over time than uninfected children with comparable weight and height measures at birth (European Collaborative Study, 2003).

In Brazil, among 127 vertically infected children, the severity of AIDS manifestations was associated with nutritional status and with the age at onset of symptoms. The mean age at onset of HIV-related symptoms was lower among undernourished children with lower mean weight-for-age and weight-for height (Centeville et al., 2005). Malnutrition can result from several nutrient deficiencies. A study in the U.S. found that HIV-infected adolescents had significantly decreased iron intake as well as decreases in vitamin C and E intake compared to uninfected youth (Kruzich et al., 2004).

Infant-feeding methods used by HIV-infected mothers have significant implications on the infant's HIV-status, mortality, and morbidity: There is strong evidence that breastfeeding reduces the incidence, severity, and mortality of infectious diseases in infants, particularly compared to unsafe replacement feeding resulting from unclean water or poor health care practices (Lauer et al., 2006; WHO Collaborative Study Team, 2000; Edmond et al., 2006). But there is also strong evidence that HIV is sometimes transmitted from HIV-positive mothers to the infant through breastmilk, and probably is linked to the duration of breastfeeding (Piwoz & Ross, 2005) and the viral load of the mother (Phiril et al., 2006; Coovadia et al., 2007). Several studies found that mixed feeding resulted in a significantly higher rate of HIV transmission than either exclusive breastfeeding or exclusive replacement feeding (Coovadia et al., 2007; Nduati et al., 2000; Iliff et al., 2005). Early evidence suggests that *abrupt* cessation of breastfeeding (to enable exclusive replacement feeding) does not yield higher HIV-free survival and probably causes additional health problems for the mother and baby (Kourtis et al., 2007; Kafulafula et al., 2007; Thomas et al., 2007; Onyango et al., 2007). (Guidance for PMTCT programs and evidence-based advice regarding infant feeding by HIV-infected mothers is addressed in the Intervention sub-section of Nutrition below.)

5.2.2 Recurrent themes for which the situational evidence is moderate

HIV/AIDS-affected children reside in food-insecure (see text box) households more often than unaffected children: Because both malnutrition and food insecurity often accompany poverty and because HIV/AIDS-affected households tend to suffer declines in socioeconomic status (Alkenbrack et al., 2004; Cornia, 2002; Niang & van Ufford, 2002), one worrying manifestation about HIV/AIDS-affected children is worsening food security.

There is good evidence that food security is a key challenge for orphans and children affected by HIV/AIDS as compared to unaffected children. Analysis of data from two sub-national

UNICEF surveys in Malawi and Jamaica found that a much larger percentage of orphans (versus non-orphans) lived in households classified as “food insecure with child hunger” (39.3% and 38.6% of paternal and double orphans, respectively, versus 14.9% of non-orphans). This study defined “food security” by an eight-question interview with heads of households that asked if the household head or the children in the household had, for lack of funds in the last 30 days, cut the size of meals, skipped a meal, gone hungry, or not eaten for a whole day. In addition, 40% percent of households with more than one orphan were classified as “food insecure with child hunger” much more than non-orphan households (49.1% versus 15.2%). Households classified as food insecure were more likely to house orphans (37.9%) than households classified as food secure (only 17.1% have an orphan), and households with chronically sick members were also found to be more food insecure (Rivers et al., 2004).

Food Security

Food security, as defined by the UN Food and Agriculture Organization, “exists when all people, at all times, have physical, social and economic access to sufficient, safe and nutritious food which meets their dietary needs and food preferences for an active and healthy life. Household food security is the application of this concept to the family level, with individuals within households as the focus of concern. Food insecurity exists when people do not have adequate physical, social or economic access to food as defined above.” However, “food security” is defined differently from one study to the next depending on the operational definition used in the questionnaire, ranging from estimates of household income based on telltale household assets in relation to the estimated expenditures to meet the minimum daily food standard for household members to estimates of food (and nutrient) consumption of household members. Definitions of food security based on household income are closer to socioeconomic challenges rather than nutritional ones, whereas definitions based on food consumption are probably closer to nutritional challenges. Thus, the relationship of food security of households and the nutritional status of individual children in the household are tenuous because (1) household problems do not necessarily transfer through to individuals in the household, (2) there is a wide range of operational definitions of food security, and (3) because youth especially may obtain food outside the household.

Similar findings have been reported for children living in HIV-infected households. A cross-sectional study of 136 households in rural China reported that 60% of children living in HIV-infected households (with at least one parent infected but both parents still alive) reported having eaten no meat in the past week, whereas 25% of unaffected children had not (Jianhua et al., 2006). Data from seven research sites in Senegal documented that the percentage of people who said “the quantity of food served had decreased” was much higher in HIV/AIDS-affected households (defined as households that included any HIV-infected members or any orphans due to AIDS): for HIV/AIDS-affected households, the percentage increased from 11% to 32% from 1996 to 2001, whereas it remained low and stable for non-affected households (Niang & van Ufford, 2002). In addition, the Food and Agriculture Organization, among others, estimates that in both high and low HIV-prevalence countries food production and consumption drop dramatically – as much as 40% – in households affected by HIV/AIDS as a result of illness and death, including insufficient transfer of farming skills and knowledge to their children (USAID-AED, 2004).

5.2.3 Gaps in information on the nutrition situation

Assessment of undernutrition in older children and across caretaking situations:

There were relatively few studies examining nutritional status among HIV/AIDS-affected

children who were older than five years. The main indicator used to measure nutritional status among young children is weight-for-age z-score, while a substantial proportion of HIV/AIDS-affected children are in older age groups such as those living with HIV-positive parents (Rivers et al., 2004). Most nutrition evidence from our search concerned orphans versus non-orphans, rather than multiple categories of vulnerable and affected children across age groups. Other indicators may be more appropriate for capturing changes in nutritional status in HIV-infected children and other vulnerable children, including length or height measurements or other food security indicators, such as reduction in the number of meals per day (Rivers et al., 2004; Arpadi, 2005).

Evidence on leading causes of undernutrition: Among infants and newborns, substantial evidence shows the consequences of feeding practices as a key cause in nutrition-related morbidity and death, even though choice of feeding must consider several individual and community-level factors. However, for older HIV/AIDS-affected children, not only is there less documentation on the extent of under-nutrition (as noted above), but in cases where food security is identified, gaps still remain on specific causes leading to inadequacies in food intake or consumption. For example, is under-nutrition a consequence of existing poverty that is exacerbated by HIV/AIDS, by household perceptions of the nutritional value of foods, or by limitations in access to food? Effective nutrition programming requires identifying the causes leading to the situation, not just establishing magnitude and/or presence.

Specific identification of disparities between affected and unaffected children: Our review attempts to present findings regarding differences in the nutritional status of affected children relative to unaffected children. The terms “unaffected” and “affected” do not represent homogeneous groups, however, so even in comparative studies, examination of disparities was not always done with clarity. More evidence is needed that specifically examines how categories of affected children (i.e., caretaking situation, location, age-group, infection status, etc.) differ with regard to under-nutrition and food security. Two analyses of different survey data, one from 40 countries (UNICEF et al., 2006) and the other from 30 countries (Rivers et al., 2004) found no statistical difference in nutritional of orphans and non-orphans, but did not address orphans due to AIDS, who might have a different nutritional status than other orphans or non-orphans. In some communities, these may be linked with significant and apparent inequalities, while in other cases children in general may be undernourished with no specific increased risk resulting from HIV/AIDS.

5.3 Interventions to address nutrition challenges

There is strong evidence that vertical transmission of HIV via breastfeeding and during pregnancy and delivery can be diminished by short-course antiretroviral therapy to the mother and baby, and moderate evidence that programs to improve infant-feeding counseling and mother knowledge can also reduce HIV transmission by fostering safer feeding practices. Although vitamin A supplementation has been shown to reduce malnutrition in HIV-infected children (Irlam et al., 2005), this is an intervention relevant to improve the care and treatment of HIV/AIDS, outside the focus of this review.

5.3.1 Findings with strong intervention evidence

Short-course antiretroviral therapy significantly reduces vertical transmission of HIV to infants during labor, delivery and breastfeeding. Two excellent reviews of evidence on the effectiveness of ARV therapy in preventing mother-to-child transmission of HIV

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conclude that short-course ARV therapy to HIV-infected mothers and their newborns (36 weeks after gestation through one week postpartum) significantly reduces transmission of HIV (Gaillard et al., 2004; Volmink et al., 2007). Gaillard et al. (2004) reports on studies with a range of methodologies and at various stages of completeness, including randomized controlled trials (RCTs), non-randomized trials, and animal studies. Volmink et al. (2007) is a Cochrane review of the RCT evidence on the impact of ARV regimes on mother-to-child transmission of HIV during pregnancy, delivery and infant feeding.

Gaillard et al. (2004) summarizes the available evidence at the time of the HIV transmission rate from infected mothers to their babies by general categories of feeding mode (no breastfeeding or any breastfeeding), living conditions (developed or undeveloped countries), and ARV therapy (complete, short-course, or none), as summarized below:

Category	Transmission rate	References
Breastfeeding (mixed and exclusive) in poor under-developed settings, no ARV therapy.	30-45% at 24 mths	DeCock et al., 2003
Breastfeeding (mixed and exclusive) in poor under-developed settings, short-course ARV received by mother and baby perinatally.	16-23% at 12-24 mths	Jackson et al., 2003; Leroy et al., 2002; Petra Study Team, 2002
Breastfeeding (mixed and exclusive) in poor under-developed settings, best short-course ARV received by mother and baby perinatally.	9.0% at 7 mths	Thior et al., 2006
Non-breastfeeding in developed countries, potent full-course ARV therapy received by mother and baby.	1%	Dorenbaum et al., 2002; Cooper et al., 2002

There is strong evidence that safe breastfeeding can reduce the transmission rate even further, by adhering to exclusive breastfeeding rather than mixed feeding and by weaning appropriately (not abruptly) at 6 months rather than continuing to breastfeed. This evidence was discussed above in section 5.2.1 on "Findings with strong situational evidence about nutrition." It is vital to remember that the objective of an infant feeding strategy is to maximize HIV-free survivors, not to minimize transmission of HIV, as discussed below in section 5.3.2 on "Recurrent themes for which the intervention evidence is moderate."

The Cochrane review (Volmink et al., 2007) performed a comprehensive search for all RCTs in all languages and found 18 randomized controlled trials that met their eligibility criteria conducted in 16 countries with 14,398 participants. The trials compare use of ARVs versus placebos, longer versus shorter duration regimes for mother and/or baby, regimes using different drugs, and regimes spanning different times during pregnancy, delivery and infant feeding. The 14 single country trials were from Thailand (5), South Africa (3), Malawi (2), and one each from Cote d'Ivoire, Kenya, Uganda and Zimbabwe, while the 4 multi-country trials included populations from Cote d'Ivoire & Burkina Faso (1), South Africa, Tanzania & Uganda (1), USA & France (1), and USA, Puerto Rico, Europe, Brazil & Bahamas (1). The review concludes that there are significant differences in the effectiveness of different regimes, but short courses of certain ARV regimes consistently reduce mother-to-child transmission of HIV, with no safety concerns in the short-term. Three trials compared ARV to placebo in breastfeeding populations and all found significantly lower HIV transmission at 1-2 months of

age in the ARV group, reducing the transmission rate by as much as 63% (range 32-63%) in the three studies. (The three – DITRAME in Cote d'Ivoire and Burkina Faso, RETRO-CI in Cote d'Ivoire, and PETRA in Tanzania, South Africa and Uganda – are reported in numerous publications, given in Volmink et al., 2007. Some key references to the three studies are: Dabis et al., 2001; Dabis et al., 2003; PETRA Study Team, 2002; Sibailly et al., 2000; Wiktor et al., 1999.) Gaillard et al. (2004) assessed the same three studies and drew similar conclusions. Volmink et al. (2007) also concluded, based on findings from the two RCT studies that measured infant HIV status at 3-4 months of age (DITRAME, RETRO-CI), that the ARV therapy significantly reduced HIV transmission (by 34-37%) at 3-4 months, providing further evidence of the impact of ARV therapy on reduced transmission via breastfeeding. Recent conference presentations of large, controlled, non-randomized studies in high prevalence countries appear to support the conclusion that short-course ARV therapy reduces HIV transmission for the first 4-7 months after birth to 1-4% of breastfed infants, especially if they are exclusively breastfed (Quinn, 2007).

Transmission of the virus is equally undesirable whenever it occurs, so that although this chapter focuses on transmission during breastfeeding, prevention before and during delivery is also desirable and of interest to programmers for children affected by HIV/AIDS. Although the majority of these studies on the use of ARV therapy to reduce the risk of mother-to-child transmission of HIV were undertaken in high HIV-prevalence countries, many were in low prevalence countries. Furthermore, HIV and suppression of its vertical transmission reflects biological phenomena that may not be significantly different in low and high prevalence countries.

5.3.2 Recurrent themes for which the intervention evidence is moderate

Improved infant feeding counseling and mother education can increase HIV-free

infant survivors: There is strong evidence that, for HIV-positive mothers, some types of infant feeding are always better than others, but that the best choice for a particular mother depends not only on her own situation but also on the general conditions in her area. As noted above under situational evidence for nutrition challenges, numerous well-done, controlled studies show that either exclusive breastfeeding or exclusive replacement feeding is always better than mixed feeding because they produce more HIV-free survivors than mixed feeding. Because of this finding, WHO recommends that exclusive replacement feeding should not be attempted by HIV-positive mothers if they cannot sustain it safely for six months for any reason (WHO, 2006). Furthermore, also noted under situational evidence for nutrition above, the risk of death from other infectious diseases such as diarrhea and pneumonia is substantially higher for replacement-fed babies than for exclusively breastfed babies, especially where infections are more prevalent and health services lacking. A Botswana report documents the excess infant deaths that can occur from replacement feeding (Creek et al., 2007), particularly when exclusive replacement feeding is not safe or sustainable.

One study (Piwoz & Ross, 2005) of the relative risk of infant mortality and HIV infection compared exclusive replacement feeding from birth to exclusive breastfeeding for six months using Ethiopia data. They concluded that the number of HIV-free survivors at 24 months of age was maximized by exclusive replacement feeding where IMR is less than 25 infant deaths per 1000 live births (25/1000) and maximized by exclusive breastfeeding for six months where IMR is larger than 25/1000. Comparative studies of the mortality and HIV-free survivor rate have yielded mixed results, reflecting the degree to which safe breastfeeding and antiretroviral

therapy was practiced and the context-specific nature of infant-feeding (Nduati et al., 2000; Becquet et al., 2006; Thior et al., 2006).

The context-specific nature of the best mode of infant feeding has led to confusion among counselors and mothers. Some studies in high prevalence countries indicate that HIV-free survivors can be increased by programs that improve counseling to HIV-positive mothers on infant feeding. An intervention trial of 437 mother-infant pairs in Zimbabwe tested the effectiveness of promoting safer breastfeeding practices by HIV-infected mothers, especially exclusive breastfeeding, better breast care, and safe sex, with a series of counseling sessions and written materials. Not only did they find a 38% reduction in postnatal HIV transmission in those fully exposed to the program, but a strong dose effect in which mothers receiving more counseling sessions had greater reductions in HIV transmission (Piwoz et al., 2007). A small sample evaluation of an intervention (counselor job aids, training for counselors, and take-home materials for mothers) to improve infant-feeding counseling in a Tanzanian PMTCT program found that the quality of the counseling and knowledge of the mothers improved significantly in the intervention setting relative to the comparison setting (Leshabari et al., 2007).

Community-based education and supplementary feeding programs improve nutritional status in some contexts: There is moderate evidence to suggest that, as an intervention, community-based education and supplementary feeding is an effective strategy to improve the nutritional status of HIV/AIDS-affected children. A successful example of this was in Guinea: using the “positive deviance” model, caretakers with positive household feeding practices worked with trained volunteers to educate caretakers of undernourished HIV/AIDS-affected children in how to prepare nutritious meals and improve prevention and care-seeking practices. Evaluation data showed that 85% of malnourished children (including children orphaned by AIDS) had substantial weight gain (Kadio et al., 2005).

Effective supplementary feeding programs, defined as “the provision of extra food to poor children or families beyond the normal ration of their home diets” (Sguassero et al., 2007), have also been shown to be effective in high HIV-prevalence countries. For example, over half of HIV-infected Malawian children receiving home-based nutritional therapy reached 100% weight-for-height measures in the absence of ART (Ndekha, 2005). In addition, in South Africa, 169 HIV-infected children aged 6–36 months who received enhanced calorie and protein supplements had significantly more weight gain than those on the standard diet (Rollins et al., 2007).

Despite findings, this evidence base is moderate given the difficulties in establishing causality or controlling for potential confounding. A review carried out through the Cochrane Collaboration examined results from two randomized controlled trials in Indonesia and one each in Jamaica and Guatemala to evaluate the effectiveness of community-based supplemental feeding to promote growth of poor pre-school-aged children (not affected by HIV/AIDS) concluded that supplemental feeding programs involve complex interrelations with poverty, sanitation, and health that raise significant methodological issues for evaluating their effectiveness. This leaves very little quality evidence to date to measure the impact of supplemental feeding for children across categories of vulnerability. Furthermore, the extent to which these findings can be generalized to low prevalence settings has yet to be documented in consideration of differences relevant to targeting, cost-effectiveness, or contexts of stigma and discrimination in low prevalence and concentrated epidemic settings.

5.3.3 Gaps in information on interventions

Little evidence on interventions that work: Except for reduction of mother-to-child transmission of HIV, there is a paucity of studies examining the effectiveness of nutritional interventions in low prevalence or concentrated epidemic settings, although our search provided several examples of unevaluated, on-going efforts in low prevalence settings (Sussman, 2006). Those studies with evidence on effectiveness were predominately from high prevalence countries, however, and it is unclear whether similar advances can be made elsewhere. Our search revealed some proposed efforts for improving the nutritional situation such as establishing a community-based fund for nutritional support of HIV/AIDS-affected children (Wilson & Findley, 2006), but by and large, there is little evidence of what works and what doesn't work in these communities.

Unanswered questions regarding implementation and targeting: The intervention data provided does not address questions regarding how to identify those most in need of nutritional support, whether long-term versus short-term strategies are more appropriate in providing support, or how much support should be provided for which children or even for which members of the affected families (Sussman, 2006). Nutrition efforts may also be integrated with other interventions, although the evidence base does not delineate how effectively this can be done.

Information on current household strategies to mitigate malnutrition: In some settings, HIV/AIDS-affected children (regardless of age or socioeconomic status) may not experience high levels of malnutrition or mortality. There may be specific household practices that are important for developing local strategies that will be acceptable and sustainable in affected communities. Evidence is needed on informal household efforts, outside of external interventions, that have proved effective for nourishing and supporting vulnerable children.

5.4 Conclusions about nutrition

There is a clear nutritional challenge to be addressed for HIV/AIDS-affected children. On the one hand, efforts are needed to ensure that children of all ages and in diverse caretaking situations have access to the best possible feeding and food support programs available, including monitoring their nutritional status over time and removing barriers to overall good nutrition. Our findings show that a moderate body of evidence exists on the nutritional and food security status of children affected by HIV and orphans in general, but much of it comes from high prevalence countries (in some cases low HIV prevalence) but *developed* country settings. A key question stands out sorely – that is, how relevant are these findings in low prevalence settings, independent of biomedical or physiological similarities? Evidence is needed urgently to resolve this question.

From what is available, however, strong evidence points to substantially reduced mother-to-infant transmission of HIV via breastfeeding as a result of safer breastfeeding practices and short-course antiretroviral therapy. Although much of this evidence comes from studies in high HIV-prevalence countries, it is consistent with similar evidence from low prevalence and concentrated epidemic countries and therefore is likely to apply to mothers and infants in low HIV-prevalence countries, especially given its biological nature. Furthermore, moderate evidence indicates that interventions that improve mother education and counseling of mothers with respect to infant feeding improves infant-feeding practices and reduces HIV transmission.

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Moderate evidence also exists on the heightened vulnerability of certain households – those with multiple orphans and those with HIV-infected caretakers – in terms of food security.

Chapter 6 Socioeconomic situation

The evidence on the socioeconomic situation of children affected by HIV/AIDS is extensive, but not always very strong. Low prevalence and concentrated epidemic countries are well represented in the literature (with the exception of Latin American countries), but controlled, longitudinal studies of the impact of HIV on household socioeconomic status are still lacking. Broadly speaking, the evidence shows that HIV/AIDS can have a devastating impact on household economies and that children living in these households are vulnerable as household capacity to provide basic material needs declines. The negative socioeconomic effects of the disease are felt across age groups, caretaking situations, and prevalence contexts, although the degree to which children are made more vulnerable may differ in magnitude based on the context.

Evidence cited on socioeconomic situation and children affected by HIV/AIDS (n = 23)

Authors	Rigor	Type (Location)
Abbott Labs Fund 2001	Good	Descriptive qualitative (Burkina Faso)
Abbott Labs Fund 2002a	Poor	Descriptive qualitative (Burkina Faso)
Alkenbrack et al. 2004	Good	Controlled, cross-section, quantitative (Cambodia)
Case et al. 2003	Good	Cross-sectional quantitative (South Africa)
Haacker 2004	Good	Descriptive quantitative, modeling (Worldwide)
Hennessey 2001	Fair	Descriptive qualitative (Thailand)
Jackson 2006b	Good	Descriptive qualitative (St. Vincent and Grenadines)
Jianhua et al. 2006	Fair	Controlled cross-sectional quantitative study (China)
Knodel & Saengtienchai 2005	Fair	Descriptive qualitative (Thailand)
Loudon et al. 2007	Fair	Descriptive qualitative (India)
Mather et al. 2004a	Good	Descriptive quantitative (sub-Saharan Africa)
Mather et al. 2004b	Good	Descriptive quantitative (Rwanda, Kenya, Malawi, Mozambique, Zambia)
New Era Team 2006	Fair	Descriptive qualitative (Nepal)
Pradhan et al. 2006	Good	Controlled cross-sectional quantitative study (India)
Rawlings 2004	Fair	Quasi-experimental design (multi-country Latin America)
Rawlings & Rubio 2005	Good	Indirect non-experimental analysis (Worldwide)
Safman 2004	Good	Descriptive qualitative (Thailand)
SCF/UK 2006a	Fair	Descriptive qualitative (China)
SCF/UK 2006e	Fair	Descriptive qualitative (multi-country Asia)
Sealy-Burke 2005a	Fair	Descriptive quantitative/qualitative (St.Lucia)
UNICEF 2002	Good	Descriptive qualitative (Nepal)
Webb & D'Allesandro 2004	Good	Qualitative study/literature review (Worldwide)
Wyss et al. 2004	Good	Controlled, cross-sectional quantitative (Chad)

6.1 Information needed for programming around socioeconomic challenges

To effectively address the socioeconomic challenges children face, information on the economic situation of their families (if they live in a household) is needed: Which families are most vulnerable? What are their socioeconomic challenges? What resources do they have? What

strategies are they using? Why are some children living outside family care, what are their socioeconomic challenges, and can they be returned to family care?

Changes in household economies due to HIV/AIDS: Information is needed on the changes that HIV infection brings in household socioeconomic status, such as increasing expenditures for health or declines in earned income. Key in this assessment is understanding the factors contributing to socioeconomic changes, such as the role of the infected household member (breadwinner or not), impact at different stages of the disease, and coping strategies affected families have employed to meet those changes (selling assets, borrowing money, changing jobs, fostering, institutional care, etc).

Impact of socioeconomic changes on children in affected households: How do these changes affect the children in the household? What percentage of children are affected? Are certain age groups, gender, or fostered children (for example) more vulnerable? What trade-offs are being made in terms of expenditures – food, clothing, education, or other basic services, especially in comparison with children living in unaffected households? This includes information regarding the expressed needs of affected families relating to their capacity to care for their children and their perceptions concerning changes in children's socioeconomic quality of life as a result of HIV/AIDS. What is the impact on the rates/types of child labor?

Options for programs to mitigate poverty in households: Are HIV/AIDS-affected households reached by other programs to mitigate poverty? What are the traditional social safety nets? Are they including/excluding HIV-affected households? To what extent?

6.2 Situational findings on socioeconomic status

The evidence documenting the negative socioeconomic effect of HIV/AIDS on children and the households where they live is strong and fairly consistent across regions. The impact of declining socioeconomic status among households affected by HIV may have repercussions in many other areas – health, food security, education, child care, and child protection.

6.2.1 Findings with strong evidence

Households with HIV-positive adults have lower incomes, and lost productivity contributes to economic decline: A cross-sectional case-control study of 500 HIV-affected households in Cambodia (Alkenbrak et al., 2004) found that current monthly household income (per capita) was 42% lower among HIV-affected households ($p < 0.001$), unemployment rates were higher (49% in HIV-affected versus 30% in unaffected households, $p < 0.001$), and 77% of respondents in HIV-affected households said their income had decreased in the last year, compared to 54% in the control group ($p < 0.001$). Being an HIV-affected household had a significant ($p < 0.000$) negative impact on household income, controlling for other facts (as did rural location, low education). In a large study of 2068 HIV-affected households and 6224 control households in six high prevalence Indian states (Pradhan et al, 2006),¹⁵ income loss attributed to HIV/AIDS totaled just over 9% of household income in HIV-affected households, a percentage similar to estimates from east and southern Africa (Pradhan et al., 2006; Haacker, 2004). In a small qualitative study in Thailand, grandmothers reported resuming participation in the formal economy to compensate for increased economic hardship, and younger caregivers such as aunts or adult siblings took on additional work or reduced discretionary spending to mitigate household financial shifts (Safman, 2004). A retrospective cross-sectional case

¹⁵ No statistical analysis was presented.

controlled study of 193 HIV-infected persons in Chad found that AIDS-affected households lost an average of 24 days in their major income-generating activity, whereas control households lost on average 2.5 days (Wyss et al., 2004).¹⁶

HIV-affected households face increased expenditures, especially for health: Several comparative studies provide evidence of a second effect of HIV on household socioeconomic status: an increase in overall expenditures, especially on health. In Chad (Wyss et al., 2004), a study of 193 households with and 193 without HIV reported that HIV-affected households spent an average of \$81.80 on health care expenditures compared to \$17.80 in non-affected households. The HIV households were more likely to borrow money, sell household assets/goods, or receive a gift(s) from someone outside the household to pay health-related expenses. In India, a study of 2068 HIV-affected households and 6224 non-affected households, medical expenses (hospitalized and non-hospitalized illnesses) of HIV-affected households were found to be four times higher than medical expenses for unaffected households (Pradhan et al., 2006). In Cambodia (Alkenbrack et al., 2004), health spending was also a significantly higher (22%) percentage of household expenditures in 500 HIV-affected households than in the 500 unaffected households (8%) ($p < 0.001$). To meet their needs, affected families were significantly more likely to ration their spending on other goods, sell their assets, or incur debt by borrowing. Sixty-three percent of affected families said they spent less on children's needs in order to pay for health care or purchased less food to pay for health care (69%) as compared to unaffected families, 44% and 53%, respectively ($p < 0.001$). In India (Pradhan et al., 2006), HIV-affected households ($n = 2068$) spent 11% of their income on health care, compared to 3% in neighboring comparison households ($n = 6224$).

Other economic measures show that HIV-affected households, especially female headed ones, are worse off than unaffected households: Though lacking in longitudinal analyses of changes over time, there is a mounting body of evidence documenting the differences in economic hardship between affected and unaffected families. Several controlled, cross-sectional analyses have found that the financial situation of affected families is more difficult, especially in settings already afflicted by poverty. In Cambodia, for example, a cross-sectional study found that fixed socioeconomic indicators such as educational status, water source, or materials for roofs or floors were comparable between affected and unaffected families, but indicators that were more likely to change over time, such as income or expenditures, were significantly different. In the Cambodia example, while household expenditures were the same in both groups, earnings were significantly lower in affected families (Alkenbrack et al., 2004). In a cross-country analysis of household response to HIV mortality in rural east and southern Africa, four high prevalence countries and one low prevalence country (Rwanda) were compared in terms of welfare implications. This analysis concluded that the gender and household position of the deceased largely determined the welfare effects on the household, but that affected households had similar household income and land and labor ratios compared to unaffected households. Certain subgroups, however, did have lower income and land holdings after death, especially those who lost a male household head (Mather et al. 2004a and 2004b). In China, compared to that of unaffected families, earned income of affected families was significantly lower where financial aid accounted for nearly 40% of affected families' income (Jianhua et al., 2006) versus less than 1% in unaffected families. In both Cambodia and India studies where controls were selected from the

¹⁶ Days lost = (Number of days normally spent on income-generating activities in a month when healthy) minus (days spent on activity in last month). This was calculated for ill persons and other family members.

same communities with similar socioeconomic characteristics (and in many high prevalence country studies), one manifestation of the socioeconomic decline brought on by HIV is the liquidation of assets and the taking on of debt. Findings from a large household survey from six high prevalence states in India showed that among HIV-affected households, 46% had borrowed in the previous year, as compared to 27% of unaffected households. Within the sample of HIV-affected households, 43% had borrowed or liquidated assets to compensate for loss of income (since the time the household member was found to be HIV-positive). This percentage was highest for low income households (56%) and declined with higher income levels (Pradhan et al., 2006). This same study also documented lower average household saving and savings in liquid assets in HIV-affected households than unaffected ones.

6.2.2 Recurrent themes for which evidence is moderate

As a consequence of HIV/AIDS, children have increasing socioeconomic responsibilities in the households, but the effects on their lives is mixed: Analysis of large household survey data in India (Pradhan et al., 2006) showed that workforce participation rates for children 0–14 years old were more than twice as high for un-infected children in HIV-affected households (1.54) as children 0–14 living in non-affected neighboring households (0.60). A Cambodia study (Alkenbrak et al., 2004) found that children and adolescents living in HIV-affected households were more likely to work for money than their peers (21% compared to 12%, $p < 0.001$). Even across categories of children affected by HIV/AIDS, differences in impact were observed. For example, in China, children living with HIV-infected adults ($n = 107$) had significantly fewer reports of new clothes (33%) than children orphaned by AIDS (58%, $n = 39$) whose annual household income was also greater and children from unaffected families (68%, $n = 137$) ($p < 0.02$) (Jianhua et al., 2006). Yet in these studies (Cambodia and China), the malnutrition rates were similar in cases and controls, as were school enrollment rates and reports by adolescents needing vocational training and food assistance, demonstrating both tradeoffs and a certain level of absorptive capacity of households to economic shocks caused by HIV/AIDS. Also, in Lao PDR, there were no observed differences in factors related to poverty, such as having enough to eat or school enrollment (SCF/UK, 2006e).

Families affected by HIV/AIDS express concerns about meeting basic needs: Even in cases where empirical data on impact are not available, the economic concerns of affected families are prevalent. Caretaker concerns include uncertainty in paying for school fees, clothing, and/or child care costs. Focus group discussions examining the welfare of non-institutional caregivers (mostly grandparents) for orphans due to AIDS in Thailand found that costs associated with child care and education were the most focal concern of caregivers (Safman, 2004). On average, these orphans were pre- or primary-school age, and grandparents bemoaned current costs and expected increases once the children graduated to secondary schools. A study on barriers to services for children with HIV-positive parents in five high prevalence Indian states, however, found that exclusion, rather than economic factors, was the most often cited barrier to accessing services for children in HIV-affected households (Loudon et al., 2007). In Burkina Faso, a community-based needs assessment of children orphaned by AIDS found that the primary challenge identified by the community caretakers was the expense of providing education and clothing to fostered orphans (Abbott Labs Fund, 2001; Abbott Labs Fund, 2002a). Lack of clothing was also a major concern among 53% of families caring for orphans in urban areas and 60% of families caring for orphans in rural areas in the Burkina study. Inability to afford school fees was one of the most common reasons given by affected children who dropped out of school in China, Indonesia, Lao PDR, Myanmar, and Cambodia (SCF/UK, 2006e). As one affected child said, “We don’t have rice for today’s meals.

Food is more important than schooling" (SCF/UK, 2006e). Children still enrolled in school in central China worried as well that they would have to drop out because of lack of money (SCF/UK, 2006a).

Socioeconomic support services are inadequate in many cases: Despite these concerns, the evidence suggests that little is being done to support caretakers, and when support is provided, coverage and access are limited. Research on available and potential support systems for 394 families supporting affected children in Thailand (Knodel & Saengtienchai, 2005) suggests that loans for income generation were difficult for families to access and that coverage was as low as 21% from the provincial public welfare office and local NGOs, though the poorest households were more likely to receive support (32% versus 13%). Reasons for low coverage included participation being too complicated for many applicants who were likewise discouraged by the requirement to open a bank account. There were also challenges in sustainability of caretaker support: in over two-fifths of cases that received welfare, assistance was given only once or lasted for only a month or less (Knodel & Saengtienchai, 2005). Still, in Cambodia, while only 15% of impoverished households affected by AIDS were receiving income assistance, an even lower percentage (6.4%) of comparison households received income assistance (Alkenbrack et al., 2004).

When economic caretaker support is provided, the evidence about the adequacy of monetary support is mixed. Interviews with members of the national HIV/AIDS support program in St. Lucia said that special public assistance funds available to persons who were HIV-infected were inadequate to meet all of their economic needs (Sealy-Burke, 2005a), and child welfare systems in Nepal were criticized for being poorly funded (UNICEF, 2002). In Thailand, a qualitative study assessing households with older-aged parents who were caring for HIV-adult children and their children found that 43% of poor families receiving welfare assistance thought the amount was not helpful, compared to 33% who said it was only somewhat helpful and 24% who said it was very helpful (Knodel & Saengtienchai, 2005). On the other hand, in Cambodia, although coverage was substantially low, most families receiving income assistance said it was very helpful (Alkenbrack et al., 2004).

Beyond adequacy, some studies found that economic support was not available to the HIV-affected households that needed it most. In Nepal, economic problems were most pronounced among women whose husbands had died of AIDS or who themselves were seropositive (New Era Team, 2006). Once widowed by AIDS, women reported being denied shares of their husband's property and thus deprived of opportunities to use it as collateral for borrowing. With the exception of loans, no other economic services were provided. In China, families with the lowest per capita income were those with one or two HIV-infected parents who were ineligible for financial support, whereas family income was higher among families with children orphaned by AIDS who were eligible for government financial support (Jianhua et al., 2006). In the Caribbean region, evidence suggests that differences in the legal definition of "family" have led to the exclusion of households needing assistance, particularly in communities where households may commonly be female-headed, partnered under common law, or include several parental partners (Jackson, 2006b).

6.2.3 Gaps in information on the situation

Documenting impact: As no controlled longitudinal studies examining socioeconomic changes attributable to HIV were found in low prevalence countries, it is difficult to segregate and evaluate the magnitude of the impact on households and, further, on children living there. In

addition, long-term follow-up studies are needed to examine the socioeconomic effects on affected families that may not be apparent in short-term follow-up.

Socioeconomic effects at different stages of the disease: The literature has not yet fully documented the evolution of economic impact of HIV on families throughout the varying stages of disease and thereafter with children after the death of their parents to explore the extent of the resilience of children, families, and communities, especially for children who no longer live in a household situation.

Differences in socioeconomic safety nets: Social safety nets are likely to differ widely depending on the context (low or high prevalence, religion, general socioeconomic situation, cultural setting, and even legal protection framework). Little evidence is available on how these different social safety nets mitigate socioeconomic impact by including or excluding households affected by HIV/AIDS. To what extent do HIV-affected households *not* take advantage of available services to protect their privacy?

6.3 Interventions to address socioeconomic challenges

While there may be interventions in place to mitigate the socioeconomic challenges faced by children and households affected by HIV/AIDS, there has been virtually no documentation of mechanisms used or evaluation of their impact to constitute an evidence base. There is, however, some evidence about effective interventions for general socioeconomic strengthening and targeting poor and vulnerable children that have not yet been applied in the context of children affected by HIV/AIDS.

6.3.1 Findings with strong evidence

No strong evidence was available documenting effective socioeconomic interventions for children affected by HIV/AIDS in low prevalence settings.

6.3.2 Recurrent themes for which evidence is moderate

Cash transfer programs appear to help, though no specific evidence marginal impact in children affected by HIV/AIDS: Conditional cash transfer programs are an emerging form of social assistance that provides money to poor families conditional upon investments in human capital, usually education and regular health center visits (Rawlings & Rubio, 2005). The aim of these programs is to exceed short-term poverty alleviation and income distribution to achieve long-term economic growth of families by providing incentives for human capital development. Moderate evidence suggests their positive effect in many Latin American countries. For example, Rawlings (2004) summarizes the evidence from a series of evaluations of cash transfers. In quasi-experimental trials in Mexico and Nicaragua, studies found that after accounting for household and community characteristics, average enrollment rates increased for girls, in both primary and secondary schools, in addition to significant increases in nutrition monitoring and immunization rates. There were also decreases in illness rates and the probability of stunting among children ages 12 to 36 months. Food consumption also rose with higher expenditures on fruits, vegetables, and animal products in Mexico, but remained unchanged in Nicaragua, likely due to worsening economic conditions in the country.

South Africa also has well-documented, promising experience with child support grants. These are monthly stipends given to primary care givers of poor children (based on means testing) under the age of 7. A study of 12,865 children under the age of 7, 3,754 of whom were actively receiving a child support grant found that although the grants do not specifically target

HIV-affected children, they have been successful in reaching children in poorer households, and girls as much as boys (Case et al., 2003). Moreover, less well educated mothers and fathers, unemployed mothers and fathers, and divorced/ separated/or widowed mothers were found to be significantly more likely to report receiving a grant. Children whose mothers were not present in the household were significantly less likely, however, to receive a grant. Street children and child-headed households had trouble accessing the grant because they did not have the necessary identity documents to apply, or they did not know how to apply. After five years of implementation, about one-third of age-eligible children had been reached by these grants. Although school enrollment was significantly higher for children receiving the grants than similar children who did not, and also higher than older siblings when they were the same age but did not receive the grants, after controlling for age, gender, family and household characteristics, the study concluded that explanations other than the grants could have explained the difference, and so did not conclude the grants had an impact on school enrollment.

6.3.3 Gaps in information on economic strengthening interventions

Interventions not adequately documented; impact not yet evaluated: Although myriad economic strengthening activities were mentioned to address the socioeconomic challenges of families and children, most of the literature had very little description of specific processes or mechanisms of interventions or any evaluation data examining their effectiveness. Examples of interventions that were mentioned included conditional cash transfers, savings and loan schemes, grants, cost-sharing schemes, income-generating activities, and technical skills training. For example, micro-credit loans are being used by Save the Children in Vietnam to support families to care for HIV-positive children (Webb & D'Allesandro, 2004), and in Thailand, joint community funding is conducted through fundraising activities to support children orphaned by AIDS (Hennessey, 2001). However, scant documentation or evaluation of these interventions makes their replication impractical, if not unwise. Questions remain as to how well these interventions may work in different resource-poor settings.

6.4 Conclusions about socioeconomic situation

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. There is mixed evidence, however, about the impact of worsening socioeconomic status on children living in HIV-affected households, especially to what extent rising health costs result in reduced spending on children's needs. While many children affected by HIV/AIDS were already living in poor households, clearly, HIV infection in the household worsens overall household socioeconomic status.

There are economic strengthening interventions, such as South Africa's child support grant, that demonstrate effectiveness at reaching poor children, although the impact of such assistance on child outcomes such as school enrollment and health care indicators has yet to be documented conclusively and has not specifically targeted children affected by HIV/AIDS.

Chapter 7 Education

This chapter, on educational challenges of HIV/AIDS affected children, reviews the evidence on the extent to which affected children are enrolled in and attending school, and on their academic performance.

A number of multi-country studies with control groups have examined school enrollment related to orphan status, and several have compared HIV-affected and unaffected households in a given country. Geographic spread and the evidence are quite broad, although no studies were found from Latin America or the Caribbean.

Evidence cited on education and children affected by HIV/AIDS Base (n=26)

Authors	Rigor	Type (Location)
Ainsworth & Filmer 2002	Good	Controlled, cross-sectional quantitative (worldwide)
Ainsworth & Filmer 2006	Good	Controlled, cross-sectional quantitative (worldwide)
Alkenbrack et al. 2004	Good	Cross-sectional with controls (Cambodia)
Amolo et al. 2003	Fair	Descriptive qualitative (Nigeria)
Borthwick 2004	Poor	Literature review (Southeast Asia)
Case et al. 2004	Good	Controlled, cross-sectional quantitative (Africa)
Dekens & Charruau 2003	Fair	Descriptive qualitative (DR Congo)
GCE 2004	Fair	Literature review (worldwide)
GECA et al. 2005	Fair	Controlled, cross-sectional quantitative (Benin)
Gregson et al. 2001	Good	Descriptive qualitative analysis (sub-Saharan Africa)
HRW 2005	Good	Descriptive qualitative interviews (Russia)
Jianhua et al. 2006	Fair	Controlled, cross-sectional quantitative (China)
Kelly 2006	Fair	Qualitative analysis (worldwide)
Loudon et al. 2007	Good	Qualitative study (India)
New ERA Team 2006	Fair	Descriptive qualitative interviews (Nepal)
Pradhan & Sundar 2006	Good	Controlled, cross-sectional quantitative (India)
Safman 2004	Good	Descriptive qualitative (Thailand)
SCF/UK 2006d	Fair	Descriptive quantitative/qualitative (Thailand)
SCF/UK 2006e	Fair	Descriptive quantitative/ qualitative (Asia)
UNICEF 2002	Good	Descriptive qualitative (Nepal)
UNICEF & SCF 2007	Good	Controlled, cross-sectional quantitative (PR Lao)
USAID-AED 2004	Fair	Literature review (Africa)
Vandemoortele & Delamonica 2000	Good	Descriptive (worldwide)
Webb 2004	Good	Qualitative study, literature review (worldwide)
WHO & UNAIDS 2000	Fair	Descriptive quantitative (worldwide)
World Bank 2002	Fair	Descriptive qualitative (worldwide)

7.1 Information needed for programming around educational challenges.

Programmers need to understand the impact of the HIV epidemic on existing education determinants for the population under consideration; such determinants include household resources; household education level; gender; age; orphan status; and barriers, such as level of infection, work load outside the school, stigma, and discrimination that children affected by HIV/AIDS face in enrolling, attending, and completing school.

Impact of HIV/AIDS on the common determinants of school enrollment among the affected household: *Socio-economic status of the household:* Is HIV/AIDS compounding the impact of poverty on school enrollment or is school enrollment a direct result of income level, regardless of HIV status of the household? *Gender:* Is the gender gap in education compounded by the HIV epidemic? Are girls, living in HIV-affected households or girl-orphans at increased risks of not being enrolled in school than girls living in non-HIV-affected household? *Education level of the household:* Is the normal positive impact of head of the household's education level on school enrollment affected by HIV/AIDS? Or does the level of education remain a "protective factor" in terms of HIV/AIDS preventive behaviors, regardless of the level of infection in the household?

Factors influencing the effect of HIV/AIDS on education: *Level of infection in the household, including the child's infection status:* Are children affected by HIV/AIDS at increased risks of dropping out of school or/and absenteeism due to the disease burden within the household? How is this impact affecting children affected by HIV/AIDS by gender, age groups, and area of residence? *Perceptions of safety in school-the role of stigma and discrimination:* How is the school environment perceived by HIV affected households? Is school perceived as a less safe place because children are living in an infected household or are themselves infected by HIV? How is stigma and discrimination affecting the decision to enroll and keep children in school? *Relationship with caretaker:* Are some groups of children affected by HIV/AIDS more at risk of not being enrolled in school because of living and foster care arrangements? Are some groups more at risk than others, such as paternal orphans, maternal orphans, or double orphans?

Consequences of not addressing the impact of HIV/AIDS on the education:

Is the vulnerability to infection of school-age children and adolescents affected by HIV/AIDS linked to limited access to information and preventive messages? Is access to education a "vaccine" against HIV as described in some of the research?¹⁷ Finally, has school attendance been linked to increased resiliency in children affected by HIV? Are these children more able to develop coping mechanisms than children affected by the disease and not enrolled in school?

7.2 The situational findings on education

The evidence on educational challenges for children affected by HIV/AIDS in low prevalence and concentrated epidemic countries combines both large multi-country studies examining the effects of orphanhood (not specific to AIDS) on enrollment and attendance in school, several cross-sectional studies with control groups (mostly from Asia) on enrollment, drop-out rates and attendance, and a wide array of qualitative studies examining the challenges children and caretakers affected by HIV/AIDS face to keep children in school.

7.2.1 Findings with strong evidence

In Asia, younger children living in HIV/AIDS-affected households are not generally less likely to be enrolled in school: A large cross-sectional study with control households in India (Pradhan & Sundar, 2006) examined the household impact of HIV/AIDS on children's schooling, comparing children by gender and age groups (6–14 and 15–18 years old) living in HIV-affected households to same age groups living in non-HIV-affected households: 93% of the

¹⁷ Education level has often been associated with positive health behaviors and reduction of risks, such as using family planning and delaying first sexual experience (Vandermoortle & Delamonica, 2000).

1562 children aged 6–14 in HIV households were *ever* enrolled in school, compared to 97% of the 4861 children of that age from non-affected households. *Current* enrollment rates showed a similar pattern: 90% among children 6–14 in HIV households compared to 95% of children in the same age group in non-HIV households.¹⁸

A cross-sectional study with controls in Cambodia (Alkenbrack et al., 2004) reported similar findings. It compared 500 households affected by HIV/AIDS with the nearest neighboring household (n = 500): 442 children (6–12 years old) in the case group were interviewed; the comparison group included 414 children. Enrollment rates were high with no differences between cases and controls (97% to 98%).

In China, a cross sectional study compared attendance for 43 children orphaned by AIDS, 78 children living in HIV/AIDS-affected households, and 94 non-affected children in the same communities (where transmission was mainly due to blood selling). Enrollment rates were high overall, and no differences were seen among children living in HIV/AIDS affected households and unaffected children. Children orphaned by AIDS had lower attendance but the difference was not significant (Jainhua et al., 2006)

In Lao PDR, a quantitative study interviewed 115 children aged 6–18 years, of which 69% were HIV affected and 31% were not: 95% had *ever* been to school, and 83% were currently attending. No statistically significant differences between HIV-affected and non-affected children were found in enrollment rates. However, the mean number of years in school was lower for children affected by HIV/AIDS: 4.4 years compared to 5.6 years, but only significant at the $p = 0.054$ level (UNICEF & SCF, 2007).

In low prevalence Africa, where enrollment rates are generally not as high as in Asia, there were small differences in enrollment. A cross-sectional study interviewing 1013 children in Benin found 77% of orphans and vulnerable children 6–18 years old being enrolled compared to 82% of non-orphans (GECA et al., 2005).

Older children affected by HIV/AIDS appear less likely to be enrolled and attend school than their unaffected counterparts: Several studies allowed for a separate analysis of older children. For example, in India (Pradhan & Sundar, 2006), caretakers of 360 children 15–18 years old from HIV-affected households and 1981 from non-affected households were interviewed about enrollment. While differences were small for *ever* being enrolled in school (92% compared to 97%), they were larger for being *currently* enrolled: only 67% of those from HIV households were currently enrolled, compared to 81% in non-HIV households. For 15–18 year old children, this current enrollment gap was larger for girls living in rural areas (61%:79%) than for rural boys (69%:80%), urban girls (67%:80%), or urban boys (69%:83%). Adolescent girls (15–18 years) in HIV affected households were twice as likely to drop out of school as adolescent girls in non-HIV households: 34% of adolescents in HIV-affected households reported dropping out of school compared to 17% of girls in non-HIV households. Adolescent boys (26%) in HIV-affected households reported dropping out of school compared to 16% of adolescent boys in non-HIV households (Pradhan & Sundar, 2006).

¹⁸ No statistical analysis was presented of these results, although with such a large sample size, they are likely to be significant, even though the magnitude of the difference is not large.

Data from Cambodia (Alkenbrack et al., 2004) indicate lower enrollment rates for adolescents in HIV-affected households (13–18 years) compared to their peers in non-affected households: 68 percent compared to 74% ($p < 0.05$). Data from the qualitative research component revealed that children and adolescents were experiencing a high level of disruption in schooling for several reasons: lack of money to purchase uniforms, school supplies, and informal fees charged by the teacher; needing to work to supplement family income; or needing to stay at home to look after younger children or sick relatives.

Pradhan & Sundar's (2006) study in India also investigated the reasons for dropping out of school: the study indicated no difference in "could not afford" as the reason for dropping out, either among children 6–14 or those 15–18. However, the study showed increased responsibilities for children in HIV-affected households is a major reason for leaving school. Children 15–18 years of age living in HIV-affected households were more likely to drop out to take care of younger siblings or household chores, to take a job, or take care of ill family members (36% compared to 21% in the comparison group). This gap is larger for girls (32%:13%) than for boys (39%:29%), and girls drop out to take over household tasks, whereas boys drop out to take a job.¹⁹

Other qualitative studies also reported on the shift of responsibilities for children affected by HIV. These children in both low and high prevalence African countries were compelled to engage in domestic, agricultural, or wage work (Webb, 2004). The Cambodian study (Alkenbrack et al., 2004) did not find major differences in rates of general household work, but children and adolescents in HIV-affected households were significantly more likely to engage in activities usually conducted by guardians: children 6–12 years old working for money (21% in an HIV household: 12% in a non-HIV household, $p < 0.001$) and adolescents 13–18 years old (53%:40%, $p < 0.001$). However, no results were presented in light of enrollment rates.

7.2.2 Recurrent themes for which the evidence is moderate

The role of orphanhood on enrollment is mixed and not clear cut: Several multi-country comparative studies have been conducted using Demographic and Health Survey (DHS) data to examine the association of orphanhood and school enrolment. However, these studies were not able to separate out the causes of orphanhood and examine the effect of AIDS on this mix.

One analysis (Case et al., 2004) of Demographic and Health Survey data from eight high and two low prevalence African countries (Niger and Ghana) and covering 1992–2000 looked at children aged 14 and below. The results found a statistically significant difference in mean school enrollment rate between orphans and non-orphans. In both countries, double orphans showed the highest mean difference of school enrollment compared to non-orphans, followed by paternal orphans. Being a maternal orphan in these countries showed no impact in Niger and a positive association in Ghana on school enrollment. These low prevalence country-specific findings align with the general conclusions of the analysis of all ten African countries. The study estimated that overall single orphans were about 5% less likely to be enrolled in school than non-orphans, and that double orphans were 12% less likely. Lower enrollment for orphans was accounted for not solely by wealth, but also by the degree of relatedness to their caretakers (Case et al., 2004).

¹⁹ No statistical analysis presented in study.

A larger study of 102 national surveys from 51 countries worldwide found that the relationship between orphan status and child school enrollment varies significantly among low-income countries. As Table 1 shows, the evidence is mixed regarding the impact of orphanhood on school enrollment. The evidence is clear that there is no statistically significantly positive impact of double orphanhood on school enrollment (Ainsworth & Filmer, 2006).

Table 6: Relationship of orphanhood and school enrollment
n = 102 household surveys in 51 countries
(Ainsworth & Filmer, 2006)

	Paternal Orphans	Maternal Orphans	Double Orphans
Statistically significant negative impact on enrollment	39%	47%	53%
No significant impact on enrollment	61%	42%	48%
Statistically significant positive impact on enrollment		14%	

Another study (Ainsworth & Filmer, 2002) of 28 countries worldwide, using 39 nationally representative household surveys from 1992–2000 (34 DHS and 5 Living Standards) examined the relationship of parental survival, poverty, and school enrollment. The results show substantial heterogeneity in terms of enrollment differentials among orphans and non-orphans, regardless of HIV prevalence: for example, in Chad (low) and South Africa (high), the study found no difference in enrollment rates between orphans and children living with parents; in both Benin (low) and Kenya (high), single and double orphans had lower enrollment rates than children living with parents; in Tanzania (high) and Nigeria (low), orphans had higher enrollment rates than children living with parents. The role of poverty was inconsistent across countries; however, the study found that the gap between poor and non-poor children enrolled in school “dwarfed” the differential of enrollment rates between orphans and non-orphans.

Household structure and relationships affect the probability of orphans attending school: This conclusion is based on one study of demographic surveys in 10 African countries (Case et al., 2004). It found that issues of limited social connectedness, bias, and discrimination within the household, including blended households, are negatively associated with orphanhood schooling: the probability of school enrollment is inversely proportional to the degree of relatedness of the child to the household head. For instance, children listed as “grandchildren” are generally at the smallest disadvantage, and children with the lowest rates of school enrollment are those who live in households headed by non-relatives, presumably foster children. In Ghana and Niger, orphans living in a household headed by a non-relative were four times less likely to be enrolled in school than those living in a household headed by a relative, and orphans living with grandparents had no difference in enrollment than compared to non-orphans. In Niger, though the risk was not in the same magnitude, the trend held true: the stronger the family relation, the more likelihood of being enrolled.

Children and their families fear discrimination from the school administration, teachers, peers, and the community: A large qualitative study in India (Loudon et al., 2007) of children affected by HIV (with an HIV-positive parent or orphaned by AIDS) reported that stigma was one of the major reasons for dropping out of school. In focus groups of 281

pre-adolescents (aged 9–12), 295 adolescents (1–17), 487 care givers, and 441 heads of households, questions sought to identify the barriers to services for children affected by HIV. The children reported that ostracism and humiliation by their peers were their major concerns. Young children reported losing interest in their studies, becoming depressed, and even dropping out of school because of taunts by peers. The findings highlighted that in some cases teachers actively discriminate and even mistreat affected children in the classroom by neglecting or abusing them. The adult caregivers all unanimously reported that stigma and discrimination by the teachers was the major educational barrier. Some caregivers reported that some children with positive parents were refused school admission.

In several smaller qualitative studies in Russia, Thailand, and East Asia/Pacific, respondents said that discrimination was a major concern of caregivers of children affected by HIV/AIDS. The fear of disclosing the HIV status of their parents and family members with peers is high among affected children, with the anticipation that disclosure can lead to further discrimination (Borthwick, 2004; HRW, 2005; New ERA Team, 2006). Reports of discrimination, such as being expelled from school when HIV status is known or being taunted, were documented as anecdotal evidence (Bothwick, 2004). A qualitative study with focus group discussions and unstructured interviews with 21 caregivers (grandmothers), conducted in one district in Thailand, reported that preschools and daycare centers were reluctant to include AIDS-affected children in their programs (Safman, 2004). Such anecdotal reports are suggestive only, identifying issues that need to be investigated more systematically.

Children affected by HIV/AIDS drop out of school because of economic factors, but not necessarily because of the cost of school: In India (Pradhan & Sundar, 2006), a large cross-sectional study with controls found a trend in income associated with school enrollment: households with higher incomes are more likely to enroll and keep their children in school, and this same pattern is true for HIV/AIDS-affected households.²⁰ Only at the highest income levels are there no differences in enrollment between HIV-affected and non-affected households. As mentioned in reasons for dropping out, “could not afford” was not significantly different between the two groups.

A number of qualitative studies in Asia, Africa, and Russia cite lack of funds as a factor of great concern for caretakers related to ensuring schooling for children living with ill parents or orphaned by AIDS (New ERA Team, 2006; UNICEF, 2002; USAID-AED, 2004; HRW, 2005; Jianhua et al., 2006). A small qualitative study in three different locations in Thailand, which included focus group discussions with 21 caregivers of children who had lost at least one parent to AIDS, reported that their dominant concern was the cost of child-rearing. Respondents (grandmothers) reported that education was deemed necessary, but they were unsure whether they could sustain costs and fees related to education (Safman, 2004). Another report examining the educational opportunities of children affected by HIV/AIDS in six Southeast Asian countries shows that if children were sent to live with grandparents when parents became sick or died, they received fewer opportunities to attend school due to financial constraints (SCF/UK, 2006e). However, these are reports, rather than a control study, and may reflect concerns rather than experiences.

²⁰ However, no statistical analysis is presented on this trend.

7.2.3 Gaps in information on the situation

Information from a wider range of countries (and continents) is needed on the impact of HIV/AIDS in the household on school enrollment: Data from several case-control studies indicate that where enrollment is generally high, no significant differences exist between HIV-affected and non-affected households. However, few studies show HIV's potential effects in Africa or Latin America. In addition, the affects of HIV/AIDS on education differ depending on the stage of illness – as parents become more severely impaired and then die, and the children move to other guardianship, barriers to education may vary. This dynamic nature merits closer examination: much more information on education is needed on rates of enrollment, completion, segmentation by age group (young children, young adolescents, older adolescents), gender issues, costs, and psychosocial factors regarding orphans and schooling.

Barriers to education related to or exacerbated by HIV/AIDS: While the economic impact of HIV/AIDS on the education of children when parents are ill appears clear (see Chapter 6 as well), the dynamics are not so clear: are children dropping out because of the cost of education (school fees, uniforms, other direct expenses) or its opportunity cost (ability to help in the household when parents are ill, ability to help earn income for the household)? How does this vary in different cultural and socio-economic settings?

The dynamic nature of the effect of HIV/AIDS on education: While there is some evidence about children who live with HIV-positive parents and about the impact of orphanhood in general, evidence is limited on orphans due to AIDS and their education, and about the transition period between the time when children are still living at home and caring for sick parents and the time after their parents' deaths. How long does it take for children whose parents die to re-enter the school system? What factors influence their enrollment after a parent's death?

Academic performance and HIV/AIDS: Data are also lacking on the educational problems of children affected by a parent's death, the psychosocial impact on their educational performance, and the educational needs of children born with HIV. Furthermore, despite the limited evidence on orphan status and enrollment rates, enrollment rate is only one education-related indicator. There is limited information on the quality of learning for children affected by HIV/AIDS and for orphans and vulnerable children in general. Children might be enrolled in school but not learning because they are grieving, worried, and/or hungry, or missing classes to take care of family members.

7.3 Interventions to address education challenges

Few studies have examined educational interventions and their impact on the families affected by HIV/AIDS or the community. Fewer still have evaluated interventions, and no data exist on the effectiveness of such interventions across different settings.

7.3.1 Findings with strong evidence

No data were found on education interventions that have been systematically evaluated.

7.3.2 Recurrent themes for which the evidence is moderate

The "Education Vaccine" against HIV: Reports describe in general terms the importance of education in providing protection against HIV infection; in reducing girl's vulnerability to HIV by contributing to female economic empowerment, delayed marriage, and increased use of family

planning; in bringing students, parents, teachers, and community members together (World Bank 2002). World Bank-sponsored studies show that once the epidemic's transmission methods were known, educated people were more likely to adopt safer behaviors. Other studies showed also that as the epidemic was better understood; educated people had lower rates of infection, especially among the younger people (World Bank, 2002; Gregson et al., 2001; Kelly, 2006; Vandemoortele & Delamonica, 2000)

An analysis of 32 post-1990 demographic and health surveys from 32 countries (both high and low prevalence) found that nearly half of illiterate women lacked the basic knowledge to protect themselves against HIV (Vandemoortele & Delamonica, 2000). Their lack of minimum knowledge about AIDS is about five times higher than for women with post-primary education. The results of the analysis clearly show that knowledge about the various aspects of HIV/AIDS increases with higher level of education. In 17 countries in Africa and 4 in Latin America, better-educated girls tended to delay sex and were more likely to require their partners to use condoms (WHO & UNAIDS, 2000). Women with some schooling are nearly five times more likely than uneducated women to have used a condom the last time they had sex. During the 1990s the HIV infection rate fell by almost half among educated women, with little decline for women without any formal schooling. (Vandemoortele & Delamonica, 2000). An analysis of UNICEF's Multi-Indicator Cluster survey for 12 countries (3 high prevalence, 9 low prevalence, 11 in Africa) found that women with primary education were 2.5 times more likely than women with no schooling to correctly identify ways to prevent transmission (GCE, 2004).

School-based interventions are associated with delaying age at first sex, number of sexual partners, and condom use. A review of 113 studies from 5 continents found that school-based AIDS education that focus on specific age-appropriate behavioral objectives are effective in reducing early sexual activity and high risk behaviors. (Kirby et al., as cited in GCE, 2004).

Financial subsidies might help increase enrollment of vulnerable children in some countries: Programs to subsidize school fees for children affected by HIV/AIDS (or specifically orphans due to AIDS) have been promoted and tried in a number of high prevalence countries. The Vulnerable Children Project implemented by the Centre for Development and Population Activities in Benue State in Nigeria reported an increase in school enrollment and retention among orphans and vulnerable children once school subsidies were implemented. The Project conducted a baseline study, identified 3033 orphans (including those orphaned by AIDS but not exclusively), and found that 83% who had been reported as being enrolled in school were not attending due to expulsion for fees and other costs, although it did not include a comparison group of non-orphans. The evaluation conducted at the end of the Project showed that 1000 orphans were enrolled in the Project, that they were attending school on a regular basis and that there were no incidents of school expulsion due to non-payment of fees (Amolo et al., 2003).

In DRC, a UNICEF project specifically targeted orphans and vulnerable children in six primary school sites. At the beginning of the project, the enrollment rates nationwide for double orphans was estimated at 48%, for single orphans at 58%, and other non-orphan children at 68%. The project strategy was to convince schools that were already receiving UNICEF support to remove school fees or "motivation payments" for orphans, through advocacy campaigns, community mobilization, and seed money for schools to develop income-generating activities to replace the loss of income from the removal of "motivation fees." These activities resulted in

more than 16,000 orphans, 6–14 years old, being enrolled in school or 70% of identified orphans in this age group (Dekens & Charruau, 2003).

7.3.3 Gaps in information on education interventions

Many interventions have been proposed to alleviate the problems and barriers to education for children affected by HIV/AIDS in Africa and elsewhere, but few have been properly evaluated to measure their impact. The following are examples of interventions to improve education for affected children for which our search found no evidence of effectiveness or ineffectiveness:

Targeting orphans and vulnerable children: Tailored programs targeting orphans with school subsidies are sometimes cited as contributing to discrimination and jealousy within communities. For example, Nigeria's Vulnerable Children Project also reports that though communities were empowered to identify the most vulnerable children to enroll in the Project, this might have increased the stigma experienced by these orphans. In addition, the distribution of free uniforms and other items to a small group of orphans created jealousy among the other children from very poor households who received no subsidy (Amolo et al., 2003). However, no identified study explored this issue in depth and tested other solutions (Stigma is covered in Chapter 11).

Harnessing community-based resources: Although several studies mention use of community resources, such as "homework centers" in Vietnam (Borthwick, 2004) and teachers in Thailand at the Life Home Center who are helping to take children to school (SCF/UK, 2006d) and indicate that these may be useful interventions, no data were presented to evaluate their effectiveness or efficiency.

Though in qualitative studies, stigma, perceived or real, has been associated with under-enrollment of HIV/AIDS affected-children, limited evidence of interventions in low prevalence countries to address such stigma and discrimination barriers was found.

7.4 Conclusions about education

The evidence base related to education and HIV/AIDS includes a number of studies that examine the effects of HIV/AIDS in the household on the education of the children. However, these studies, although often with control groups, do not fully examine this issue. The lack of statistical analysis in some studies and the lack of clear documentation and presentation of results precludes strong conclusions. In addition, the stronger evidence is mostly focused on Asia. Our search highlights the need for more research explaining the impact of HIV/AIDS in low prevalence countries on education for orphans and vulnerable children. Clearly, the impact of orphan status on school enrollment is country-context specific. It will depend on the socioeconomic and cultural contexts, including the role of extended families, communities, and norms about responsibility. It will also depend on the extent of orphanhood in the country. Causes other than AIDS lead to orphanhood, including other threatening illnesses, wars, and living conditions. The extent of orphanhood will also affect how societies build systems to care for these children, HIV affected or not.

This research highlights the priority to conduct country-specific research, to explain which factors affect enrollment of children affected by HIV, infected by HIV, and orphaned by HIV. The findings from this research pointed to the complexity of the relationship among poverty,

*The evidence base for programming for children affected by HIV/AIDS
in low prevalence and concentrated epidemic countries*

stigma and perceived stigma, increased responsibilities of children affected by HIV, level of education of the household, and gender.

Evidence on interventions revealed limited tailored approaches to address the different segments of children affected by HIV and maybe other long-term illnesses (HIV affected, HIV infected, and HIV orphans). Most of the studies regrouped the children under the general term orphans and vulnerable children (OVCs), while the India studies showed that young girls affected by HIV are highly vulnerable to drop out of school to take care of younger siblings, and young boys affected by HIV are at increased risk of not completing their education to look for work.

Two trends from the research emerge: (1) children affected by HIV in low prevalence countries are at increased risk of not completing school to take care of a member of the affected household or to supplement the income. Increased responsibilities for the affected household seem to be a major barrier for affected children to complete their education. (2) Stigma and discrimination, real or perceived, have been reported by many studies as being a factor deterring parents to enroll their children in school.

Finally, studies in high prevalence countries have shown that as the epidemic progresses, the poor and illiterate are increasingly affected. This underscores the essential priority in low prevalence countries to prioritize programs tailored to the most economically disadvantaged households to keep children in school, regardless of HIV status. Education might be the most powerful tool for slowing and reversing the trend of the epidemic, even in low prevalence countries. Research about the "Education Vaccine against HIV" makes a compelling case for using education as one of the most powerful tools for slowing and reversing the spread of HIV.

Chapter 8 Psychosocial support

“Psychosocial support” refers to a broad category of issues relating to the social and emotional needs of children, including stability, affection, and reassurance as well as their psychosocial well-being, such as being happy, hopeful, or feeling that one belongs. Such support is determined by the material and social environment surrounding children and a child’s age-appropriate, developmental capacity for psychosocial experiences. Ideally, care and support to meet these needs come from interactions with families, community members, and peers. However, for children affected by HIV/AIDS, this kind of support may be limited for several reasons: increased demands on the families to care for members infected by HIV, the loss (due to AIDS) of the caregivers who would provide this support, and limited community involvement due to fear, stigma, and discrimination. In such cases, affected children may require additional mechanisms of support, such as counseling or mentoring, although all affected children are not always vulnerable or in need of external support. In addition, children affected by AIDS may be more vulnerable to psychosocial distress than their peers due to exposure to illness, death, stigma, and discrimination, and resulting poverty and social isolation.

The vast majority of quantitative evidence that has been documented on psychosocial support comes from developed countries, especially the United States. Several descriptive qualitative studies from low prevalence or concentrated epidemic countries, especially Thailand, were reviewed, as were a comprehensive literature review and a few studies from high HIV-prevalence countries that appeared relevant to this review.

Evidence cited on psychosocial support and children affected by HIV/AIDS (n = 21)

Authors	Rigor	Type (Location)
Abbott Labs Fund 2001	Good	Descriptive quantitative/qualitative (Burkina Faso)
Alkenbrack et al. 2004	Good	Controlled, cross-section, quantitative (Cambodia)
Bauman et al. 2006	Good	Uncontrolled cross-sectional quantitative study (US)
Brandt 2005	Good	Literature review (worldwide)
Carswell et al. 2005	Fair	Descriptive qualitative (Thailand, Cambodia)
Dougherty et al. 2005	Fair	Cost analysis (Rwanda)
Hennessey 2001	Fair	Descriptive qualitative (Thailand)
Hough et al. 2003	Good	Controlled cross-sectional quantitative study (US)
Jianhua et al. 2006	Fair	Controlled cross-sectional quantitative study (China)
Lester et al. 2006	Good	Randomized controlled intervention trial (US)
Loudon et al. 2007	Good	Qualitative Study (India)
NAC/Jamaica 2002	Poor	Descriptive qualitative (Jamaica)
Nostlinger et al. 2006	Good	Controlled cross-sectional quantitative study (multi-country western Europe)
Ostrom et al. 2006	Good	Descriptive qualitative/quantitative (US)
Pelton & Forehand 2005	Good	Controlled longitudinal study (US)
Pivnick & Villegas 2000	Good	Descriptive qualitative (US)
Rotheram-Borus et al. 2003	Good	Randomized control intervention trial (US)
Safman 2004	Good	Descriptive qualitative (Thailand)
SCF/UK 2006a	Fair	Descriptive qualitative (China)

SCF/UK 2006d	Fair	Descriptive qualitative (Thailand)
Tisdall et al. 2004	Good	Descriptive quantitative/qualitative (Scotland)

8.1 Information needed for programming around psychosocial challenges

To develop strategies addressing psychosocial challenges, information is needed not only on the children's psychosocial situation – Who is affected and/or vulnerable? What psychosocial needs exist? What support mechanisms are in place? – but also on interventions to support affected children and families – How are those with the greatest need identified? What has worked in addressing these needs? What hasn't worked, and why? Successful interventions may be ones that bring about an environment that supports the psychosocial well-being of children, rather than ones that try to implement specific psychosocial support functions directly.

Relative psychosocial vulnerability: Specific evidence on the psychosocial vulnerability of children affected by HIV/AIDS by age, caretaking situations, and infection status is necessary for programming. However, local conditions appear to be paramount to the understanding of psychosocial stress in affected children, such as early marriage, sexual abuse, child labor, etc. How can evidence be obtained about the relative impact of different local conditions on affected children? What factors contribute to increased vulnerabilities? Which factors, if any, have been shown to be protective?

Responsiveness of parents and/or caretakers to address children's needs: As noted earlier, not all children are vulnerable to HIV to the same extent, and for programming purposes, external support may not be needed among affected children who are supported locally by parents and family members. Thus, information is needed on the number of children without adequate support and who those children are so that programs can be put in place that reach them. This information should answer the questions: Are guardians providing needed care? What are children's perceptions regarding their environment?

Assessment of support outside the family structure: For children whose psychosocial needs remain unmet within existing familial structures, information is needed about other sources of support beyond the household. An assessment of unmet needs is crucial in designing programs to target specific challenges faced by children across ages and levels of vulnerability.

8.2 Situational findings on psychosocial support

There is substantial evidence, both quantitative and qualitative, on the psychosocial support situation of children affected by HIV/AIDS as compared to unaffected children in high prevalence settings. Little and less rigorous evidence, however, is available from low prevalence and concentrated epidemic settings.

8.2.1 Findings with strong situational evidence on psychosocial support

Children affected by HIV/AIDS are more vulnerable to psychological problems than unaffected children: There is strong evidence documenting the extent of psychosocial problems experienced by children affected by HIV/AIDS – both orphaned children and children living with chronically ill parents. This evidence suggests, but is not definitive for low prevalence countries, that many, although not all, affected children experience substantially more psychosocial problems than unaffected children. The most rigorous studies were conducted in developed settings such as North America and Europe. However, this evidence

does not tell us if the psychosocial problems of HIV/AIDS-affected children are any different from other children who also are experiencing many of the same problems as the HIV/AIDS-affected children but for reasons other than HIV/AIDS, such as stigma and discrimination, parents with debilitating diseases, or orphanhood.

A randomized interventional trial of 423 New York City adolescents with one or both parents living with AIDS assessed the teens' psychosocial state four years after study enrollment using three tests that measured "recent" anxiety disorders, "lifetime" anxiety disorders, and post-traumatic stress disorders. The study noted that the anxiety scores were "high" for the study teens compared to the non-study comparison teens and that teens whose parent had died of AIDS prior to the test (more than half had died) were more than twice as likely to have abnormal "lifetime" anxiety disorders ($p < 0.05$) as teens whose parents had not died of AIDS (Lester et al., 2006). In a controlled longitudinal study in New Orleans, 6- to 11-year-old orphans whose mothers had died of AIDS had higher rates of behavior problems both before the mother's death and two years following it than children with surviving HIV-infected or uninfected mothers (Pelton & Forehand, 2005). A cross-sectional study of 147 mother-child pairs of pre-teen youth who were living with HIV-positive women found that, compared to normative populations, the HIV/AIDS-affected children had significantly more internalizing and externalizing behavioral problems (Hough et al., 2003). These findings were consistent with results from a review of coping and psychosocial adjustment. The review summarizes evidence that children of HIV-positive mothers have an increased risk for psychosocial adjustment problems compared to children of non-infected women (Brandt, 2005). This risk may also vary by the child's HIV status: in western Europe, cross-sectional findings from clinics in 10 countries showed that when compared with HIV-negative children, HIV-positive children had significantly increased reports of suicide attempts (Nostlinger et al., 2006).

In low and middle income countries, studies reveal similar challenges regarding affected children's emotional well-being, although the evidence base lacks the rigor observed in developed settings. In China, a cross-sectional study of children aged 6- to 17-years with at least one infected parent ($n = 121$) found that they were significantly more likely to report feeling more worried, stressed, or disliked by others than children living with HIV-negative parents ($n = 94$). More than 60% of the children affected by HIV/AIDS reported being stressed, compared to 36.4% of children not thus affected. The affected children reported lower self-esteem than the non-affected, and 40% of them felt not liked by others (Jianhua et al., 2006). In this Chinese study, significantly more HIV/AIDS-affected children said they "get into more trouble than usual," and "can't shake off sad feelings" than non-affected children. More specifically, the results were: "Get into fights" – said by 17% of affected and 7% of non-affected children, "Get into trouble more than usual" – said by 60% of affected and 30% of non-affected children, "Able to make friends" – said by 81% of affected and 87% of non-affected children. None of the comparisons was adjusted for potential confounding by other factors measured in the study that might have influenced the psychosocial condition of the child. Another study in China conducted 315 interviews with children aged 5–18 years, but did not control for HIV status of the children or parents. Rather, the question was addressed more broadly – of children who had lost a parent, had a drug-using parent, or was ill. Mental distress and torment were often reported. Increased sadness, despair, and loss of confidence were reported by children who had lost a parent. Children reported discrimination both as a result of drug use by or HIV infection of family members (SCF/UK, 2006a).

In a qualitative study of children of HIV-infected parents in India, children reported being verbally abused, scolded, and kept away from neighbors, family, and peers. HIV/AIDS-affected children reported high discrimination and stigma and feelings of loneliness, depression, insecurity, and worthlessness. The affected children reported a lack of love and care from community elders, relatives, and friends. They felt ashamed about their parents' illness and were reluctant to approach other adults and friends for fear of rejection. (Loudon et al., 2007)

Not every child, however, who is affected by HIV/AIDS has increased psychosocial problems. Evidence shows that in some cases these children may not have more needs than unaffected children. In the U.S. intervention trial described above, over half of the youth reported no anxiety or depressive disorders, even in the face of parental HIV illness or death (Lester et al., 2006). Thus, while we know that HIV/AIDS-affected children have increased psychosocial vulnerability, this is not true for all of them. In Cambodia, the results of a descriptive qualitative and quantitative study on orphans and vulnerable children (between 6 and 18 years living in the community who are either single or double orphans from any cause or living in a family where one of the parents or both are infected with HIV) showed a wide variation in the psychosocial problems (Carswell et al. 2005). Despite the general conclusion that orphans and vulnerable children experience increased levels of psychological and emotional distress, there is a wide variation among these children regarding levels of psychological distress. Furthermore, the factors that are inherently part of the reasons that children are affected by HIV/AIDS and appear to cause psychological stress in orphans and vulnerable children may also be the result of conditions other than HIV/AIDS. Thus, although Carswell et al. (2005) showed that physical and verbal abuse, level of psychological distress of the guardians, and health status of the guardians were all significant predictors of psychological distress in orphans and vulnerable children, these predictors may also be caused by phenomena other than HIV/AIDS and thus apply to other children as well.

Numerous studies provide evidence regarding risk and protective factors relating to the psychosocial well-being of HIV/AIDS affected children: A cross-sectional study of 718 HIV-infected parents (one per household) and their 1136 HIV-affected children aged 0–18 years in 10 western European countries found a strong relationship between how well the family was functioning and the children's psychosocial condition, as reported by the interviewed parent. The children's emotional and behavioral problems included such symptoms as nervousness, restlessness, learning problems, physical problems, depressiveness, aggressiveness, anxiousness, guilt feelings, eating problems, and contact problems. A multivariate analysis determined that the strongest predictor of a child's emotional and behavioral problem score by far was "family functioning" ($p < 0.05$), where the mean child problem score for the worst functioning families (lowest quartile) was more than twice the mean score for the families functioning in the higher three quartiles. Other less significant predictors of the problem score included HIV/AIDS-related discrimination against parent or child, non-disclosure of HIV-positive status to children, and partner support (Nostlinger et al., 2006). In another U.S. cross-sectional study of 50 children living with HIV-positive mothers, a strong parent-child relationship was the greatest predictor of a child's mental health as measured by various psychosocial indices (Bauman et al., 2006). A comprehensive review of recent literature (123 published and unpublished studies in 1990–2005) concludes that the parenting quality and consistency over time of the primary caregiver are significant mediators of child development outcomes (predicting significantly more variance than HIV infection status) (Brandt, 2005). The review also reports that parental support is more protective than extra-

familial support. As it points out, these findings are similar to findings for children of parents with other serious physical illnesses, and as such gives credence to the Brandt's findings about HIV-infected parents but also means that the psychosocial problems faced by children of HIV-infected parents are no greater than those of children with parents with other illnesses.

Children of HIV-infected mothers tend to receive lower levels of protective support than those of non-infected mothers (Brandt, 2005). Lack of affection was perceived as a significant problem by 8% of community members in a largely descriptive needs assessment of children orphaned and made vulnerable by HIV/AIDS in Burkina Faso (Abbott Lab Funds, 2001), and in a descriptive study of 111 Thai children living with HIV-infected parents, children reported being neglected by parents who themselves were burdened or depressed as a result of HIV infection (SCF/UK, 2006d).

8.2.2 Recurrent psychosocial themes with moderate situational evidence

HIV-AIDS-affected children of different ages face different challenges: In western European countries, parents reported a particularly high level of vulnerability in their "pre-adolescent and adolescent children," who were more likely to know of their parent's HIV status than younger children (Nostlinger et al., 2006). Western European children aged 10–19 living with an HIV-infected caregiver have shown an increased sense of isolation and stigma, behavioral problems, and risky sexual behavior with multiple partners relative to their non-HIV-affected peers or relative to younger affected children (Brandt, 2005). A quantitative, cross-sectional study in the U.S. suggests that HIV-infected parents are more apt to protect younger children from the psychosocial consequences of HIV/AIDS – such as knowing of their parent's HIV status (Ostrom et al., 2006). The most common reason for non-disclosure among parents in this sample was wanting to avoid scaring the child and wanting to avoid jeopardizing the carefree life of the child.

Children living in HIV-affected households rate their quality-of-life lower than children in non-HIV-affected comparison households: In Cambodia (Alkenbrack et al., 2004), 718 children and adolescents living in HIV-affected households and 725 in non-affected neighboring households were asked to rate their quality of life using the KINDL index: those living in HIV-affected households scored significantly lower than neighboring children on overall quality of life ($p < 0.001$), especially on measures of emotional well-being, self-esteem, friends/social life, and school.

8.2.3 Gaps in information on the psychosocial situation

Little evidence from low prevalence and concentrated epidemic settings: Most of the evidence base comes from developed countries or those with high prevalence, with fewer studies being conducted in low and middle income countries across regions and categories of affected children. Because contextual factors play an important, and possibly even overwhelming role, in mediating psychosocial adjustment of children affected by HIV/AIDS, contextual specificities need to be assessed to inform program design. Other factors associated with increased children's vulnerability and psychosocial stress – early marriage, female genital cutting, girls trafficked into sex, sexual abuse, child labor, homelessness and poverty, and armed conflicts – are also some of the factors, depending of the country's context, that are associated with high psychosocial stress.

Psychosocial impact across stages of illness, caretaking situations, and social/cultural contexts: More evidence about the psychosocial needs of children at

different stages of HIV infection (child or caretaker) would be useful in designing and timing psychosocial interventions, especially as caretaking situations change. Further, evidence about the social and cultural contexts in which HIV/AIDS affected children live, and about the different psychological stressors and the strategies the children use to deal with them in the varying contexts would be particularly useful for designing and implementing context specific programs.

Extra-familial support: While the family's role the provision or lack of psychosocial support has been well studied, the mechanisms of support existing outside the family structure (peers, schools, inter-organizational referrals, etc.) are not as well documented. More evidence is needed on the role these support structures play.

8.3 Interventions to address psychosocial challenges

Evidence about interventions to address the psychosocial challenges for children affected by HIV/AIDS is severely lacking, especially in low and middle income countries and most glaringly from low prevalence and concentrated impact settings. Psychosocial aspects often receive low priority in HIV/AIDS programming even in high prevalence settings, so it is not surprising to find no evidence on interventions in low prevalence settings. Furthermore, psychosocial well-being is one of the hardest (least measurable) intervention outcomes to study. The limited intervention evidence described here comes from the United States.

8.3.1 Findings with strong intervention evidence on psychosocial support

No evidence was found that could be classified as strong regarding psychosocial interventions for children affected by HIV/AIDS. While there are undoubtedly interventions underway, they have not been adequately documented or evaluated to guide evidence-based programming.

8.3.2 Recurrent psychosocial themes for which intervention evidence is moderate

Psychosocial services can help to mitigate the impact of HIV on children: There is a dearth of evidence to show what interventions have been effective in addressing psychosocial challenges among affected children and families in low prevalence settings. However, among the few that have, there is moderate evidence to suggest that these challenges can indeed be mitigated by psychosocial services. Two impact studies, both conducted in the U.S., showed a positive impact on children and caretakers as a result of psychosocial support.

The first was conducted in New York with two- and four-year follow-up periods between randomized intervention and comparison groups (Rotheram-Borus et al., 2003; Lester, 2006). The intervention group consisted of 206 adolescents ages 11 to 18 and 153 HIV-infected parents who were trained in cognitive-behavioral skills to address challenges, such as coping with diagnosis, dealing with emotional distress, overcoming communication barriers, and making decisions in succession planning. At two years following the intervention, there were significant differences in the intervention and comparison groups in the psychosocial indicators for adolescents and parents, but at the four-year follow-up, both groups were comparable for all psychosocial indicators. The authors contribute the absence of impact in the later period to the short duration of the program – highlighting the need for strategies to ensure maintenance of program effects.

The second impact study assessed risk and resilience using qualitative methods among 25 children ages 10 to 18 years who were orphaned or living with HIV-infected adults and enrolled in a therapeutic after-school and summer program (Pivnick & Villegas, 2000). HIV-infected

parents were also enrolled in a community-based HIV service program providing long-term social and emotional support. Although there was no comparison group, the authors attribute reductions in depression and risk-taking to the psychosocial support received by parents and children.

8.3.3 Gaps in Information on psychosocial support interventions

Psychosocial interventions have not been adequately documented or evaluated to serve as evidence for programming: Several activities are underway that aim to improve the psychosocial well-being of children affected by HIV/AIDS. These include counseling and mentoring of children and/or caretakers, self-help groups, and various types of community mobilization. In some cases, psychosocial interventions are designed specifically for children and youth. For example, in Rwanda, children living in child-headed households are paired with mentors who are trained in psychosocial counseling and receive assistance in developing activity plans; and in Thailand, children's camps provide children with trained counselors to discuss their concerns and experiences (Hennessey, 2001; Dougherty et al., 2005). Self-help groups such as weekly clubs and after-school programs where children can discuss their concerns with individuals similar to themselves have also been implemented (Tisdall et al., 2004; Pivnick & Villegas, 2000).

In other settings, given the importance of the parent's or caretaker's own emotional well-being on that of the children living with them, interventions have coupled parental psychosocial support services with services for their children. In the U.S., group sessions with parents and youth were held. Yet little information is provided that details *how* these processes are implemented, what strategies were effective, and which were not. In fact, a wide range of the literature mentioned interventions aiming to provide psychosocial support to affected children and their families, including rather innovative approaches such as training of local spiritual leaders, although little is reported regarding how this is done.

Though some studies have been conducted evaluating the impact of psychosocial interventions, many more are needed that are specific to the various types of psychosocial support activities being conducted. For example, the evidence is scarce at best regarding effectiveness of self-help groups, mentoring, or other types of support – particularly in low and middle income countries and even more so in low prevalence and concentrated epidemic settings.

What additional psychosocial support can help affected children in disintegrating HIV/AIDS affected families: As HIV-infected families break down and their members become unable to meet children's psychosocial needs, alternatives are needed. Many HIV/AIDS-affected children cannot cope on their own, and their psychosocial situations often worsen rather than self-correct. Child-led surveys in central China found that children who had lost a parent to AIDS said they did not know who could help them given the limited availability of social networking links (SCF/UK 2006a). A qualitative study of orphaned children in Jamaica found that they were unprepared for their parent's death, and little counseling support was available for caretakers (NAC/Jamaica, 2002).

A variety of external support programs have been attempted to fill the need, and many have reported problems. For example, in a Scottish program, individual counseling by social workers was not deemed helpful by interviewed youth, with high turnover and too rigid an approach given as reasons (Tisdall et al., 2004). In Thailand, neither caregivers of orphans due to AIDS or key informant health workers identified psychosocial needs as an important area needing

attention during semi-structured interviews, focusing instead on material and financial issues (Safman, 2004). Innovative interventions need to be proposed that look beyond social services and careful investigations carried out that provide evidence on their effectiveness and costs to varying groups in varying contexts.

Environments that support psychosocial well-being: Information is needed about what interventions strengthen environments so that they support psychosocial well-being of affected children in different situations. The point is to enhance the environment and not to provide the psychosocial service directly.

Antiretroviral therapy and the psychosocial situation of children affected by HIV/AIDS: Given the evidence of the importance of parenting consistency and family support, the impact of ART on the psychosocial situation of children in HIV-affected households should be examined. Parents on ARVs are living longer and are healthier, thus ARVs may remove important stressors and risks for children affected by HIV/AIDS. On the other hand, the advent of ART may reveal the identity of HIV-affected households, increasing stigma and discrimination against household members. It may also induce stress, guilt, and secretive non-compliance behavior with the strict ARV compliance procedures. There is much uncertainty, and it will be important to investigate the real impact of ART on the psychosocial situation of HIV/AIDS affected children.

8.4 Conclusions about psychosocial support

While most of the evidence comes from developed country settings, there is rigorous evidence that indicates children affected by HIV/AIDS, especially adolescents, are indeed more vulnerable to psychosocial problems than children not affected by HIV/AIDS. In this setting, it is also clear that their families are often unable to provide adequate psychosocial support because of HIV infection in the household and that these children are not receiving necessary psychosocial support from sources outside the home. The same level of evidence does not yet exist regarding effective interventions for psychosocial support for these children or their caretakers.

Chapter 9 Protection: Policy/Law and Human Rights

Children affected by HIV/AIDS, like other children, are vulnerable to violence, exploitation, abuse, and neglect. This section will focus on the specific challenges related to protection that children affected by HIV/AIDS face; it examines the evidence on the existence of adequate policies and their implementation to protect children's rights not to be subjected to harm.

The role of government in protecting all children, including those affected by HIV/AIDS, includes *respecting* rights – having laws that do not violate their rights; *protecting* rights – enforcing laws and policies; and *fulfilling* rights – creating mechanisms to realize rights (Gruskin and Tarantola, 2005). The rights of children are defined in the *Convention on the Rights of the Child* (United Nations, 1989).

While any child may be vulnerable due to lack of adequate protection, children affected by HIV/AIDS are hypothesized to be at additional risk (UNICEF, 2007a) because of the effects of HIV/AIDS on their households, increased likelihood of leaving school early and/or seeking life on the street, and having to work for family income.

Enhanced Protection for Children Affected by AIDS (UNICEF, 2007a) outlines several focus areas for the protection of children: social protection, legal protection and justice, alternative care, stigma, and strengthening the social welfare sector. This chapter will focus on legal protection and justice; social protection is covered in Chapter 6; alternative care in Chapter 10; and stigma in Chapter 11. Legal protection covers several facets: inheritance, civil registration, and legislation and enforcement policies on child labor, trafficking, sexual abuse, exploitation, and discrimination. All these facets are important for vulnerable children, whether or not they are affected by HIV/AIDS, and there is little evidence that abuse of rights is different for HIV/AIDS vulnerable children than other vulnerable children, specifically in low prevalence and concentrated epidemic countries.

The bulk of evidence uncovered on protection of children affected by HIV/AIDS is descriptive and qualitative in nature comprised mainly of analyses of the legal frameworks to protect these children, with some descriptive studies on the lack of protection faced by children affected by HIV/AIDS. Systematic analyses of legal frameworks came mainly from the Latin America and Caribbean region, with a few from Asia. Little, if any, quantitative data were found on the number of children affected by HIV/AIDS who suffer from lack of protection, compared to other children.

Evidence cited on protection and children affected by HIV/AIDS (n = 27)

Authors	Rigor	Type (Location)
Abbott Labs Fund 2001	Good	Descriptive qualitative (Burkina Faso)
Borthwick 2004	Poor	Literature review (Southeast Asia)
de Lind van Wijngarden 2007b	Poor	Descriptive qualitative (Asia)
Dunn 2007	Poor	Descriptive qualitative (Pakistan) -- DRAFT
Foreman et al. 2003	Good	Literature review (worldwide)
GECA et al., 2005	Fair	Cross-sectional with controls (Benin)
Heijnders & Van der Meij 2006	Fair	Literature review (worldwide)
Hennessey 2001	Fair	Descriptive qualitative (Thailand)
HRW 2005	Good	Descriptive qualitative (Russia)

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IAA 2006	Fair	Descriptive qualitative (India)
Jackson 2006a	Fair	Descriptive qualitative (Guyana)
Jackson 2006b	Good	Descriptive qualitative (St. Vincent and Grenadines)
Kacker et al. 2007	Good	Descriptive quantitative (India)
Monasch et al. 2007	Good	Descriptive qualitative (sub-Saharan Africa)
NAC/Jamaica 2002	Poor	Descriptive qualitative (Jamaica)
NCCA/Lao 2004	Poor	Descriptive qualitative (Lao PDR)
Plan International 2006	Fair	Descriptive qualitative (Togo)
Samaras 2004	Poor	Case study (Senegal)
Sanigest 2006	Good	Descriptive qualitative (multi-country Central America)
SCF/UK 2006e	Fair	Descriptive qualitative (multi-country Asia)
Sealy-Burke 2005a	Good	Descriptive qualitative (St. Lucia)
Sealy-Burke 2005b	Fair	Descriptive qualitative (Grenada)
Sealy-Burke 2006	Fair	Descriptive qualitative (Grenada, St. Lucia, St. Vincent)
UNICEF 2002	Good	Descriptive qualitative (Nepal)
UNICEF 2005c	Good	Descriptive quantitative (Bangladesh)-- DRAFT
UNICEF 2005d	Good	Descriptive quantitative (Barbados, St. Lucia, St. Vincent)
UNICEF 2007a	Good	Descriptive qualitative (worldwide)

9.1 Information needed for programming around protection challenges

Legal protection often refers to the policies and their implementation by the State (government), but can also refer to the roles that other “organizational” units in society play to ensure the safety of children, such as local communities and families. Much of this will be cultural and political context specific. For programming related to protection, information is needed on several levels:

Existing legal protections for children: Programmers must know whether current legal frameworks include adequate protection for children in general and cover issues critical for those affected by HIV/AIDS (whether infected, living in an HIV/AIDS household, or orphaned), such as legal provisions related to discrimination, inheritance, placement and guardianship, and consent to treatment.

Enforcement of laws to protect children: If not enforced, laws and policies provide no protection. It will be important to understand the mechanisms that enforce laws to protect children, how accessible these mechanisms are to children, and how well they work.

Magnitude of “unprotected” children in general and specifically those affected by HIV/AIDS: How many children are not being protected, according to the various types of protection needed? Are children affected by HIV/AIDS facing specific or additional problems? Which protection issues should have highest priority?

Risk factors for lack of protection related to HIV/AIDS: Not all children are equally at risk of suffering from lack of legal protection – what are key risk factors for suffering harm due

to HIV/AIDS, whether it be infection itself or harm suffered from being from an HIV-positive household? Which children are most at risk? Do girls face additional vulnerability?

Barriers to protection: Several barriers may influence the level of protection afforded to children, including birth registration, age criteria, perceived legitimacy, orphanhood status, caste, etc. Which barriers are most important for children affected by HIV/AIDS? How do they differ from those faced by other vulnerable children?

Existence of organizations that can provide additional protection to children: Programmers need to know what other structures – national associations, local groups, local governments, etc.– can be brought in to intervene on behalf of children affected by HIV/AIDS and ensure their rights.

9.2 The situational findings on protection

While there is a large body of research on child protection issues in general, particularly by UNHCR (the UN Refugee Agency) the evidence base focusing on protection issues related to HIV/AIDS is both very uneven and thin. Several studies analyzed legal frameworks for the protection of children affected by HIV/AIDS. Some qualitative studies describe a number of areas where children affected by HIV/AIDS are being harmed, but they are country-specific, relating to specific legal situations and other socio-cultural or political factors in those countries. They are presented below, not because their findings have universal application, but because they highlight areas that would need to be verified in each programming context.

9.2.1 Findings with strong evidence

Vulnerable children in general (which includes children affected by HIV/AIDS) suffer from various forms of deprivation and abuse in many countries where there is inadequate protection by the state: The child protection literature documents children's vulnerability in many circumstances: refugee situations, war zones, street children, etc. Apparently, states are not providing adequate protection of children in these situations, although this review did not uncover rigorous studies connecting protection frameworks and programs to the deprivation and abuse of vulnerable children. No studies were identified that provide rigorous, quantitative data on the kinds of violence, exploitation, abuse, and neglect that children affected by HIV/AIDS experience, nor how this lack of protection is specific to HIV/AIDS.²¹

9.2.2 Recurrent themes for which the evidence is moderate

Legal frameworks in low prevalence and concentrated epidemic countries often make no specific mention of children affected by HIV/AIDS or of orphans and vulnerable children: No global comparative review of legal frameworks with respect to children affected by HIV/AIDS was uncovered. The detailed reviews of legal frameworks in several countries in the Caribbean [Guyana (Jackson, 2006a), St. Vincent (Jackson, 2006b), St. Lucia (Sealy-Burke, 2005a), and Grenada (Sealy-Burke, 2005b)] and in India (IAA, 2006) focused mostly on the entire group of orphans and vulnerable children, with few specific mentions of HIV/AIDS-related to discrimination. The analyses of legal frameworks in Central

²¹ India (Kacker et al., 2007) recently completed a large quantitative study of child abuse that includes extensive data on the magnitude of various types of abuse in several groups of children (children in institutions, children with families, street children, etc.). However, it does not parse out differences for children affected by HIV/AIDS.

America (Guatemala, Honduras, El Salvador, Nicaragua, Costa Rica, and Panama) addressed HIV/AIDS among vulnerable populations, without a specific focus on children (Sanigest, 2006).

In their review of Orphans and Vulnerable Children Programming indices for 36 sub-Saharan African countries, Monasch et al. (2007) showed that legislative review was the weakest area of the overall index for both high and low prevalence countries – only 13 countries had enacted any laws to protect orphans and vulnerable children, for which 11 included protection from violence and abuse, 11 exploitation, 9 loss of inheritance, and 9 discrimination. Programming indices for legislative review were generally lower among low prevalence countries: West Africa (average legal index = 32%) and central Africa (11%), compared to east Africa (55%)

Legal systems are not providing all the necessary protections for children in general, and specifically for those affected by HIV/AIDS related to financial support and provision: Financial support and provision from a legal point of view can encompass insurance of adequate intra-familial support, adequate public assistance, and protection of inheritance rights. While these issues are not limited to children affected by HIV/AIDS, evidence from Chapter 6 (Socioeconomic situation) indicates that these children are often more likely to be in vulnerable households and thus in need of financial support and provision assistance.

Inheritance issues were cited frequently Asia and Africa. In Benin (GECA et al., 2005), laws exist to protect inheritance, but inadequate coverage of birth registration and lack of knowledge of right has led to expropriation of inheritance: in a study of 1155 orphans and vulnerable children, only 63% had their birth registered, and this varied by religion (ranging from 48% among traditional religions to 73% among Catholics) and ethnic group.²² Descriptive qualitative studies in Thailand (Henessey, 2001) and Burkina Faso (Abbott Labs Fund, 2001) point out the lack of legislation granting women and children rights to inheritance: in HIV/AIDS affected households, when the husband/father dies, the extended family and grandparents take over the property.

Without adequate legislation to protect the economic capacity (through inheritance and financial supports) of vulnerable families in general and families affected by HIV/AIDS in particular, children may be forced to work in order to compensate for increased financial vulnerability. Yet several legal analyses indicate that legal protection for child labor is limited and/or poorly enforced (Borthwick, 2004; UNICEF, 2002).

Issues of *public assistance and interfamilial support* vary from continent to continent and from country to country. A number of analyses of legal frameworks in the Caribbean and Central America point out gaps in intra-familial support and adequate public assistance protections for children; for example, there is a duality in the family law that discriminates against poor and unwed mothers in Grenada, St. Lucia, and St. Vincent, including low child support awards and restrictions in Maintenance Acts (Sealy-Burke, 2006).

Legal systems in many countries are not providing all the necessary protections for children in general and specifically for those affected by HIV/AIDS related to care and protection: From a legal point of view, stronger care and protection includes providing systems for alternative care (see Chapter 10), safeguarding from sexual abuse and exploitation,

²² Even though data was collected on a control group of non-orphans/vulnerable children, comparative data were not presented in the report.

and ensuring age-appropriate juvenile justice. The last two relate to children affected by HIV/AIDS: reducing risk of infection due to sexual abuse and exploitation, and providing adequate HIV preventive services to children who are involved in sex work or who are injecting drug users. No studies were found that specifically linked children affected by HIV/AIDS and sexual abuse, but qualitative studies in several countries indicate that children affected by HIV/AIDS are at increased risk of vulnerability (due to socioeconomic factors – see Chapter 6), which generally leads to increased risk of sexual abuse and exploitation and thus increased risk of HIV infection. In India, a large quantitative survey of 12,000 children found that 51% of children had suffered some kind of sexual abuse, and 21% suffered severe forms of sexual abuse (Kacker et al., 2007), and such sexual abuse increases exposure to HIV. In Pakistan, qualitative interviews indicate that many children (boys and girls) are vulnerable to HIV due to sexual abuse and exploitation as prostitutes (Dunn, 2007), and anecdotal reports from interviews with school children in Togo suggest that female children may be frequently sexually abused by their teachers, putting female students at risk of infection (Plan International, 2006).

Yet, legal safeguards for children against sexual exploitation and abuse are few.

Comprehensive analyses of legal frameworks in several Caribbean countries indicate that legal systems in St. Lucia (Sealy-Burke, 2005a), Grenada (Sealy-Burke, 2005b), Guyana (Jackson, 2006a), and St. Vincent (Jackson, 2006b) do not adequately cover protection from sexual abuse. A similar situation was found in Barbados as well (UNICEF, 2005d). For example, age of consent for sexual intercourse is below international standards, and protocols for managing child abuse are absent (Sealy-Burke, 2005a and 2005b; Jackson, 2006b). In Asia (de Lind van Wijngaarden, 2007b), age of consent differs across countries: Japan (13), China (14), Thailand and Pakistan (15), India, Malaysia, Nepal, and Cambodia (16), Indonesia (17), Vietnam and Philippines (18). While older ages can be protective of sexual abuse, these can also create access problems to reproductive health services and preventive services for HIV for sexually active children of younger ages.

With regard to juvenile justice, in Grenada, has no legislation for juvenile offenders (Sealy-Burke, 2005b), and it appears that street children are dealt with in a more punitive than protective legal approach in St. Vincent (Jackson, 2006b). In Asia, Borthwick (2004) noted that in Vietnam, HIV/AIDS was still considered a “social evil,” and most measures are punitive rather than protective. Criminalization of drug use, sex work, and sexual relations between men have sometimes been deterrence to access to prevention programs among these key high risk groups (de Lind van Wijngaarden, 2007b).

Legal systems are not providing all the necessary protections for children in general and specifically for those affected by HIV/AIDS related to access to important services: Legal rights to access to health and education are important components of legal protection for children in general and specifically for children affected by HIV/AIDS. In the Caribbean, legal frameworks do not adequately protect children with regard to medical consent and confidentiality, impeding access to needed health care, nor do they adequately protect children from stigma and discrimination in St. Lucia (Sealy-Burke 2005a), Grenada (Sealy-Burke 2005b), St. Vincent (Jackson, 2006b), or Guyana (Jackson, 2006a). For example, neither St. Lucia nor Grenada has anti-discrimination legislation to ensure access to education.

A less rigorous assessment of the legal framework in Jamaica (NAC/Jamaica, 2002) also indicates inadequate protection for people living with HIV. The legal frameworks in Central

America do specify confidentiality of diagnostic testing and provision of timely care, while prohibiting compulsory counseling/testing and any discrimination against people based on their willingness to test for HIV (Sanigest, 2006). While these reviews did not focus on children, the legal framework will influence the parents' access and willingness to test and thus be eligible for treatment, and we consider it likely that it will also effect their children.

In Nepal, HIV and AIDS are legally categorized as contagious infectious diseases, allowing segregation and inhibiting children's rights to education (UNICEF, 2002).

Enforcement of child protection laws in general – and for children affected by HIV/AIDS in particular – is weak in most countries: While no multi-country studies on enforcement were found and much of the data are somewhat anecdotal, there is consistent mention of lack of enforcement when laws do exist. Bangladesh has legislation to protect women and children affected by HIV/AIDS, but it is not well known, implemented, or enforced (UNICEF, 2005c). Similar comments appear in legal framework analyses from the Caribbean about lack of effective enforcement of laws protecting children affected by HIV/AIDS (Sealy-Burke, 2005a and 2005b; Jackson, 2006a and 2006b). In Jamaica, the government has made efforts to protect children against domestic violence, but they are not sufficient (NAC/Jamaica, 2002); in Nepal, many children suffered from "property grabbing" and loss of inheritance even though legally they have the right to inherit property (UNICEF, 2002); similar findings exist for Thailand (Hennesey, 2001). Similar weaknesses in enforcement were observed in Russia where qualitative data indicate that although illegal, HIV-positive children are often not accepted by orphanages (HRW, 2005). Descriptive qualitative data from interviews with over 2000 children in six southeast Asian countries highlight the major impacts on children affected with HIV/AIDS: lack of protection, exploitation and abuse, becoming street children, and trafficking (SCF/UK, 2006e).

9.2.3 Gaps in information on the situation

There are two major gaps in information related to protection and children affected by HIV/AIDS. First is the magnitude of the different types of *protection problems* (whether related to lack of legislation or lack of enforcement) for children affected by HIV/AIDS – as most of the data is based on qualitative data on a limited sample – and second is whether there are *additional vulnerabilities* for children affected by HIV/AIDS beyond those of vulnerable children in general.

9.3 Interventions to address protection challenges

Interventions can be categorized into three major groups: strengthening the legal framework to provide adequate protection for children affected by HIV/AIDS; building advocacy to change the laws, and creating mechanisms to ensure enforcement of existing laws. No evidence of systematic evaluation of interventions that address protection of children affected by HIV/AIDS was found, including strengthening of legal frameworks, and this was confirmed by two literature reviews (Heijnders & Van de Meij, 2006; Foreman et al., 2003).

9.3.1 Findings with strong evidence

No such findings were uncovered.

9.3.2 Recurrent themes for which the evidence is moderate

A variety of interventions to increase protection for children affected by HIV/AIDS have been implemented by nongovernmental organizations and many have been successful on an

individual basis, based on limited documentation. However, without systematic evaluation, it is difficult to state that these are the most appropriate and effective interventions. Some limited evidence was uncovered supporting the facilitation of enforcement, presented below.

Facilitating enforcement: assisting families living with HIV/AIDS to obtain their rights, particularly related to discrimination: One review of strategies to protect those vulnerable to HIV/AIDS in Central America (not specifically children), using qualitative surveys of key authorities and health professionals working in HIV/AIDS (Sanigest, 2006) found some non-profit organizations employing a rights-based approach to defend the rights of people with HIV/AIDS to secure treatment, share experiences, build an alliance with other community stakeholders, and raise awareness among the general public; these efforts have shown some success, yet their actual effect is as yet unevaluated. In Senegal (Samaras, 2004) and Thailand (Borthwick, 2004), individuals and centers, such as the Center for AIDS Rights in Thailand, have helped families living with HIV/AIDS gain access to services within their rights, such as education, employment, housing, etc. This is often done by talking to parents, teachers, and district authorities and increasing both awareness of the laws and understanding about HIV/AIDS. These efforts appear to have been successful on an individual basis in ensuring rights and on a wider basis on changing attitudes.

9.3.3 Gaps in information on protection interventions

Gaps in information on protection interventions focus here on evidence that is contradictory or was not found for interventions that are strongly advocated (UNICEF, 2007a).

In some countries, **mechanisms for community support** have been implemented, but some experiences show that these still need accountability: in rural Lao PDR, village chiefs were to propose and guardians to ensure adequate care of village orphans. Yet, a qualitative cross-sectional study found this intervention was unsuccessful. Better health professional supervision along with a commitment from external organizations helped the program succeed (NCCA/Lao, 2004).

Birth registration has been promoted to ensure that children affected by HIV/AIDS are granted their rights, such as inheritance and access to education. No documentation was found that evaluated the effects of birth registration on increased protection and which interventions were needed to remove barriers from the registration process or to ensure that rights concomitant with registration were obtained.

No documentation of interventions was uncovered related to sexual abuse and exploitation among children affected by HIV/AIDS or children in general.

9.4 Conclusions about policy/law and human rights

Evidence on protection challenges and interventions tends to be limited and qualitative in nature, and links between improved legal frameworks and actual rights respected and protected have not been validated. Evidence on the magnitude of the problem of children without adequate protection is also thin, and few interventions have had their effectiveness documented in either low or high prevalence countries. In addition, we uncovered little evidence, positive or negative, that children affected by HIV/AIDS are "different" from other vulnerable children. Among the range of protection issues, only legal discrimination or lack of enforcement of anti-discrimination legislation appears specifically related to HIV/AIDS.

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Differences among countries in the legal protection of children in general and specifically for children affected by HIV/AIDS are frequent, but appear to be linked to origin of legal frameworks in general, degree of rule of law and enforcement, cultural practices, and economic and political factors, rather than HIV/AIDS epidemiology. The proportion of children affected by HIV/AIDS among all vulnerable children is larger in high prevalence countries, and thus, the visibility of the legal issues may be greater, as seen in the percentage of countries in East Africa having reviewed legal frameworks (Monasch et al., 2007).

Children affected by HIV/AIDS do have a few additional needs for protection beyond those of orphans and vulnerable children in general, such as legal protection against discrimination related to infection status and its consequence on access to essential services (health, education, etc). However, most of the protection issues faced by children affected by HIV/AIDS also confront other children, since the perception of the rights of children is generally weak.

Chapter 10 Placement

Placement of children involves providing those lacking adequate adult care a safe and secure environment, including shelter and guardianship. *The Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS* (UNICEF et al., 2004) calls for the establishment of specific standards for alternative care for children without family support, including keeping siblings together, seeking family-based placements (using institutionalization as a last or temporary resort), and involving children in the decision-making regarding their placement. "Alternative care" refers to care that places children under guardians who can meet the children's basic needs. Formal alternative care typically involves a third party, such as an official of the state, who arranges for alternative care such as a foster home or institutional care, whereas informal alternative care typically involves placing the children with the extended family or a close neighbor without an outside third party.

Alternative care for orphaned and vulnerable children is provided in various ways. In many settings, the traditional safety net is extended families. Placement options vary by context and may include: informal fostering by extended family, "community fostering" by non-relatives, adoption, group homes (sometimes known as children's villages), and orphanages.

The evidence base on placement is generally good, largely qualitative, and widely representative. Quantitative data comes primarily from Africa, with one study from Latin America.

Evidence cited on placement and children affected by HIV/AIDS (n = 41)

Authors	Rigor	Type (Location)
Bartlett et al. 1985	Good	Descriptive quantitative (USA)
Bharadwaj 2003	Good	Descriptive qualitative (India)
Black & Farrington 1997	Fair	Descriptive qualitative (Indonesia)
Borthwick 2004	Fair	Literature review (multi-country, Asia)
Caceres & Jiminez 1998	Good	Qualitative (Peru)
Case et al. 2004	Good	Cross-sectional with control group (Africa)
Collet et al. 1994	Good	Descriptive quantitative with control (France)
Deininger et al. 2001	Good	Descriptive quantitative (Africa)
de Lind van Wijngaarten 2007b	Poor	Descriptive qualitative (Asia)
Dutt et al. 2007	Good	Cochrane research protocol (worldwide)
Frank et al. 1996	Good	Literature review (worldwide)
Gillman n.d.	Good	Case study (Malawi)
Hennessey 2001	Fair	Descriptive qualitative with control (Thailand)
Hodges & Tizard 1989	Good	Descriptive qual/quant with control (Britain)
HRW 2005	Good	Descriptive qualitative (Russia)
Inciardi & Surrat 1988	Fair	Descriptive qualitative (Brazil)
Knodel & Saengtienchai 2005	Good	Cross-sectional qual/quant (Thailand)
Madhavan 2004	Fair	Literature review (South Africa)
Miller et al. 2005	Good	Cross-sectional quant with control (Guatemala)
Monasch & Boerma 2004	Good	Descriptive quantitative (sub-Saharan Africa)
Nostlinger et al. 2006	Good	Controlled cross-sectional quantitative study

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		(multi-country, western Europe)
Pivnik & Villegas 2000	Good	Descriptive qualitative (USA)
Pringle & Bossio 1958a		(Summarized by Frank et al. 1996)
Pringle & Bossio 1958b		(Summarized by Frank et al. 1996)
Ratnapala 1998	Good	Qualitative (Sri Lanka)
Rau & Lee 2005	Good	Descriptive qualitative (India)
Rotheram-Borus et al. 2005	Good	Literature review (worldwide)
Safman 2004	Good	Descriptive qualitative (Thailand)
Saltz 1973	Good	Descriptive quantitative (USA)
SCF/UK 2005a	Poor	Descriptive qualitative (China)
Shadick 2006	Fair	Descriptive qualitative (Guyana)
Siaens et al. 2003	Good	Descriptive quantitative (Rwanda)
Subbarao & Coury 2003	Good	Descriptive qualitative (Sub-Saharan Africa)
Tizard & Rees 1975	Fair	Cross-sectional quant with control (Britain)
Tobias 2000	Fair	Descriptive qualitative (Russia, E. Europe)
UNICEF/Belize 2004a	Fair	Descriptive qual/quant (Belize)
UNICEF 2005e	Good	Descriptive qual/quant (Jamaica)
UNICEF 2006a	Fair	Case studies (Africa)
UNICEF 2007b	Good	Descriptive qualitative (South Asia)
UNICEF/SCF 2007b	Good	Cross-sectional with control (Lao PDR)
Vithayasai & Vithayasai 1996	Fair	Non-experimental descriptive (Thailand)

10.1 Information needed for programming around placement challenges

Information on current residence of children affected by HIV/AIDS: As noted in Chapter 3, "Who are the children affected by HIV/AIDS," information on where children live and with whom is important for programming that targets specific groups of vulnerable children. Key questions include: With whom do orphans and other children affected by HIV/AIDS actually reside? Are affected children living with elderly caregivers or in households with high dependency ratios? What proportion of affected children are living in female- or child-headed households or on the street? Do living situations differ by age or gender, or as compared to other vulnerable children?

Factors leading to changes in placement and care for orphans and non-orphans: Because changes in placement of children may happen regardless of parental morbidity or mortality, evidence is needed on local factors that lead to changes in placement for affected and unaffected children, including information on the contribution of HIV/AIDS to placement challenges among youth. Information on why non-orphaned children may be separated from parents, for example, will inform the design of context-specific strategies to improve their caretaking situation both in terms of prevention (if prior placement is more advantageous for youth) and/or mitigation of placement challenges.

Local perceptions and practices for alternative care: Not all placement strategies will be appropriate or feasible in all settings, so information is needed on local perceptions and practices for alternative care. How might new placement models be integrated in communities where conventional strategies are saturated? What is the general perception regarding who should care for vulnerable children? How might perceptions change in the context of HIV/AIDS? Are local views regarding care the same for girls versus boys or older versus younger children? How can traditional protective child care practices be supported and built upon?

Key placement challenges such as existing interventions, barriers, and unmet need:

In addition to local perceptions and practices, information is needed on existing barriers in placement as well as identification of gaps in the provision of care for children (and guardians) in need. Do formal fostering arrangements exist? How does the legal framework support or undermine the various options? Are skilled professionals such as social workers available to participate in placement decisions? What are the local coping mechanisms for dealing with abandoned or neglected children, and how can they be strengthened? What barriers exist for certain groups of children based on age, gender or HIV infection status? Is placement timely and/or permanent, or do challenges exist regarding long-term care of children orphaned by AIDS and HIV/AIDS vulnerable children?

10.2 The situational findings on placement

There is extensive, relatively strong qualitative and quantitative evidence about the placement situation of children orphaned by AIDS. Since very few HIV-positive parents make fostering arrangements before dying and since formalized placement systems tend to be inadequate, especially amid a growing number of orphans, the predominant response for these children is informal and tends to be culturally and community-specific.

10.2.1 Findings with strong evidence

The majority of HIV/AIDS-affected children live with HIV-positive parents: In many settings, uninfected children living with HIV-positive parents make up the largest proportion of HIV/AIDS-affected children. In Vietnam, for example, over 280,000 children are estimated to be affected by HIV/AIDS – 93% of whom are uninfected, non-orphans living with HIV-positive parents (de Lind van Wijngaarden, 2007b). In South Asia, the majority of affected children were also uninfected, non-orphaned children living with HIV-positive parents (UNICEF, 2007b), although a substantial portion of affected children included orphans due to AIDS. In Europe as well, a study of several countries showed that most children affected by HIV/AIDS were HIV-negative themselves, but living with HIV-positive parents receiving antiretroviral (ARV) treatment (Nostlinger, 2006). The prevalence of both parents being infected was 41% (Nostlinger, 2006).

Children orphaned by AIDS are largely and informally fostered by extended families:

Informal fostering patterns seem to be regionally specific and fairly consistent (sub-Saharan Africa, southeast Asia, for example). Caretakers of orphans are determined by tradition and social norms, including especially the relation of adults and children in extended families and the number of adults available to act as caretakers. For example, in sub-Saharan Africa, with several high prevalence countries, a child's grandparents or relatives of the parents' generation (aunts, uncles) take him or her in, with community fostering by non-relatives being relatively uncommon (Deininger et al., 2001; Subbarao & Coury, 2003; Monasch & Boerma, 2004). Using data from Tanzania, Uganda, Zambia, and elsewhere in east Africa, Subbarao & Coury (2003) found that approximately 90% of all orphans had been taken in by family members. However, sometimes in high prevalence countries where the functioning adult population is significantly reduced due to HIV and AIDS, fewer adults than in low prevalence may be available to be caretakers.

Examples of orphan care that is predominately assumed by extended families in high HIV-prevalence countries is also observed in low prevalence and concentrated epidemic settings. A

community-based survey of HIV/AIDS-affected children living in households, institutions, or on the streets estimated that there were roughly 20,000 orphans in Jamaica (i.e., children who had lost one or both parents), over 99% of whom lived in households (UNICEF, 2005e). Among orphans in households, while 44% lived with the surviving parent (i.e., single orphans), an estimated 37% (also predominately single orphans) lived with grandparents (i.e., informal fostering) – highlighting that single orphans, especially maternal orphans, often do not stay with the surviving parent (Case et al., 2004).

There may be challenges for the legal protection, however, of orphans who are fostered informally since this practice may not involve designating a legal guardian, creating a situation where orphans may not have full legal protection of their rights (Subbarao & Coury, 2003).

Grandparents are often caretakers of orphans due to AIDS: Grandparents serving as caretakers is a widely acceptable practice for placement of HIV/AIDS-affected children. A qualitative study in Thailand interviewing 48 caretakers and community members (21 of whom were grandmothers) about placement of children affected by HIV/AIDS found that their unanimous opinion was that orphans should be placed with extended family rather than with an unrelated person, preferably with the maternal grandmother who was “experienced in child-rearing” and would have an equal measure of interest in the child’s welfare as the parents (as opposed to aunts/uncles who may favor biological children) (Safman, 2004).

Indeed, across several regions, grandparents are absorbing a large share of caretaking for orphans. One study that analyzed Demographic and Health Survey data from 40 sub-Saharan African countries found that in the 13 countries that included information on the relationship between orphans and the household head, the grandparents were caretakers for about half of all orphans, and in the 4 low HIV prevalence countries (Cameroon, Ethiopia, Ghana, Nigeria) grandparents were the caretakers of about 35% of the orphans (Monasch & Boerma, 2004). In Thailand, approximately 25% of grandparents had custody of a child orphaned by AIDS although only 1.8% of adults were HIV-positive (Rotheram-Borus et al., 2005). In another study from Thailand with nationally representative findings, grandparents were caretakers for 55% of all orphans due to AIDS and 67% of double orphans due to AIDS (Knodel & Saengtienchai, 2005); and some consolidated trend data from 40 sub-Saharan African countries indicate that grandparents are increasingly becoming caretakers over other, younger members of extended families (Monasch & Boerma, 2004; Subbarao & Coury, 2003). Hypotheses for this shift include a greater level of morbidity and mortality among the “aunt and uncle” generation as a result of HIV/AIDS, as well as an increasing unwillingness to foster among extended family members in efforts to avoid the associated drop in economic welfare and its impact on biological children.

Despite these findings, there has been concern that although grandparents can provide a nurturing home, care of orphans incurs increased economic constraints during a less productive phase of life for these adults and may not constitute a long-term solution among older grandparents (Subbarao & Coury, 2003).

Informal fostering can lead to household welfare loss: As discussed in Chapter 6, regarding socioeconomic challenges, HIV/AIDS-affected households may experience deterioration in their socioeconomic situation, including families fostering HIV/AIDS-affected children. In many places where informal fostering is the cultural norm, households are

generally poor, and absorbing orphans can drive them further into economic vulnerability or destitution. Fostering additional children increases the dependency ratio of the household, decreasing the per capita level of resources. Evidence from Rwanda, a high prevalence country, shows that the “consumption shock” brought on by fostering even in non-poor households may lead to welfare loss (Siaens et al., 2003), and a similar phenomena may occur in low prevalence countries where similar adult to child ratios apply. A study using panel data from Uganda similarly demonstrated that fostering an additional child not only reduced consumption and expenditure per capita, but also reduced the household’s long-term capital accumulation (Deininger et al., 2001): in most settings, governments provide no systematic support to ease the financial burden of informal fostering (UNICEF, 2006a; Subbarao & Coury, 2003). No studies from low prevalence or concentrated epidemic countries were found that addressed this issue, but the consistent findings from high prevalence countries suggests that perhaps this may be true in low prevalence countries as well, by the logic that more children often mean more costs.

10.2.2 Recurrent themes for which the situational evidence is moderate

Non-institutional placement options are less commonly used and mired by legal constraints: Formal placement options refer to alternative forms of care that are provided through formal organizations or networks. Examples of formal placement include adoption, fostering (such as within welfare systems), or use of institutional care for permanent or temporary shelter. In many south and central Asian countries (e.g., Afghanistan, Pakistan, India, Maldives, Sri Lanka, and Nepal), the policy for orphaned and abandoned children is to place them in long-term institutions, while other formal placement options such as fostering or adoption are inexistent (e.g. Pakistan and Afghanistan), underdeveloped, or plagued by legal and policy gaps (UNICEF, 2006a; UNICEF, 2007b). In India, for example, residential care remains the primary option, despite a legal framework that supports foster family care (UNICEF, 2007b). Interviews with 43 individuals at adoption agencies or attending in-vitro fertilization clinics in India found that recent laws to promote adoption had not helped to raise the cultural curtain of suspicion and distrust in the adoption system (Bharadwaj, 2003).

Beyond access or use, constraints related to financial, material, and human resources are also impediments to ensuring well-functioning formal fostering systems, where sound supervision practices – such as periodic social worker visits to foster families – are essential (Subbarao & Coury, 2003). Standardization of practices to ensure adequacy and quality of placement can also be compromised, since interpretation and implementation of placement laws are left to individual states (UNICEF, 2006a).

HIV-positive children face greater barriers to placement than other orphans and vulnerable children: “Children’s villages” – a type of semi-institutional setting that tries to retain a family-like setting – often have age limits (children must be under seven in Lao PDR, for example) and do not accept children with chronic diseases, such as HIV (UNICEF/SCF, 2007). An in-depth qualitative study in India found that orphanages, children’s homes, and even families often refuse HIV-positive children claiming an inability to provide needed “specialized care” (Rau & Lee, 2005). In Russia, several orphanages were created specifically for HIV-positive children and abandoned children (whose infection status was unknown) of HIV-positive mothers. The rationale for this segregation is that they are better reached with medical assistance, but criticism is strong that their very existence fuels stigma and discrimination, rendering it illegal. Qualitative interviews with staff and caregivers in non-AIDS-specific

orphanages found fear of contact with the HIV-affected children who lived there and some indication that staff retention suffers as a result (HRW, 2005).

Evidence from Russia, Thailand, and Vietnam and some eastern European countries indicates that many HIV-positive mothers abandon their children in the hospitals where they deliver, assuming that their babies are HIV positive. For example, an early Thai study found that children born to HIV-positive mothers were 5.4 times more likely to be abandoned than other newborns in hospitals (Borthwick, 2004). In such cases, the clinical staff, notably the nurses, and the facility become responsible for these children until they are transferred to institutions (if they are), creating a group of extremely vulnerable and developmentally disadvantaged children (Borthwick, 2004; HRW, 2005). (See Section 10.3.1 on problems of institutional care.)

Perceptions about placement needs and priorities differ between children and

adults: Large-scale studies interviewing children and adults from various backgrounds in China and Malawi about placement exposed a stark contrast in adults' versus children's opinions of what is needed and what children want in a home (SCF/UK, 2005a; Gillman, n.d.). In in-depth interviews of 75 children (aged 8–12) and their guardians in Malawi, children indicated their preference to remain in a familiar, identifiable community with friends, attend school, and maintain family relationships, while guardians felt that material and financial support should take priority (Gillman, n.d.). The consistent findings of these two studies (one from a low prevalence country and one from a high prevalence country) suggest that possibly this phenomena may be widespread in both low and high prevalence countries.

Fostered children may experience discrimination and abuse in non-kin households:

A literature review from six Asian countries and a descriptive quantitative study from sub-Saharan Africa showed that fostered children may be treated differently than biological children in the same household (so called "Hamilton's law"). Foster children may be given more chores and fewer opportunities. A South African study concluded that the probability of school enrollment is inversely proportional to the degree of relatedness of the child to the household head (Chase et al., 2004). The forms and level of discrimination and abuse vary and include sexual abuse of the orphans by stepfathers, relatives, and neighbors or reduced educational opportunities (Borthwick, 2004; Case et al., 2004; Gillman, n.d.).

10.2.3 Gaps in information on the situation

Adequacy of current caretaking situations: Although there have been studies examining the socioeconomic and/or psychosocial situation of children affected by HIV/AIDS that has been stratified by caretaking situations (i.e., children living with chronically ill adults; children living in institutions), there is an apparent gap in the evidence base which evaluates the adequacy of caretaking situations unilaterally for HIV/AIDS-affected children. While it is agreed that affected children are best situated within their own families and with their siblings, evidence is needed regarding specific needs *within* caretaking situations and what opportunities exist for ensuring, for example, that parents who desire to keep their children (rather than send them away) are enabled to do so; what are the factors that determine whether grandmothers, as caretakers, have sufficient capacity to provide basic needs to orphans; or in the case of informal fostering, if children's placement challenges are thus resolved. In South Africa (a high prevalence setting), one study distinguished between "crisis-led" and "voluntary" fostering of HIV/AIDS-affected children, suggesting that caretakers who are prepared to assume additional dependents are able to provide better care (Madhavan, 2004). However, no such situational analyses were identified in low prevalence settings which examined adequacy within caretaking

situations, or how placement processes (such as planned versus unplanned; formal versus informal) might impact the overall care of HIV/AIDS-affected children.

Youth living outside of adult care: To date, the evidence on child-headed households and street children is scant, anecdotal, and based on small numbers. While a few studies have examined the situation of highly vulnerable children – for example, a qualitative study in two states in India found 275 child-headed households, a sample of which were mostly girls (59%) and 15-18 years of age (65%), indicated that a third were double orphans, as compared to single orphans or children living with chronically ill parents. In Belize, the 2000 census identified 8 households out of 52,000 as having heads of household younger than 15 years of age and 696 households under the age of 20, though there was no specific link to HIV/AIDS (UNICEF/Belize, 2004a) – we have included information on children living outside of adult care as an “information gap” given the overall, very limited measurement or documentation of situational challenges for HIV/AIDS-affected children living outside of adult care in low prevalence settings. It is unclear as well to what extent these children are supported by adults elsewhere or whether they are effectively destitute and “on their own.”

Orphans living with siblings: Following the death of one or more parents, it is important to ensure that orphaned children continue living with their siblings, but few studies have examined the extent to which this recommendation was practiced. In a small sample study of one and two-parent orphans (not just orphans due to AIDS) in Jamaica, 16 of the orphans living in households had siblings less than 18 years old, and only 2 of them (15%) reported living with *all* of their siblings. 47% of the Jamaica orphans with siblings under 18 years of age who were living in institutions reported living with *at least* one of their siblings (UNICEF, 2005e).

10.3 Interventions to address placement challenges

The following sub-section addresses what we know about the best placement alternatives for children affected by HIV/AIDS whose current placement is inadequate or insecure.

Interventions addressing placement for children affected by HIV/AIDS are generally small-scale and lack evaluation, rendering them difficult to assess or recommend. Only one theme emerged with strong evidence (i.e., reliance on institutions as a last resort), and there were no placement interventions identified with recurrent or moderate evidence for effectiveness, though some cost data were available comparing low and high prevalence African countries. In general, evidence of impact for non-institutional “placement” interventions such as informal fostering and use of children’s villages, is very limited. Several models have been proposed and implemented, but research is needed on the value-added from these interventions.

10.3.1 Findings with strong evidence

Institutional care should be a last resort for affected children: In general, 1–3% of all orphans worldwide reside in institutions (Subbarao & Coury, 2003). Extensive evidence shows that children placed in orphanages (whether HIV-infected or not) fare significantly worse than those children with their families or in foster settings (Tobias, 2000; UNICEF/SCF, 2007; Deininger et al., 2001). A comprehensive review of the substantial scientific literature on child institutionalization documents that, compared to home care, children under five years in institutions are especially vulnerable to infectious disease transmission and inadequate cognitive development (Frank et al., 1996). That review’s scientific conclusions, published in a peer-reviewed medical journal and apparently comprehensive and objective, are largely based on controlled studies from the U.S., Egypt, Finland, India, Iran, Romania, Thailand, and others.

Regarding infectious disease morbidity, the reviewed studies consistently report that children in institutionalized settings suffer increased frequency and severity of infectious diseases, especially diarrhea and respiratory infection, but also secondary complications such as tuberculosis, even at the best institutions. The two studies (France, U.S.A.) that analyzed the relationship of institutional size to infectious disease found the increased risk of infection attained statistical significance with more than three children in day care settings (Bartlett et al., 1985; Collet et al., 1994). The review also reported consistent conclusive evidence of severe deficits in the cognitive development of institutionalized children compared to similar home-cared children, particularly in language skills. Three reviewed studies reported that such cognitive and reading deficits tend to persist into adolescence, with the largest persistent deficits found in children institutionalized at the youngest ages and for the longest time (Saltz, 1973; Pringle & Bossio, 1958a and 1958b as reported in Frank et al., 1996). Two studies in the review found that IQ deficits in institutionalized infants and toddlers are partially preventable or even reversible by high staff-to-child ratios (1 staff to 2–3 children) and if the child is placed with a family before age four (Tizard & Rees, 1975; Hodges & Tizard, 1989). There is a fundamental tension in such institutional settings between effective infection control measures (“isolation, face masks for staff, and strict sterilization procedures for toys and eating utensils”) and the psychological and developmental needs of these children (“frequent and intense interpersonal contact”). The Frank et al., (1996) review also looks at the evidence for impact of institutionalization on children related to nutrition (inconclusive evidence), socio-affective development (limited but strong evidence that early institutionalization of impoverished children increases the risk that they will grow into psychiatrically impaired and economically unproductive adults), and abuse (ad hoc evidence of substantial but secretive sexual and physical abuse in many low quality institutions). The Frank et al., (1996) review and associated articles deal with all institutionalized children, not just HIV affected children, but because the findings are negative, concluding that institutionalization of young children is definitely not effective, we believe that this finding is also relevant to HIV affected children.

A study of adopted children from Guatemala, using a retrospective chart review and control group, compared the impact of foster and orphanage care on the health of 103 children (not related to HIV/AIDS): children from orphanages had significantly lower height ($p=0.03$), weight ($p=0.01$), and head circumference ($p=0.001$) than children who had been in foster care.²³ Foster care children also scored significantly better for cognitive skills than those who had lived in orphanages before adoption, although no differences were found between the two groups in terms of the prevalence of medical diagnoses (Miller et al., 2005).

Orphanages and large institutional systems of care are also the most expensive option, yet remain the default first and often permanent “formal” response to orphans and vulnerable children, especially in Asia, central and eastern Europe, and the former Soviet Union (Tobias, 2000; UNICEF 2006a). There is almost unanimous international agreement that institutionalization should be a “last resort” for placement, although for the most vulnerable of orphans, it may be the “best of the worst” option. Still, as the number of orphans grows, institutional coverage becomes less and less possible from a cost perspective.

10.3.2 Recurrent themes for which the evidence is moderate

Cost estimates are higher for placement programming for affected children in low prevalence settings: A study on the welfare and investment shock of AIDS-induced

²³ No information was available on the type of foster care – whether with a relative or within the same community.

orphanhood in Africa made several estimates of the relative costs of various methods of subsidizing and caring for orphans. The following subsidy estimates were provided for two low prevalence countries in Africa (Deininger et al., 2001). The cost of a subsidy to provide school and nutrition supplementation (excluding administrative costs) to all vulnerable children (not just orphans) in foster families was estimated to be \$148 per child annually in Burundi and \$105 per child annually in Uganda. This was compared to Tanzania (where institutionalization of orphans cost \$649 per child annually in 1990), Eritrea (where this cost was estimated to be \$1350 in 1998), and Burundi (where it was estimated to be \$689 in 1999). We do not have any reason to believe that cost in low prevalence countries would differ.

10.3.3 Gaps in information on placement interventions

Evaluation of community-based interventions: Despite advocacy regarding community-based responses, community support for placement of children orphaned by AIDS is usually negligible, though small-scale experimentation abounds. Our search identified two kinds of placement intervention that have been initiated although gaps remain on the effectiveness of these interventions for placement of HIV/AIDS versus all affected children.

Children's homes for temporary placement: Homes have been established in Thailand, China, and elsewhere to focus on children affected by (including living with) HIV/AIDS, to house them for short periods, and to help them find permanent foster homes. In Thailand, the Vienping Children's home, maintained by district officials, temporarily houses children affected by and infected with HIV while permanent placement is sought. The experience has been replicated in the community to support children through fostering for short periods before they return to their families or are adopted (Hennessey, 2001). Another Thai example is the Support the Children Foundation, which provides homes for HIV-affected children, in addition to HIV testing and treatment and education at local schools (Hennessey, 2001). Each home employs foster parents who care for six children and also provide support to HIV-infected parents by identifying alternate caretakers for the children (Vithayasai & Vithayasai, 1996).

Incentive-based foster care: Several foster care models have been developed in Beijing and Shanghai to stem increasing costs of housing children institutionally. In 2000, 576 out of 989 children under the care of Beijing Children's Welfare Home (BCWH) were placed in foster care. To encourage fostering, the BCWH pays living costs to foster parents for each foster child; each family can foster a maximum of five (the average is three). BCWH regularly sends its doctors to care for children in rural area, and efforts are underway to improve health and education services locally by placing better-trained doctors and teachers there.

There is also the "*Shanghai model*," which was initiated as a cooperative project between the government, civil society, and citizens in 1997. The project is unique in that there are professionally managed procedures in placement, child care, and after-placement supervision and support with standardized application, assessment and training of prospective caretakers. The first three months are considered "probationary," a time when the Shanghai foster care office is supposed to visit these families monthly and make telephone contact weekly, although monitoring is maintained twice annually thereafter. The per child cost of living is divided between the municipal government, which pays approximately 35%, while non-governmental resources cover the balance.

Evidence on effective contribution of succession planning for placement: Succession planning refers to the process of prior organization among chronically-ill parents regarding who

will assume custody of their children in the event of their death or during the last stages of their disease. It also entails protecting children's rights pertaining to inheritance, participation in decision-making, etc. We identified several studies that referred to succession planning activities being implemented to support affected children, but none of these studies evaluated pre-emptive planning as an intervention or outlined how such planning is enacted in various local settings.

Costs of caring for an HIV-positive orphan versus another orphan: Given the specialized care needs of HIV-positive children, the costs of caring for an HIV-positive child may be higher than those who are not HIV-infected. Better information about such differences is important in designing programs and subsidies to support parents and/or foster families.

Effective interventions to reduce risky behaviors of street children: Street children represent one type of placement, or lack thereof, so we have included the lack of evidence about interventions that are effective with street children here. The Cochrane Collaboration is undertaking a systematic review of evidence on interventions to modify sexual risk behaviors for preventing HIV infection in street children and youth people in low and middle income countries (Dutt et al., 2007). Numerous studies from high HIV-prevalence countries indicate that street children engage in high risk sexual behaviors that are likely to spread the transmission of HIV, and some similar reports from low-prevalence and concentrated epidemic HIV countries, including Brazil (Inciardi & Surrat, 1988), Indonesia (Black & Farrington, 1997), Peru (Caceres & Jiminez, 1998), and Sri Lanka (Ratnapala, 1998). It is hoped that the Cochrane review will fill the gap.

10.4 Conclusions about placement

With the increasing number of HIV cases, the number of children displaced and orphaned is rising. Solid cross-regional evidence shows that a vast majority are being absorbed by grandparents and extended family. While other, more formal placement options exist at the community level, through non-governmental fostering schemes and temporary group homes, as well as government-run orphanages, recourse to them for large numbers of orphans has been hampered by material, human resource, and logistical constraints. Adoption, although legally supported in most countries, has not benefited large numbers of orphans either, often due to cultural bias against the practice and legal/bureaucratic barriers.

The placement issues for HIV/AIDS affected-children do not differ dramatically from those of other orphans, although of course HIV-positive orphans have even greater barriers. HIV-positive orphans are less willingly accepted in a variety of placement settings and may incur greater health care costs for their caretakers. Child-headed households are typically quite precarious and are of particular concern to programmers addressing placement challenges.

Placement practices tend to be highly correlated to cultural norms and traditions regarding orphans in general. In all settings, there is a need for a continuum of placement models for orphans and vulnerable children, as well as collaboration between public policy and community-level coping mechanisms to ensure effective case management.

Chapter 11 Stigma and Discrimination

Stigma has been described as a “social process or related personal experience characterized by exclusion, rejection, blame or devaluation that results from an adverse social judgment about a person or group” (Alkenbrack et al., 2004). It can manifest as discrimination or “behavior in which a distinction is made against people that results in the person being treated unfairly or unjustly on the basis of them belonging, or being perceived to belong to a particular group” (Alkenbrack et al., 2004). One can also make a distinction between real and perceived stigma – where real stigma manifests as concrete actions of discrimination, and perceived stigma is the fear people have of stigmatizing behavior by others (Brown et al., 2003). Both can have profound effects on victims.

Infection status (one’s own or a family member’s), socio-cultural environment, developmental phase, and the caretaking situation will all mediate how children experience HIV/AIDS-related stigma. Much has been documented concerning stigma and discrimination, especially as experienced by HIV-infected and affected adults all over the world. The evidence base on stigma and discrimination as it affects children is moderately good with most of the evidence coming from Asia. Much of it consists of descriptive studies that are qualitative in nature, although there are a few cross-sectional studies with control groups and several literature reviews on stigma and discrimination related to HIV/AIDS.

Evidence cited on stigma and children affected by HIV/AIDS (n = 28)

Authors	Rigor	Type (Location)
Abadia-Barrero & Castro 2006	Good	Descriptive qualitative (Brazil)
Alkenbrack et al. 2004	Good	Controlled, cross-section quantitative (Cambodia)
Borthwick 2004	Fair	Literature review (multi-country, Asia)
Brown et al. 2003	Good	Literature review (worldwide)
Busza 1999	Good	Literature review (Southeast Asia)
Carswell et al. 2005	Fair	Descriptive quantitative/qualitative (Cambodia)
Castro & Farmer 2005	Fair	Literature review (Haiti)
Cree et al. 2004	Good	Descriptive qualitative (Scotland)
GECA et al. 2005	Fair	Cross sectional with control (Benin)
Gopalakrishnani 2006	Fair	Time series quantitative (Botswana)
Hiejnders & Van der Meij 2006	Fair	Literature review (worldwide)
Hennessey 2001	Fair	Descriptive qualitative (Thailand)
Loudon 2006	Poor	Case study (Haiti)
Loudon et al. 2007	Fair	Descriptive qualitative (India)
Mills et al. 2006	Good	Literature review (worldwide)
New Era Team 2006	Fair	Descriptive qualitative (Nepal)
Nostlinger et al. 2006	Good	Controlled cross-sectional quantitative study (multi-country, western Europe)
Paxton et al. 2005	Good	Descriptive qualitative/quantitative (multi-country, Asia)
Pradhan et al. 2006	Good	Cross-sectional with control (India)
Rao et al. 2007	Fair	Descriptive qualitative (U.S.)
SCF/UK 2005a	Fair	Descriptive qualitative (China)

*The evidence base for programming for children affected by HIV/AIDS
in low prevalence and concentrated epidemic countries*

SCF/UK 2006a	Fair	Descriptive qualitative (China)
SCF/UK 2006c	Fair	Descriptive quantitative/qualitative (Indonesia)
SCF/UK 2006d	Fair	Descriptive quantitative/qualitative (Thailand)
SCF/UK 2006e	Fair	Descriptive quantitative/qualitative (multi-country Asia)
UNICEF 2002	Good	Descriptive quantitative/qualitative (Nepal)
UNICEF & SCF 2007	Good	Cross-sectional with controls (Lao PDR)
Verma et al. 2002	Fair	Descriptive quantitative (India)

11.1 Information needed for programming on stigma challenges

Prevalence, nature, and manifestations of stigmatizing attitudes towards HIV-

affected children: Information on the origins, locus, and propagation of stigmatizing attitudes among community members toward children affected by HIV/AIDS and their caretakers is needed to develop appropriate strategies to address discrimination regarding HIV-affected children. This includes understanding local terms and factors contributing to stigma, such as knowledge of HIV or fear of infection and identifying drivers of stigma, such as key opinion leaders who may fuel or discourage discrimination.

Negative attitudes towards HIV-affected children may not be limited, however, to adults. Rather, it may also be reflected in the views and opinions of children, both affected and unaffected. Thus, information is needed on children's views regarding HIV/AIDS, including attitudes of affected and infected children towards themselves (i.e., self-stigmatization) and the factors that contribute to the formation of their views and opinions.

Real and perceived experiences of stigma among children: Experiences of HIV/AIDS-related stigma among children may be real or perceived based on individual- and community-level factors shaping the social consequences of the disease. Developing effective stigma-reduction strategies requires evidence on the experiences of stigma among children across social contexts, such as schools, the household, religious organizations, health services, etc. Documentation of these experiences should reflect the gender and age-specific developmental level of children, as well as their family and socio-cultural environments. In particular, programmers need evidence that differentiates between actual and perceived stigma.

Consequences of stigma and discrimination on child outcomes and/or experiences:

Stigma and discrimination may have significant short- and long-term effects on children both from their own experiences and that of their caretakers. Identifying strategies to mitigate such experiences requires understanding how children are affected by it, at what stage, when, and to what degree. Evidence is also needed on the extent to which stigma raises barriers to services, such as medical care and education, family and community support, and psychosocial services.

Relationship of HIV/AIDS-related stigma to other causes of stigma: Those with HIV may also be targets of stigma due to other factors, such as poverty and association with other stigmatized social groups. Programmers must understand the relationships among these to be able to effectively target HIV/AIDS-related stigma, discrimination, and their consequences in children.

11.2 Situational findings on stigma and discrimination

The situational evidence on HIV/AIDS-related stigma and discrimination among children is moderate, but quite diverse regarding aspects of stigma. The bulk of the literature comes from studies conducted in Asia, although a handful comes from other parts of the world.

Although often lacking in methodological rigor, there is substantial evidence that AIDS-related stigma toward children and adults is common in low prevalence settings. Recurrent themes indicate that communities often discriminate against children affected by HIV/AIDS (regardless of HIV status) and that children have strong expectations regarding experiences of stigma in their communities. Gaps in the evidence relate to drivers of stigma (i.e., sources of information), differences in perceived and real experiences of stigma and discrimination, and the impact of these experiences.

11.2.1 Findings with strong evidence

HIV/AIDS-related stigma toward children is prevalent: Studies report HIV/AIDS-related stigma against children in many low prevalence and concentrated epidemic countries. Although this evidence (with some exceptions) is not based on rigorous methodologies, the sheer number and consistency of reports of HIV/AIDS-related stigma toward children is, in our opinion, strong evidence for this finding. In brief, there is strong evidence that there is significant stigma and also discrimination (bit less consistently reported than stigma) against children who are HIV-positive, living with chronically ill parents, or orphaned by AIDS. The following low prevalence or concentrated epidemic countries have studies that document such stigma: Benin (GECA et al., 2005), China (SCF/UK, 2005a; SCF/UK, 2006a), India (Verma et al., 2002; Loudon et al., 2007), Thailand (Borthwick, 2004; SCF/UK, 2006d). Information on these studies, including the intensity and nature of the stigma and the strength of the evidence, appears in the moderate evidence section. A low prevalence of stigma against children was found in Lao PDR (UNICEF & SCF, 2007).

11.2.2 Recurrent themes for which evidence is moderate

Communities discriminate against children affected by HIV/AIDS: In some districts in Nepal, community members said that orphaned children, especially newborns, were considered “bad luck” and were given such names as “mother eater” or “father eater” if one of the parents had died (UNICEF, 2002). A qualitative study in Thailand found that some unaffected parents would not allow their children to play with infected or affected children (Borthwick, 2004). In fact, near the Thai-Cambodia border, a descriptive qualitative study based on interviews with 194 children and caretakers found that about a quarter of orphans and vulnerable children (mostly children affected by HIV/AIDS) said they experienced discrimination, usually verbal abuse from community members (Carswell et al., 2005). Interviews with 111 Thai children regarding acceptance by their community of HIV/AIDS, revealed that they believed that parents and teachers would understand, while their neighbors would discriminate against them (SCF/UK, 2006d). A comparative study in India of three types of households – those with an AIDS death (118 households), those with a non-AIDS death (100 households), and those with no death (100 households) – showed that 20% of children from households with an AIDS death reported having been discriminated against, versus 2.8% in households with a non-AIDS death, and 3.5% from households with no death (Verma et al., 2002). Qualitative findings from focus groups including 1500 HIV-affected children, their caregivers, and heads of households in five states in India confirm the experience of stigma and exclusion against children whose parents were HIV-positive, including verbal abuse, scolding, harassment, exclusion from access to common facilities, and not being allowed to play with other children; this treatment came from

family, friends, and relatives (Loudon et al., 2007). A national cross-sectional study of 1155 orphans and vulnerable children affected by HIV/AIDS in Benin found that at least 20% had experienced other children not wanting to play with them, and this percentage varied by region from 1–58% saying only some children would play with them and 0–11% saying no children would play with them (GECA et al., 2005).

Children affected by HIV/AIDS often face discrimination in access to public services, especially in schools: Expectations of experiencing discrimination appear well-founded given the mounting numbers of studies reporting children's experiences of discrimination across regions in schools. Stigma and discrimination may be enacted on children by teachers, administrative staff, or peers. Anecdotal evidence from a case study in Haiti suggests that schools do not welcome children who are perceived to be HIV positive (Loudon, 2006). The same was reported in Indonesia where a local district education officer admitted that the school's regulation was to expel any HIV-infected child (SCF/UK, 2006c); and in Thailand, a qualitative descriptive study using interactive activities (111 children) and in-depth interviews of 25 children found that those with HIV were denied admission to school. Although Thai law ensured access, educators expressed fears regarding the reactions of other (unaffected) parents to having HIV-positive students enrolled (SCF/UK, 2006d). The qualitative findings from 1500 people in India indicate that HIV-affected children experience discrimination from both peers and teachers, including exclusion from school in some cases. Moreover, that study reported key informant interviews with more than 300 service providers where 43% reported being aware of the exclusion of HIV-affected children for services related to well-being, 29% were aware of exclusion related to education, and 41% were aware of exclusion within the health sector (Loudon et al., 2007). A large household survey in India interviewing 6225 adults from non-HIV affected households indicated that 58% of women and 43% of men would not send their children to a school that had an HIV-positive child attending.

Infected and affected children who are granted admission and attend school have been ridiculed or ostracized by peers according to some studies. For example, in case studies in Haiti and Brazil, infected teens reported experiencing violence and peer-fighting in schools as a response to teasing about their HIV status (Abadia-Barrero & Castro, 2006; Loudon, 2006); and in western Europe, a cross-sectional study of children and adolescents living with HIV-positive parents found that HIV-positive children had significantly more reports of discrimination than HIV-negative ones (Nostlinger et al., 2006). In Benin, a cross-sectional study of orphans and vulnerable children (including those affected by HIV/AIDS) with a control group showed that orphans and vulnerable children were more likely to be rejected or isolated at school than the control children, although the percentage was not high nationally (5.3% compared to 2%), but in some regions the percentage of rejected orphans and vulnerable children rose to 15% (GECA et al., 2005).

Children affected by HIV/AIDS have strong expectations of experiencing stigma: In Thailand, in in-depth interviews with HIV-negative children regarding their views on the impact of HIV/AIDS on others, an 18-year-old boy said, "I think a person with HIV/AIDS will be hated by the community and will have no friends, but someone would understand," while a 16-year-old girl said, "People would gossip about someone who has AIDS. They discriminate against family members who are not infected, too" (SCF/UK, 2006d). Children also reported on what would happen if they had AIDS: responses included "losing love and care from [my] parents" or fearing that friends would dislike and ridicule them. Others indicated they would be afraid of

infecting their friends or wanting only to tell close friends to prevent others from knowing, although no quantitative data were collected to describe the extent of these beliefs or concerns.

Data from a qualitative study of 28 children of HIV-positive parents in Scotland indicate that children (especially adolescents) expect stigma, although those for whom parental status had been disclosed to others found it less damaging than expected (Cree et al., 2004). Additionally, in 611 interviews with children in Lao PDR, 70% of those aged 11–14 years and 85% of those aged 15–18 said that the impact of having HIV would be that “their friends would discriminate” against them, so they would not be able to go to school (reported in SCF/UK, 2006e). Children in China expressed similar feelings in qualitative children’s research by children (SCF/UK, 2005a).

Stigma, discrimination, and abuse can occur within caretaking situations:

Discrimination may also be experienced in households and communities among orphaned children who are not themselves HIV-positive or whose HIV status unknown. In the home setting, a qualitative study among 50 affected and infected children in Brazil found one case of children who were being fostered by extended family members and who had been locked in an outdoor shed and fed through a narrow opening due to the family’s concerns of virus transmission, although both girls tested HIV-negative (Abadia-Barrero & Castro, 2006). In Nepal, qualitative field research on community attitudes toward AIDS-orphaned and vulnerable children found that in most surveyed districts, community members felt that orphans were “treated badly” in households, and in some cases respondents said even worse treated by step-parents (UNICEF, 2002). Qualitative data from Benin (GECA et al., 2005) indicate that fostered orphans and other vulnerable children are often treated differently than other children in the household, including having to do extra work and being served less food. A quantitative component of the study found that of 145 children who had recently been ill, those who were orphaned and vulnerable were more than twice as likely to be required to work despite their illness as non-vulnerable children.

Children can be directly affected by HIV/AIDS stigma aimed at their parents or guardians:

Children may also be affected by experiences of stigma or discrimination aimed at their guardian(s) or parent(s). A qualitative study of children by children in China reported that bullying, stigma, and discrimination stemmed from being part of a family with HIV/AIDS (SCF/UK, 2005a). There are even some cases where children were taken from their parents as a result of the parent’s infection: in a multi-country study with 764 HIV-positive adults in Thailand, India, Indonesia, and the Philippines, 2.4% of respondents reported that their children had involuntarily been taken away as result of their HIV status (Paxton et al., 2005). Qualitative data from Thailand indicate that children may not be stigmatized as much as their parents because “they are children and [HIV/AIDS] is not their fault” (SCF/UK, 2006d). However, data from children’s research on children in China (SCF/UK, 2006a) indicate that children reported that attitudes and behaviors of other people usually significantly influenced their self-respect, attitudes, behaviors, and self-identification. In Cambodia, a study of 500 parents of children living in HIV-affected households, 44% said their children had been discriminated against due to the HIV status of their guardian(s) (Alkenbrack et al., 2004). In a large study of 2385 people living with HIV (Pradhan et al., 2006), 10% said they had been treated differently because of their HIV status, and of those, 29% mentioned that their children were not allowed to play with other children; in interviews with 6224 adults in non-HIV-affected

households, 44% of men and 56% of women said they would not allow their children to play with a child from an HIV-affected household.

Children experience stigma due to factors beyond HIV/AIDS: Stigma is not just related to the infection or illness but to perceived reasons for having contracted it, such as living on the street, using drugs, or engaging in immoral sexual activity. Qualitative data from 80 in-depth interviews and 33 focus group discussions in Nepal (New ERA Team, 2006) indicate that HIV/AIDS stigma is related to the social perception that HIV/AIDS results from immoral behavior (sexual and injecting drug user transmission) and that those who are ignorant of modes of transmission do not display stigmatizing behavior. In a study in Europe, many HIV-positive individuals were migrants and faced stigma for that reason as well (Nostlinger et al., 2006).

Stigma/discrimination is not an automatic response: Despite these findings, there is some evidence that stigma and discrimination are not automatic responses and in some cases may not dominate the experiences of HIV/AIDS-affected children. While data from a descriptive qualitative study using focus groups near the Thai/Cambodia border found some reports of stigma and discrimination, reports of community support far outweighed those of discrimination, according to the authors. These results suggest that relationships tend to remain constant before and after infection, reflecting the families' previous relationships with other community members (Carswell et al., 2005).

11.2.3 Gaps in information on the situation

Real versus perceived stigma in children: Few data are available on the relationship between real and perceived stigma for children. Qualitative studies tended to focus on children's concerns and not on actual experiences or observed experiences, given the ethical issues of asking children about this directly, especially as parents do not always reveal their HIV status to their children.

Drivers of stigma for HIV/AIDS: Among the documents reviewed, few discussed the drivers of stigma in terms of sources of information for community beliefs.

Effects of stigma and discrimination for children affected by HIV/AIDS: Most of the evidence on stigma and discrimination focuses on adults infected with HIV, leaving a need for more research on the effects of stigma and discrimination on children. There was one qualitative study of 25 HIV-positive adolescents in the U.S. (Rao et al., 2007), which found that stigma and discrimination by peers and family were driving factors for non-adherence to treatment. Findings showed that half the participants skipped doses of treatment "when they feared friends or family might discover their status" (Mills et al., 2006). However, by and large, there were few studies examining the effects of stigma across categories of child outcomes.

11.3 Interventions to address stigma challenges

Interventions to address stigma can be described as addressing 1) attitudes in the general population, 2) the behavior of health workers, and 3) coping skills of those infected or otherwise affected by HIV/AIDS (Brown et al., 2003). While many interventions and actions are being taken worldwide to combat HIV/AIDS stigma and discrimination, overall the evidence is slim with regard to specific improvements in stigma and discrimination among affected children or how gains for adults may affect children.

11.3.1 Findings with strong evidence

We found no studies with strong evidence on the effectiveness of interventions to reduce stigma.

11.3.2 Recurrent themes for which evidence is moderate

ART reduces stigma: While there is strong evidence documenting the effectiveness of HAART in decreasing HIV/AIDS-related morbidity and death, examination of the effectiveness of treatment in reducing stigma and discrimination among infected individuals, particularly children, is limited. We found one study examining the impact of ART on children's experiences of disease-related stigma with promising findings that ART is an important component of stigma-reduction strategies. Following interviews with 50 children (up to age 15 years), the study concluded that dramatic improvements in their health post-HAART led to significant reductions in discrimination/stigma experiences (Abadia-Barrero & Castro, 2006). Reports from institutional caretakers noted that community perceptions of how infected children "should look" had changed, resulting in more positive outlooks for HIV-positive children themselves. The study also noted a willingness among family members to resume care for institutionalized children who appeared healthy and no longer required substantial care. Thus, the authors concluded that access to HAART reduced disease-related stigma by transforming the conceptualization of AIDS to a manageable, chronic disease, although children continued to face discrimination from other structural forces such as poverty, gender inequalities, being orphaned, or being an ethnic minority. Effective HAART in school children and adolescents was also associated with reduced stigma against children in Haiti (Castro & Farmer, 2005). A study from Botswana in 2004 highlighted another aspect of ARV therapy and stigma: that perceived access to treatment (ART) was independently associated with decreased odds of holding at least one stigmatizing attitude (Gopalakrishnani, 2006).

Increase the visibility and participation of persons with HIV/AIDS: Community-based initiatives that include HIV-infected or affected children could normalize HIV/AIDS. Outreach can demonstrate that casual and close contact does not carry risks of transmission and is particularly effective in settings where the disease is relatively uncommon and has not been highly stigmatized. In Haiti, La Maison L'Arc en Ciel, a residential care facility for HIV-infected children, invited community leaders to share meals with orphaned children to share positive experiences of caring for HIV-infected children with other community members (Loudon, 2006). As parts of its focus on building social tolerance, the shelter also enrolled HIV-positive children in public schools while training staff to relate to the children in a non-discriminatory manner. Anecdotal evidence indicates that these efforts resulted in increased acceptance and concern by community members to support HIV-affected children, including a renewed commitment among parents to care for HIV-affected and infected children. Furthermore, in Indonesia, the Yayasan Pelita Ilmu Support Center introduced a "buddy system" with PLHIV to increase contact and sensitization among community members, which the authors attribute to perceived greater acceptance of persons living with HIV (Busza, 1999). In Cambodia, the Home Health Care project, which included home visits, normalization of casual contact, and services for other chronically ill (non-HIV/AIDS) patients, led to 60% of patients and families reporting less discrimination (Busza, 1999, citing Wells).

Improve coping skills of those affected by HIV/AIDS: Children affected by HIV/AIDS can benefit from opportunities to be with others who are affected. A descriptive qualitative study of children by children in China (SCF/UK, 2006a) found that participating in child-to-child research

and working with other children affected by HIV/AIDS and with adults gave them opportunities to create relationships and feel less isolated. This is supported by evidence from the US and elsewhere (not limited to HIV/AIDS) of the role that self-help or support groups can play in helping people cope with discrimination and stigma (Heijnders & Van der Meij, 2006).

Increase health workers' willingness to treat people infected by HIV: Education alone will have little impact on stigma reduction. A literature review of rigorous studies (with at least an experimental design) indicates that programs designed to increase health workers' willingness to treat people infected by HIV through information, skills building and contact does increase knowledge but does not necessarily reduce fear of infection or change behavior (Brown et al., 2003).

Schools can be an effective vehicle for anti-stigma information: In Thailand, a study on available and potential support systems for infected and affected children examined the roles of schools in community-based support. School-produced newsletters and leaflets were delivered to parents to increase awareness and knowledge of HIV/AIDS and community participation in school-led activities. The project credited these activities with changes in local attitudes on fear and discrimination toward PLHIV and to increased acceptance (Hennessey, 2001).

Non-targeting approaches are effective in normalizing HIV/AIDS. There is moderate evidence to suggest that not specifically targeting children affected by HIV/AIDS is effective in normalizing HIV/AIDS by removing perceptions that HIV-infected individuals are inherently different from other chronically ill patients. In Cambodia, a study of home-based care services offered to all chronically ill persons rather than only those who are HIV-positive estimated that 60% of families and patients reported less discrimination after the project initiated services to other chronically ill patients (Busza, 1999). Again, data were not available on specific changes relevant to children, but the strategy does appear to have been effective in reducing stigma among families in general.

11.3.3 Gaps in information on anti-stigma interventions

Anti-stigma and anti-discrimination are recognized as critical areas for interventions for people with AIDS, yet the evidence base (which tends to focus more on stigma issues for adults and rarely specifically for children) is very limited. Much of the rigorous research related to stigma and HIV/AIDS involved small samples and hypothetical situations rather than direct observation, and few studies have looked at the long-term impact of interventions (Brown et al., 2003).

The literature mentions a number of interventions or strategies with little or no evidence available yet. These include *advocacy as an anti-stigma strategy* and *engaging local leaders in anti-stigma programs* to change the power relationships that surround stigma. Most of the interventions seeking to increase coping skills focused on adults, not children.

The evidence on the effect of education on reducing stigma appears mixed in that it shows an effect on knowledge but not on removing the deep-seated fears that will affect behavior towards people with HIV/AIDS.

Although there is much discussion in the literature, there is little if any evidence of the effects of *anti-discrimination policies and legislation* as stigma- and discrimination-reduction tools on changes in behavior. In Thailand and Malaysia, the Business Coalition of AIDS (BCA) worked with local businesses in developing non-discrimination policies for workplace settings (Busza,

1999). Along with education and efforts to increase awareness of the experiences of PLHIV, these activities were suggested by authors to have increased the participation of unaffected individuals in activities to support HIV-affected individuals. Similar strategies may be adopted to reduce discrimination in school settings to directly benefit children with and affected by HIV/AIDS, although our search provided no evidence of the effectiveness of anti-discrimination policies and legislation in schools for the benefit of children.

11.4 Conclusions about stigma and discrimination

Children may experience HIV/AIDS-related stigma when they are infected themselves or live in HIV/AIDS-affected households. When stigma is mainly related to fear of infection, access to treatment will reduce symptoms and thus visibility of the disease. Less visibility would in turn lead to reductions in experiences of stigma. To the extent stigma related to HIV/AIDS is linked to other factors, such as moral judgments about reasons for infections, poverty, social class, etc., then removing stigma and discrimination is more difficult.

The strength of the evidence base on the situation related to stigma for HIV-affected children is still only moderate, with mostly small, qualitative studies. However, the presence of stigma and its effects on psychosocial well-being are fairly well documented, except in the case of interventions to address stigma, where the evidence base is very limited.

Like adults, children affected by HIV/AIDS appear to need interventions that help them cope on an individual level and as a group, and they need interventions that educate and inform their communities. Given the strong effects of stigma (secrecy, avoidance, and withdrawal), a multi-faceted approach will most likely be necessary. Stigma is a social construct and not an attribute of the individual, so consideration of stigma must be within the social context. Nevertheless, victims of stigma need not be passive agents (Heijnders & Van der Meij, 2006).

The challenges of stigma appear to be stronger in low prevalence countries than in those with high prevalence, possibly due to less frequent exposure in low prevalence countries to issues surrounding people with HIV/AIDS and thus less knowledge about the unlikelihood of infection by casual contact. In addition, association of HIV/AIDS with specific social groupings that are already the object of non-HIV/AIDS-related stigma will decline when the epidemic is more generalized and reaches more social groups.

Children infected by HIV or who are assumed to be HIV-infected will have an additional burden of stigma over orphans and vulnerable children in general that is specifically related to fears of infection that come from lack of knowledge about modes of transmission. This burden is always additive to the stigma coming from that suffered generally by the groups those children come from.

PART 4: SYNTHESIS OF EVIDENCE AND IMPLICATIONS FOR PROGRAMMING

Chapter 12 Synthesis of challenges and lessons learned from the evidence

Evidence presented from a review of 408 documents reveals a wide range of challenges on several continents, across a variety of socioeconomic and political environments, and in many different epidemiological HIV epidemic patterns. The evidence base is wide and deep in some areas and/or regions, and sparse and superficial in others – resulting in an incomplete picture of children affected by HIV/AIDS and the specific challenges they face in low prevalence and concentrated epidemic settings. Overall, evidence about the situation of these children is generally much stronger than that of effective interventions to improve their situation.

This chapter summarizes main findings to answer key questions that programmers in low prevalence countries are asking:

- What kinds of disparities exist between children affected by HIV/AIDS and other vulnerable children in low prevalence and concentrated epidemic countries?
- What are the barriers that explain these disparities if they exist?

Answering these questions is inherently difficult because “low prevalence and concentrated epidemic countries” do not form a homogeneous group and the evidence base itself is thin to be stretched over so many continents and contexts.

12.1 Situational evidence

12.1.1 *Situational findings with generally strong evidence*

Most of the findings described below are based on studies that had adequate samples and gathered data on at least one category of children affected by HIV/AIDS and on “control” children not affected. Some of the findings are based on strong evidence from a few countries and not necessarily representative of all low prevalence or concentrated epidemic countries: these studies were found mostly in south and southeast Asia, with few in Africa and none in Latin America or eastern Europe and the Newly Independent States.

Generally stronger evidence includes:

- In Africa (both high and low prevalence countries), *healthy* HIV-positive mothers reduce the risk of child mortality.
- HIV and malnutrition are mutually reinforcing in HIV-infected children everywhere.
- In Africa, infant-feeding methods used by HIV-positive mothers have significant implications on the infant’s HIV-status, mortality, and morbidity.
- HIV-affected households (with an HIV-positive adult) experience income decline due to lost productivity and increased health expenditures, and this is greater than other similar households.

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- In Asia, younger children affected by HIV/AIDS attend school at fairly similar rates to non-affected children, but older age groups affected by HIV/AIDS are less likely to be enrolled and attend school than their counterparts.
- Children affected by HIV/AIDS are more vulnerable to psychological problems than unaffected children.
- There is strong evidence regarding the risk and protective factors relating to the psychosocial well-being of HIV/AIDS affected children.
- Vulnerable children in general (including children affected by HIV/AIDS) suffer inadequate protection from the state in many countries.
- The majority of children affected by HIV/AIDS are living in HIV-positive households, but when orphaned, most are informally fostered by their extended families.
- Stigma and discrimination for children affected by HIV/AIDS (as well as adults) are prevalent.

12.1.2 Recurrent themes with moderate levels of situational evidence

Findings in this category were generated either mostly by smaller quantitative studies or well designed qualitative studies, many from south and southeast Asia.

- Non-infected children in HIV-infected households have about the same level of health problems as children in non-infected households.
- In some countries, children in households with an HIV-infected member make fewer health care visits.
- HIV/AIDS-affected children reside in food insecure households more often than unaffected children.
- Children living in HIV-affected households are more likely to be required to take on adult tasks of earning income for the family and taking care of siblings or ill parents in HIV affected households than non-affected children.
- Children affected by HIV/AIDS drop out of school due to socio-economic factors but not necessarily due to the costs of school. Orphanhood does not have a clear pattern for enrollment, but household structure and the relationship of the orphan to foster family do appear to influence school enrollment and attendance.
- HIV/AIDS-affected children of different ages face different challenges.
- Children living in HIV-infected households rate their quality-of-life lower than children in non HIV-infected comparison households.
- Legal frameworks in many countries do not provide adequate protection for children in general and enforcement of existing legislation is weak in most countries. Additional areas specifically for children affected by HIV/AIDS needing attention include discrimination, access to education and health services, and care and protection.
- Non-institutional placement options are less commonly used, and mired by legal constraints.
- HIV-positive children face additional barriers to placement than other orphans and vulnerable children.
- Perceptions about placement needs and priorities differ between children and adults.
- Fostered children may experience discrimination and abuse within non-kin households.
- Children experience stigma in their communities, in schools and health care settings, within caretaking situations. Stigma is often extended to the children of parents with HIV, and children experience stigma for more than the HIV infection but for other factors (immoral behavior, poverty, etc. of their parents). Children have strong expectations of stigma.

12.1.3 Gaps in situational information

Health

- Better information on children is at highest risk for infection
- More systematic information is needed about the relative importance of specific barriers to access and effective follow-up

Nutrition

- Assessment of under-nutrition in older children and across caretaking situations
- Evidence on leading causes of under-nutrition
- Specific identification of disparities between affected and unaffected children

Socioeconomic

- Documenting impact
- Socioeconomic effects at different stages of the disease
- Differences in socioeconomic safety nets

Education

- Information from a wider range of countries (and continents) is needed on the impact of HIV/AIDS in the household on school enrollment
- Barriers to education related to or exacerbated by HIV/AIDS
- The dynamic nature of the effect of HIV/AIDS on education
- Academic performance and HIV/AIDS

Psychosocial

- Little evidence from low prevalence and concentrated epidemic settings
- Psychosocial impact across stages of illness, caretaking situations, and social/cultural contexts
- Extra-familial support

Protection

- Magnitude of the different types of protection problems
- Vulnerabilities for children affected by HIV/AIDS beyond those of vulnerable children in general

Placement

- Adequacy of current caretaking situations
- Youth living outside of adult care
- Orphans living with siblings

Stigma

- Real versus perceived stigma in children
- Drivers of stigma for HIV/AIDS
- Effects of stigma and discrimination for children affected by HIV/AIDS

12.2 Intervention evidence

12.2.1 Intervention findings with strong evidence

We found only two interventions with strong evaluative evidence that either supports or rejects them – one related to nutrition and the other to placement. They are:

- Short-course antiretroviral therapy significantly reduces vertical transmission of HIV to infants during labor, delivery and breastfeeding.
- Institutional care should be a last resort for HIV/AIDS affected children.

The evidence supporting the effectiveness of safe breastfeeding practices and single dose antiretroviral therapy as interventions that reduce the transmission of HIV to breastfeeding infants is based on well-controlled studies primarily from high HIV-prevalence countries. However, it seems very likely that these results also apply to women in low prevalence and concentrated epidemic countries since it is based on individual biology and not social systems.

The evidence documenting the significantly higher infectious disease morbidity and lower cognitive development of young children residing in institutions than in home care situations, and the higher cost of institutionalized care is deep, based on many well-designed controlled studies. Much of this evidence is discussed in a comprehensive scientific review of the effect of institutional care on preschool children. The studies in this review are about all orphans and institutionalized young children, not just HIV/AIDS affected children, and address situations in developed countries as well as low and middle income countries throughout the world.

12.2.2 Recurrent themes with moderate levels of intervention evidence

Similar to the moderate situational evidence, findings in this category were generated either mostly by smaller quantitative studies or well designed qualitative studies.

- Improved infant-feeding counseling and mother education can increase HIV-free infant survivors.
- Community-based education and supplementary feeding programs improve nutritional status in some contexts.
- Cash transfer programs appear to help, though no specific evidence related to children affected by HIV/AIDS.
- There is an “Education Vaccine” against HIV.
- Financial subsidies might help increase enrollment of vulnerable children in some countries.
- Community-based resources can be harnessed.
- Psychosocial services can help to mitigate the impact of HIV on children.
- Facilitating enforcement.
- Assisting families living with HIV to obtain their rights, particularly related to discrimination.
- Cost estimates for education and nutrition subsidies are substantially lower for HIV/AIDS affected children placed in foster families than in institutions.
- ART reduces stigma (shifting population perceptions of HIV/AIDS-related illness).
- Increase the visibility and participation of persons with HIV/AIDS through community-based initiatives that include HIV-infected or affected children.
- Improve the coping skills of children affected by HIV/AIDS by providing opportunities for them to be with others who are affected.
- Increase health workers’ willingness to treat people infected by HIV:
 - Education alone will have little impact on stigma reduction.
 - Schools can be an effective vehicle for anti-stigma information.
 - Non-targeting approaches are effective in normalizing HIV/AIDS.

12.2.3 Gaps in intervention information

Health

- Effective prevention education for vulnerable children
- Documentation is lacking on effective ways to reach at-risk children
- Effectiveness of interventions to remove financial barriers

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Nutrition

- Little evidence on interventions that work
- Unanswered questions regarding implementation and targeting
- Information on current household strategies to mitigate malnutrition

Socioeconomic

- Interventions not adequately documented, impact not yet evaluated

Education

- Targeting orphans and vulnerable children
- Limited findings on educational programs to increase equity

Psychosocial

- Psychosocial interventions have not been adequately documented or evaluated to serve as evidence for programming
- What additional psychosocial support can help affected children in disintegrating HIV/AIDS affected families
- Antiretroviral therapy and the psychosocial situation of children affected by HIV/AIDS

Protection

- Mechanisms for community support
- Birth registration

Placement

- Evaluation of community-based interventions
- Evidence on effective contribution of succession planning for placement
- Costs of caring for an HIV-positive orphan versus another orphan
- Effective interventions to reduce risky behaviors of street children

Stigma

- Advocacy as an anti-stigma strategy
- Engaging local leaders in anti-stigma programs to change the power relationships that surround stigma
- Effect of education on reducing stigma
- Anti-discrimination policies and legislation as stigma- and discrimination-reduction tools

Chapter 13 Conclusions and implications for programming for children affected by HIV/AIDS in low prevalence and concentrated epidemic settings

Despite assessing a large number of documents, this review found a disturbing sparseness of strong evidence on the situation and especially on interventions for children affected by HIV/AIDS in low prevalence and concentrated epidemic countries. The diversity of countries in this category, from Benin to India to China to Honduras, requires numerous studies to be able to draw conclusions that would be reliable across such a broad category of countries. Given the relative inadequacy of the evidence base, what conclusions can we draw and what implications do they have for programming for the children of interest here?

Evidence informs when it is assessed in ways that bring together the rigors of good science, with the realities and legitimate demands of policy-makers and programmers who need to make tough decisions, today, about how to allocate resources (WHO, 2004).

This chapter will discuss how to link evidence to programming, identify areas needing more evidence, and outline some directions that programmer should consider. Three main conclusions emerge from this review:

1. ***The current evidence base is too geographically limited with insufficient evidence of the underlying causal relationships to allow for generalizable conclusions about the situation of children affected by HIV/AIDS:*** The current evidence base reviewed in this study is uneven across continents, and even though some studies have used strong study designs, the lack of adequate statistical analysis has weakened the evidence being provided.
2. ***Given the diversity of countries in the category “low prevalence and concentrated epidemic countries”, it is probably impossible (and unwise) to draw overarching, generalizable conclusions for all low prevalence and concentrated epidemic countries:*** Perhaps even more importantly, even with a larger, stronger evidence base, it is probably impossible to draw. While there is a certain progression that children affected by HIV/AIDS will pass through as HIV affects their household (infection, ill parent, and perhaps orphanhood) and certain categories of challenges that all children affected by HIV/AIDS will face, the extent of their “effect” on these children will depend significantly on the underlying socio-economic situation of the country, the types of social services and protections in place, and the political and cultural context. Thus, the evidence base must be examined, not only in terms of its findings, but in terms of what it “says” about those contexts in which the studies were done and how representative these findings would be for other contexts.
3. ***The evidence base on effectiveness and efficiency of interventions in low prevalence and concentrated epidemic settings is almost non-existent:*** Although there are many programs implementing strategies, little systematic data is collected and analyzed to tell about the effectiveness, efficiency and sustainability of these strategies to address key challenges for these children: of the 114 documents

reviewed that addressed interventions, less than a quarter applied any methodology that would allow comparisons (e.g., before/after or with a control group).

This state of the evidence base then leaves programmers in low prevalence and concentrated epidemic countries with a number of issues: How much evidence is enough? What do we need to know about children affected by HIV/AIDS in our specific country contexts? Do we target children affected by HIV/AIDS, and if not, how do we take care of their needs?

13.1 How much evidence is enough?

With a few notable exceptions, this report found low levels of evidence across the board on effective interventions, and uneven evidence for key disparities and barriers. Yet programming must go on, so how much evidence is enough? While there are criteria for assessing relative levels of evidence, with the randomized controlled trial (RCT) as the gold standard for evidence generation in medicine, it is less clear what would or should be an acceptable evidence base for other sectors such as education, law, and psychosocial services. Controlling all the factors needed for a validation study in these non-medical areas may be impossible or may, in some cases, remove some of the very factors that should be addressed in an effective program. For example, the social and cultural contexts surrounding interventions for stigma, are substantially more complex than those that typically define medical interventions. More importantly, the resources (in terms of sample size, data collection, and data analysis) necessary for RCTs or even randomized field trials are prohibitive. Policy-makers must be held accountable for the allocation decisions they make and how they balance investments in research vs. service programs. Finally, the time horizon needed to study the impact of interventions on health and social outcomes for an issue such as HIV in children is considerably longer than is typical in most program planning.

But even if we accept that RCTs will be limited, there is a need for data-based information about the effectiveness of interventions before large-scale programming occurs. Notations of the promise of particular interventions and assertions of effectiveness do not constitute a basis for true evidence-based programming. Interventions must be more rigorously and systematically evaluated so that truly effective ones can be replicated and scaled up. To support such evaluations, rigorous pre- and post-intervention data collection must be established on priority impact indicators for program activities targeting HIV in children.

Besides the “strength” of the evidence from specific types of studies, there are several other caveats about the evidence base: its tendency to examine interventions in a more narrow or vertical manner (allowing for better control of other factors), lack of evidence of the cost-effectiveness of interventions (for example, comparison of various entry points to working with children affected by HIV/AIDS), and a lack of focus on some emerging highly vulnerable groups (adolescents at increased risk of exposure to HIV and its link to being affected by HIV/AIDS). Children affected by HIV/AIDS will need an array of services that may vary by child and by the stage the family is in. Thus, an integrated package of locally appropriate service delivery that meets the needs of the children is an important component recognized by programmers but even less well reflected in the evidence base. In addition, many intervention levels for children affected by HIV/AIDS exist:

- direct intervention with children;
- intervention with families and caretakers to strengthen their capacities;

- support to community-based responses and the creation of a supportive environment with access to essential services; and
- interventions to promote a supportive and protective national context (legal, policy, universal service provision, etc.).

What are the appropriate intervention points? What is the relative efficiency, effectiveness and sustainability of resource investment at these levels?

Across programmatic areas and geographic and cultural barriers, evidence shows that adolescence is a critical period for intervention. While there has been increasing focus of prevention programs on “youth,” adolescence also includes children from 11 to 14, on whom data are scarce and an understanding of their primary challenges is weak. Adolescence is the age group with the greatest percentage of orphans. Furthermore, although we did not review this evidence, general consensus concludes that adolescence is an extremely risky period for HIV infection, when inadequate knowledge and life skills fail to prevent infection-causing behaviors. It is also a particularly vulnerable period in terms of being “affected”: the evidence base indicates that this age group suffers longer-lasting negative psychosocial effects and is more sensitive to stigma. In addition, some studies document that young adolescents (11–14) are vulnerable to being forced into situations – early marriage, living outside of the family, etc. – where they cannot control their exposure to the virus. Despite all these factors, among all age groups of children affected by HIV/AIDS, there is scant evidence on the design or effectiveness of interventions to protect this high priority group.

13.2 To target or not to target?

Another programming challenge is whether and how much to target interventions – to all vulnerable children, to double orphans, to HIV-infected children, to children living in HIV-affected households? The answer to these questions lie in several layers of analysis: 1) understanding how priority challenges for children affected by HIV/AIDS *differs* from children who are unaffected by the epidemic or vulnerable as a result of other factors, 2) what are the consequences of targeting to actually reach these children (i.e., does stigma lead to children and families avoiding these services? Does targeting create additional discrimination for these children?) and 3) can we effectively and efficiently identify the children affected by HIV/AIDS to be able to target them anyway?

One viewpoint holds that programs that try to address specific children within a community create more problems than they solve: that they create stigma, perverse incentives in order to receive benefits, or even risks to these children of abuse and theft for their benefits. Unfortunately, the evidence base in low prevalence and concentrated epidemic countries is thin on effectiveness, coverage, or consequences of interventions specifically targeted to children affected by HIV/AIDS – the documents which raised these issues tended to make generic statements about the negative impact of targeting, without data on the magnitude or consequences of problems created by targeting.

The evidence base on disparities that would justify targeting is somewhat uneven – it does appear that children affected by HIV/AIDS may not receive adequate health care services nor stay enrolled in school and live in food-secure households due to economic hardships in HIV affected households. They face psychosocial challenges relating to stress of ill parents and death in their families, as well as related to stigma. They may face additional legal constraints

(or lack of enforcement of legal protections) to access to health care and education, and appropriate placement. These are factors directly related to HIV/AIDS and may require targeting of HIV-affected households to effectively address these issues. However, the evidence base also indicates that many challenges faced by these children are also faced by other orphans and vulnerable children in their communities: stigma associated with social groups such as children of sex workers or of injecting drug users; poverty-associated challenges for education, health, nutrition; exposure to abuse and lack of protection of children's rights to inheritance, protection, legal services. Thus, no single strategy will be effective – the question may not be “to target or not to target?” but rather “how to target and how many different ways to target?”

13.3 Identifying and quantifying children affected by HIV/AIDS in low prevalence setting

Related to targeting, and also to programming in general, it remains difficult to operationally define who is “affected by HIV/AIDS” in low or high prevalence settings. The definition of “children affected by HIV/AIDS” proposed in the 2005 *Guide to Monitoring and Evaluation of the National Response for Children Orphaned or Made Vulnerable to HIV/AIDS* (UNICEF et al., 2005) does not even mention the words HIV or AIDS, but rather uses a proxy that could be used to operationally measure and count the children most likely to fall into that category. They note in the document that this definition is a good proxy in high prevalence settings, where the children affected by HIV/AIDS make up a large proportion of orphans and vulnerable children in general. This review of the evidence base in low prevalence settings focused on a more theoretical definition that could be used in research, but not necessarily by operational programs. Actually identifying children affected by HIV/AIDS is difficult, and the reasons are multiple, including:

- the fact that many people do not want to know that they are infected with HIV, especially if stigma is great and access to treatment is limited
- the difficulty in identifying *the children* of HIV-infected adults unless they are specifically integrated into case management programs;
- the low coverage of HIV testing, especially among children;
- the informal nature of family/kinship networks that provide care to children who are orphaned make it hard to count the frequency of this care arrangement
- the inadequacies of HIV surveillance systems, particularly in low prevalence countries where obtaining representative estimates is more challenging; and
- the reality that political and investment priorities are focused elsewhere.

However, programmatically, there are four overlapping categories of children affected by HIV/AIDS that have differing challenges: children infected with HIV, children orphaned due to AIDS, children living in HIV affected households, and children at high risk of becoming HIV infected (such as street children).

13.4 Differences between children affected by HIV/AIDS in low versus high prevalence countries

This 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 of HIV/AIDS 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 commitment and intentions, simply surpass their absorption capacity for meeting the needs of affected families. These differences which would be expected to be significant and widespread, are not documented and thus the implications for programming are not discussed.

13.5 How does the current evidence base translate into something useful for programmers?

A key issue for programming in low prevalence and concentrated epidemic countries is the extent to which children affected by HIV/AIDS face challenges different than those of their peers. While targeting all orphans and vulnerable children in order to reach those affected by HIV/AIDS without stigma or difficulties in identification might be valid in high prevalence countries where children affected by HIV/AIDS constitute a significant proportion of all orphans and vulnerable children, can this strategy be used in low prevalence and concentrated epidemic countries where they make up a small proportion of all vulnerable children. The evidence base, although not providing a set of hard and fast “answers” applicable in all situations, does point to some key questions programmers must ask themselves in their own country contexts, including what kind of evidence is available in their own country to determine the disparities among children affected by HIV/AIDS and other vulnerable children, specific barriers they face that create these disparities (if the disparities exist), and whether these children should be receiving specific services, and what kinds of interventions have been shown to be effective and efficient in addressing these barriers. Key questions for which programmers need to review the evidence in their own country context and settings include:

- What are the legal limitations impeding access to key services for children affected by HIV/AIDS?
- How specifically is stigma affecting children (and adults) affected by HIV/AIDS and what are the specific drivers of this stigma?
- Are children’s issues taken into account in VCT, PMTCT and ARV programs, including breastfeeding advice, access to health care, psychosocial issues?
- How big are the gaps in enrollment, attendance and performance in school? What are the drivers of these gaps?
- What kinds of gaps exist at household level (during illness and after placement if orphaned) in household resources that require children to take on additional roles and responsibilities?

The answer to each of these questions will vary from country to country, as legal systems, cultural norms, social support systems (direct costs of health and educational services,

existence of social welfare supports), and political will to address HIV/AIDS issues vary. For example, while children affected by HIV/AIDS may be less likely to be enrolled in school, the reasons may vary from context to context – in India where schooling is free, the barriers to enrollment are not school fees but probably the opportunity cost to the family of children being in school (and not performing needed household responsibilities), while in other countries where school fees exist, the school fees themselves may add another barrier.

Another key question programmers for children affected by HIV/AIDS is the overall HIV/AIDS programming context and how it affects children. *A key intervention that will positively impact children affected by HIV/AIDS is access for themselves and their parents to VCT, PMTCT and ARVs.* While there is no magic bullet for programming to improve the situation of children affected by HIV/AIDS, getting treatment to HIV-affected households (assuming uninterrupted access to drugs and compliance with treatment regimens) can have a major impact on a number of priority challenge areas. Effective ARV treatment of HIV-infected parents and children can:

- reduce childhood mortality, since a major risk to infected and uninfected children is the death of their mother;
- prevent orphaning, meaning that children remain in their parents' care, the most supportive place for them for good health and development, as well as protect against disinheritance issues;
- improve caretaking, by making infected parents healthier and better able to provide the material and psychosocial, support their children need;
- improve health, keeping parents more productive and supportive and making children more able to stay in school;
- reduce the economic damage HIV/AIDS causes to household: keeping parents healthier enables them to remain productive and spares children increased financial barriers to health, education, etc.;
- relieve children of the burden of caretaking or income-generation, making them more likely to stay in school.

It does not however mitigate what is needed now to address the issues of children already orphaned or whose parents are not yet on treatment.

13.6 Where to go from here?

A major conclusion from this review of the evidence base is that generic, overarching programming principles for all low prevalence and concentrated epidemic countries are not generally feasible, nor useful. Thus, programming principles usually must be developed locally, nationally, and perhaps regionally, based on the socio-economic, political and cultural contexts. Secondly, while the evidence base reviewed here points out some key areas where disparities may exist between children affected by HIV/AIDS and other vulnerable children, these need to be verified within different country contexts, and the specific drivers of these disparities better understood before initiating programming. Thirdly, better evidence about interventions is needed everywhere. More efforts are needed in monitoring and evaluation of effectiveness, efficiency and sustainability of interventions, and documentation of the specific processes used in their implementation and the specific socio-economic and cultural context in which they are implemented.

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It is hoped that this review of the evidence will serve as a jumping off point for discussions at regional, national and local levels about how best to identify and address the needs of children affected by HIV/AIDS and how to expand the evidence base to better help future programmers. It should not be forgotten that the HIV/AIDS epidemic is dynamic and access to ARV, PMTCT and VCT are expanding, and that these have significant influences on programming for children affected by HIV/AIDS.

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Table 7: Situation

Challenge	Strong	Moderate	Missing
Health	<ul style="list-style-type: none"> - Healthy HIV-positive mothers reduce risk of child mortality. 	<ul style="list-style-type: none"> - Non-infected children in HIV/AIDS households have about the same level of health problems as children in non-infected households. - In some countries, children living in HIV/AIDS households make fewer health care visits. 	<ul style="list-style-type: none"> - Better information on children at highest risk for infection. - More systematic information is needed about the relative importance of specific barriers to access and effective follow-up.
Nutrition	<ul style="list-style-type: none"> - HIV and malnutrition are mutually reinforcing in HIV-infected children. - Infant feeding methods used by HIV-infected mothers have significant implications on the infant's HIV-status, mortality, and morbidity. 	<ul style="list-style-type: none"> - HIV/AIDS-affected children reside in food-insecure households more often than unaffected children. 	<ul style="list-style-type: none"> - Assessment of undernutrition in older children and across caretaking situations. - Evidence on leading causes of undernutrition. - Specific identification of disparities between affected and unaffected children.
Socio-economic	<ul style="list-style-type: none"> - Households with HIV-positive adults have lower incomes, and lost productivity contributes to economic decline. - HIV-affected households face increased expenditures, especially for health. - Other economic measures show that HIV-affected households, especially certain subgroups, are worse off than unaffected households. 	<ul style="list-style-type: none"> - As a consequence of HIV/AIDS, children have increasing socioeconomic responsibilities in the households, but the affect on their lives is mixed. - Families affected by HIV/AIDS express concerns about meeting basic needs. - Socioeconomic support services are inadequate in many cases. 	<ul style="list-style-type: none"> - Documenting impact. - Socioeconomic effects at different stages of the disease. - Differences in socioeconomic safety nets.
Education	<ul style="list-style-type: none"> - In Asia, younger children living in HIV/AIDS affected households are not generally less likely to be enrolled in school. - Older children affected by HIV/AIDS appear less likely to be enrolled and attend school than their unaffected counterparts. 	<ul style="list-style-type: none"> - The role of orphanhood on enrollment is mixed and not clear cut. - Household structure and relationships affect the probability of orphans attending school. - Children and their families fear discrimination from the school administration, teachers, peers, and the community. - Children affected by HIV/AIDS drop out of school because of economic factors, but not necessarily because of the cost of school. 	<ul style="list-style-type: none"> - Information from a wider range of countries (and continents) is needed on the impact of HIV/AIDS in the household on school enrollment. - Barriers to education related to or exacerbated by HIV/AIDS. - The dynamic nature of the effect of HIV/AIDS on education. - Academic performance; HIV/AIDS.

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<p>Psycho-social</p>	<ul style="list-style-type: none"> - Children affected by HIV/AIDS are more vulnerable to psychological problems than unaffected children. - Numerous studies provide evidence regarding risk and protective factors relating to the psychosocial well-being of HIV/AIDS affected children. 	<ul style="list-style-type: none"> - HIV/AIDS affected children of different ages face different challenges. - Children living in HIV-affected households rate their quality-of-life lower than children in non HIV-affected comparison households. 	<ul style="list-style-type: none"> - Little evidence from low prevalence and concentrated epidemic settings. - Psychosocial impact across stages of illness, caretaking situations, and social/cultural contexts. - Extra-familial support.
<p>Protection</p>	<ul style="list-style-type: none"> - Vulnerable children in general (which includes children affected by HIV/AIDS) suffer from inadequate protection by the state. 	<ul style="list-style-type: none"> - Legal frameworks in low prevalence and concentrated epidemic countries often make no specific mention of children affected by HIV/AIDS, or of orphans and vulnerable children. - Legal systems are not providing all the necessary protections for children in general, and specifically for those affected by HIV/AIDS related to financial support and provision. - Legal systems in many countries are not providing all the necessary protections for children in general and specifically for those affected by HIV/AIDS related to care and protection. - Legal systems are not providing all the necessary protections for children in general and specifically for those affected by HIV/AIDS related to access to important services. - Enforcement of child protection legislation in general – and for children affected by HIV/AIDS in particular – is weak in most countries. 	<ul style="list-style-type: none"> - Magnitude of the different types of protection problems. - Vulnerabilities for children affected by HIV/AIDS beyond those of vulnerable children in general.
<p>Placement</p>	<ul style="list-style-type: none"> - The majority of HIV/AIDS-affected children live with HIV-positive parents. - Orphans due to AIDS are largely and informally fostered by extended families. - Grandparents are often caretakers of orphans due to AIDS. - Informal fostering can lead to household welfare loss. 	<ul style="list-style-type: none"> - Non-institutional placement options are less commonly used, and mired by legal constraints. - HIV-positive children face additional barriers to placement than other orphans and vulnerable children. - Perceptions about placement needs and priorities differ between children and adults. - Fostered children may experience discrimination and abuse in non-kin households. 	<ul style="list-style-type: none"> - Adequacy of current caretaking situations. - Youth living outside of adult care. - Orphans living with siblings.

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Stigma	- HIV/AIDS-related stigma toward children is prevalent.	<ul style="list-style-type: none"> - Communities discriminate against children affected by HIV/AIDS. - Children affected by HIV/AIDS often face discrimination in access to public services, especially in schools. - Children affected by HIV/AIDS have strong expectations of experiencing stigma. - Stigma, discrimination, and abuse can occur within caretaking situations. - Children can be directly affected by HIV/AIDS stigma aimed at their parents or guardians. - Children experience stigma due to factors beyond HIV/AIDS. - Stigma/discrimination is not an automatic response. 	<ul style="list-style-type: none"> - Real versus perceived stigma in children. - Drivers of stigma for HIV/AIDS. - Effects of stigma and discrimination for children affected by HIV/AIDS.
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Table 8: Interventions

Challenge	Strong	Moderate	Missing
Health			<ul style="list-style-type: none"> - Effective prevention education for vulnerable children. - Documentation is lacking on effective ways to reach at-risk children. - Effectiveness of interventions to remove financial barriers.
Nutrition	- Short-course antiretroviral therapy significantly reduces vertical transmission of HIV to infants during labor, delivery and breastfeeding.	<ul style="list-style-type: none"> - Improved infant feeding counseling and mother education can increase HIV-free infant survivors. - Community-based education and supplementary feeding programs improve nutritional status in some contexts. 	<ul style="list-style-type: none"> - Little evidence on interventions that work. - Unanswered questions regarding implementation and targeting. - Information on current household strategies to mitigate malnutrition.
Socio-economic		- Cash transfer programs appear to help, though no specific evidence of marginal impact in children affected by HIV/AIDS.	- Interventions not adequately documented; impact not yet evaluated.
Education		<ul style="list-style-type: none"> - The "Education Vaccine" against HIV. - Financial subsidies might help increase enrollment of vulnerable children in some countries. 	<ul style="list-style-type: none"> - Targeting orphans and vulnerable children. - Harnessing community-based resources.

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Psycho-social		<ul style="list-style-type: none"> - Psychosocial services can help to mitigate the impact of HIV on children. 	<ul style="list-style-type: none"> - Psychosocial interventions have not been adequately documented or evaluated to serve as evidence for programming. - What additional psychosocial support can help affected children in families disintegrating from HIV/AIDS. - Environments that support psychosocial well-being. - Antiretroviral therapy and the psychosocial situation of children affected by HIV/AIDS.
Protection		<ul style="list-style-type: none"> - Facilitating enforcement: assisting families living with HIV to obtain their rights, particularly related to discrimination. 	<ul style="list-style-type: none"> - Mechanisms for community support. - Birth registration.
Placement	<ul style="list-style-type: none"> - Institutional care should be a last resort for affected children. 	<ul style="list-style-type: none"> - Cost estimates are higher for placement programming for affected children in low prevalence settings. 	<ul style="list-style-type: none"> - Evaluation of community-based interventions. - Evidence on effective contribution of succession planning for placement. - Costs of caring for an HIV-positive orphan versus another orphan. - Effective interventions to reduce risky behaviors of street children.
Stigma		<ul style="list-style-type: none"> - ART reduces stigma (shifting population perceptions of HIV-related disease). - Increase the visibility and participation of persons with HIV/AIDS through community-based initiatives that include HIV-infected or affected children. - Improve coping skills of children affected by HIV/AIDS by providing opportunities for them to be with others who are affected. - Increase health workers' willingness to treat people infected by HIV: <ul style="list-style-type: none"> • Education alone will have little impact on stigma reduction. • Schools can be an effective vehicle for anti-stigma information. • Non-targeting approaches are effective in normalizing HIV/AIDS. 	<ul style="list-style-type: none"> - Advocacy as an anti-stigma strategy. - Engaging local leaders in anti-stigma programs to change the power relationships that surround stigma. - Effect of education on reducing stigma. - Anti-discrimination policies and legislation as stigma- and discrimination-reduction tools.

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APPENDIX 1: CRITERIA FOR RIGOR SCORES FOR DOCUMENTS AND FOR LITERATURE REVIEWS

Rigor Score for Individual Studies

Quality Assessment of Study	SCORE (Points 0 -4)
(1) Addressed a Clearly Focused Issue Was there adequate information on: <ul style="list-style-type: none"> • Population studied • Intervention or situation under observation • Previous studies and/or theory • Outcomes considered 	_____ _____ _____ _____
(2) Methodology <ul style="list-style-type: none"> • Research methods were appropriate for question being asked • Study sample selected in a purposeful way • Adequate sample size, response rate and/or participation • Employed measures to minimize bias 	_____ _____ _____ _____
(3) Analysis <ul style="list-style-type: none"> • Different sources of knowledge & understanding about the issues were explored • Used appropriate qualitative and/or quantitative analytical tools • Employed measures to account for potential biases • Thorough reporting of results and key findings 	_____ _____ _____ _____
(4) Review <ul style="list-style-type: none"> • Sufficient original evidence to justify relationship between evidence and conclusion • Discussion of study implications for policy or programming • Discussion of study limitations (i.e. interpretability, generalizability) • Identified areas for further research 	_____ _____ _____ _____
TOTAL POINTS:	

Assessment →

Good: 12 – 16 points

Fair: 8 – 11 points

Poor: < 8 points

Rigor Score for Literature Reviews

Quality Assessment of Study [LITERATURE REVIEW]	SCORE (# of points)
<p>(1) Addressed a Clearly Focused Issue Was there adequate information on:</p> <ul style="list-style-type: none"> • Purpose of the review and/or rationale of the study • Research question to be answered • Previous data or theory on study population, context or issue of study 	<p>___ ___ ___</p>
<p>(2) Methodology</p> <ul style="list-style-type: none"> • Search of review materials was taken from multiple sources • Specified inclusion and exclusion criteria to reduce biased sampling • Methodology was carried out systematically • Included published and unpublished literature • Appears to represent an exhaustive collection of materials 	<p>___ ___ ___ ___ ___</p>
<p>(3) Analysis</p> <ul style="list-style-type: none"> • Review examines multiple aspects of the issue across body of literature • Described analytical process and tools including framework for analysis • Thorough reporting of the results and key findings • Takes into account the strength of the evidence in information collected 	<p>___ ___ ___ ___</p>
<p>(4) Review</p> <ul style="list-style-type: none"> • Reported findings are well substantiated by information presented • Discussion of study implications for policy or programming • Discussion of study limitations or biases, including contradictory findings • Identified areas for further research or review 	<p>___ ___ ___ ___</p>
<p>TOTAL POINTS:</p>	
<p>Assessment → Good: 12 – 16 points Fair: 8 – 11 points Poor: < 8 points</p>	

APPENDIX 2: CHECKSHEET FOR DOCUMENT REVIEW

Title:		Country:
Author(s):		Date Reviewed:
Source (journal, etc.):		Reviewed by:
Areas	Categories	NOTES
1. Category "Affected by AIDS" <i>Circle or highlight all that are appropriate</i>	<i>Please highlight main category and add control group to Other</i> (a) Child orphaned or abandoned due to AIDS (b) Children living with HIV/AIDS (c) Children living with chronically ill adults (d) Children in households that foster children (e) Children indirectly affected by HIV/AIDS (f) Other (specify): <u>all vulnerable children- HIV or not</u>	<i>Please discuss other "affected" categories, and control if there is one. Also mention any references to living circumstances and who is taking care of child. Mention sample size.</i>
2. Risk group (of person infected – whether child or adult/caretaker) <i>Circle or highlight all that are appropriate</i>	(a) Men having sex with men (b) Commercial sex workers (c) Clients of commercial sex workers (d) Intravenous drug users (e) Blood donors or recipients (f) Prisoners (g) Other (specify): _____	<i>Please note, as appropriate, the risk group of the child itself, its caretaker/parent, and the social context it lives in.</i>
3. Age of child affected <i>Circle or highlight all that are appropriate</i>	(a) 0-5 years (pre-school) – NOTE if in early months of life (b) 6-10 years (school age) (c) 11-14 years (early adolescents) (d) 15+ years (older adolescents)	
4. Areas of study <i>Circle or highlight all that are appropriate</i>	(a) Health (b) Nutrition/food security (c) Education (d) Protection (policy and law; discrimination, human rights) (e) Psycho-social support (f) Socio-economic (g) Other (specify): _____	<i>Please note if there are specific areas of emphasis if multiple topics covered.</i>
5. Type of study	(a) Situation (b) Interventions (<i>anything implemented to address issues in 4</i>).	
6. Type of evidence for situation <i>Circle or highlight all that are appropriate</i>	(a) Study with controls over time (b) Trends over time (c) Control group – cross sectional (quantitative) (d) Descriptive quantitative or qualitative study with appropriate sampling (e)	(e) case study (f) other (specify) _____
7. Type of evidence for intervention <i>Circle or highlight the most appropriate</i>	(a) randomized controlled trials (b) direct controlled trials (c) quasi experimental design (d) non-experimental direct analysis (comparisons over time/place; Cross-sectional)	(e) non-experimental indirect analysis (f) Other (specify): _____

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8a. Intervention Rigor Score (16 possible pts: 12-16 = good, 8-11 = fair, <8 = poor)	Addressed focused issue: ■ pop studied _____ ■ intervention or sit _____ ■ prev data or theory _____ ■ outcomes _____	Methodology: ■ appr. methods _____ ■ purpose. sample _____ ■ adeq. sample size _____ ■ min. bias _____	Analysis: ■ issues explored _____ ■ appr. anal. Tools _____ ■ account for bias _____ ■ thorough results _____	Review: ■ suff. evid. for concl. _____ ■ impl. policy program _____ ■ discuss study limits _____ ■ further research _____	TOTAL SCORE
8a. Lit Review Rigor Score (16 possible pts: 12-16 = good, 8-11 = fair, <8 = poor)	Addressed focused issue: ■ rationale for review _____ ■ research question _____ ■ prev data or theory _____	Methodology: ■ multiple sources _____ ■ inclus/exclusion criteria _____ ■ systematic implem _____ ■ publish & unpublsh _____ ■ Exhaustive collection _____	Analysis: ■ issues explored _____ ■ describes anal & tools _____ ■ thorough reporting _____ ■ considers strength of evid _____	Review: ■ suff. evid. for findings _____ ■ implica policy program _____ ■ discuss study limits _____ ■ further research _____	TOTAL SCORE
9. Score of relevance (scale 1 [low] to 5 [high])	Relevance to objectives of this study: <i>who are children affected by HIV/AIDS? what are the priority challenges faced by these children? How do children affected by HIV/AIDS differ from other children in the same group? What interventions or approaches work?</i>			TOTAL SCORE	
10. Summary – key points: Brief description of key findings related to study at hand.		Use bullets – include key points related to our study, not just abstract. Include purpose of article (present evidence, advocacy, etc). If intervention, describe intervention, its effectiveness and generalizability. Describe geographical grouping (urban/rural, specific regions, etc). Note occupation, religion, ethnic group.			
<p>Study Purpose:</p> <p>Key Findings relevant to our study:</p> <p>Description of situation of children affected by HIV/AIDS (children affected by HIV/AIDSs):</p> <ul style="list-style-type: none"> Who are children affected by HIV/AIDSs? Who are the caretakers of children affected by HIV/AIDSs? <p>Key Article Findings related to situation of children affected by HIV/AIDSs:</p> <p>Information regarding Intervention:</p> <ul style="list-style-type: none"> Description of Intervention: Intervention Effectiveness: Implications for other countries: <p>Implications, Lessons learned, Added value:</p>					
Need for additional contact with author? Yes _____ No _____ If yes, on what?					
Any references that we should get a hold of? Yes _____ No _____ <i>if so, please send references to Cecilia so she can check whether we already have or obtain!</i>					

APPENDIX 3: SELECTED STUDIES WITH CONTROLS (NOT IN USA OR EUROPE)

Study	Country	Type of cases	Type of controls	Sample size	Comments
Verma et al. 2002	India	HIV/AIDS death.	Non-HIV/AIDS death; no death.	84 cases (256 kids). 70 non-AIDS death (214 kids). 69 no death (230 kids).	Cases selected from same village and urban blocks.
Ainsworth and Filmore 2006	Worldwide	Orphans.	Non-orphans.		
Alkenbrack et al. 2004	Cambodia	HIV-pos households.	Unknown status household.	500 case (442 6-12;276 13-18) 500 control (414 6-12;311 13-18)	Half urban; half rural. Matched pair for control.
Bauman et al, 2006	Zimbabwe/-USA	Children in HIV-pos households in Zimbabwe.	Children in HIV-pos households in USA.		
Brahmbhatt et al. 2006	Uganda	HIV-pos children of HIV-pos mothers. HIV-neg children of HIV-pos mothers.	HIV-neg children of HIV-neg mothers.	69 HIV-pos children. 267 HIV-neg children of HIV-pos mothers. 3,128 HIV-neg children of HIV-neg mothers.	Mothers identified during pregnancy; visited every 6 weeks.
Case et al. 2004	Africa	Orphans.	Non-orphans.	10 DHS surveys total children 275,000.	West Africa, Eastern Africa, South African
GECA et al. 2005	Benin	Orphans and vulnerable children (including those due to HIV/AIDS) 6-18 years.	Non-orphans and vulnerable children 6-18.	1,155 orphans and vulnerable children. 1,155 non-orphans and vulnerable children.	Methodology for matching not clear in report, although for fostered children, another child in the household was control. Role of HIV/AIDS in status as OVC not known.
Gilborn et al 2006	Zimbabwe				
Jianhua et al. 2006	China	Children 6-17 in HIV-pos households with parents alive. Children orphaned (1-2).	Children 6-17 in unaffected households.	107 children affected with parents. 59 orphans. 137 unaffected kids.	Site A – blood donor spread. Site B – drug use. Controls from same villages.
Kacket et al. 2007	India	Children living at home.	Children living outside of family. Children living on the street.		
Miller et al. 2005	Guatemala	Orphans in institutions.	Orphans in foster care.		Children adopted in USA based on where they were staying at time of adoption -- Cognitive,

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					anthropometrics.
Pradhan et al. 2006	India	HIV-pos households.	HIV-neg households.	2068 case 6224 controls	400 cases in each of 6 high prevalence mostly urban states. Controls (3 per case) matched according to geography and same socio-economic strata (income, occupation).
UNICEF/STC 2006	Lao	Children affected by HIV/AIDS (living with HIV positive parents, orphans or infected children.	Other children not affected.	80 affected children and 35 unaffected children.	Urban and rural. Controls selected randomly from same communities.
Wyss et al., 2004	Chad	Households with HIV-pos member.	Households without HIV-pos members.	193 AIDS households. 193 control households.	Non-random selection of cases, four localities, matching of controls to cases in same communities on age, sex, socioprofessional background.

