Introduction

HIV/AIDS and Its Long-Term Impact on Children

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HIV/AIDS has changed the world in profound and still-evolving ways. The last children born before HIV/AIDS[1] emerged in the late 1970s and early 1980s are now in their mid-twenties, many with children of their own. All children born in the foreseeable future – at least for the next several decades – will be living in a world where the epidemic persists, albeit with variable consequences for each of them. Children, among the most vulnerable members of society, are bellwethers of adult leaders' willingness and capacity to respond to economic, health, and social challenges. What happens to children and adolescents now will determine not only their futures but also the futures of their families, communities, and societies.

In the first years of the HIV/AIDS epidemic, though, there was relatively little direct focus on children, particularly children who were not themselves HIV-infected but were nevertheless significantly affected by the disease. In the past decade or so the massive and growing number of orphans in Africa has received periodic media attention and many program responses. To be sure, in developed countries in North America and Europe, pediatric HIV/AIDS has become a highly sophisticated medical specialty. Treatments to reduce mother-to-child HIV transmission have succeeded extraordinarily well in these countries and are being introduced slowly in poor countries where the need is greatest. In every country affected by the epidemic, dedicated individuals and groups – most with very meager resources – serve children and families and advocate for more attention to their needs. (See the Chronology of Important Events in this volume for some key developments.) On the whole, however, the more

[1] The human immune deficiency virus (HIV) and the acquired immune deficiency syndrome (AIDS) are commonly linked by the term HIV/AIDS; infection with the virus is the initial stage of a disease that ends with the more serious complications and opportunistic infections that define AIDS.

general impact on children has been a lower priority on policymakers' and international agendas than are adult problems.

There are many reasons for this. Biomedical responses – scientific inquiry, basic epidemiology, and initial prevention and care efforts – were understandably at the top of the priority list. Even these responses were complicated and constrained in many places by widespread official and informal denial that a problem existed. Families with ill and dying adults also struggled to take care of surviving children as they had always done – on their own. By the time the multiple, cascading impacts of HIV/AIDS on families and children became more apparent, the scope of the problem seemed too huge to tackle. Furthermore, children are generally powerless in society and have no political voice. But the silence about HIV/AIDS has now been broken, and the number of orphans is too massive to ignore. It is essential to understand that loss of parents is only the most obvious impact of the epidemic on children, and that other vulnerabilities must be recognized and addressed as well. Nevertheless, solutions proposed in haste or based on inaccurate or incomplete data will not achieve their goals, and may even have negative effects.

This book brings together in a multidisciplinary and multifaceted way what is now known, what must be learned, and (most important) what must be done to address children's needs effectively. Each chapter vividly illustrates that all the aspects of children's lives – economic, educational, medical, psychosocial, legal, and spiritual – are intertwined (see especially Chapters 3 and 4). Solutions must take into account each society's cultural, political, social, and economic infrastructure. The book's emphasis on Africa reflects the preponderance of research and experience in the field and the advanced state of the epidemic on that continent. Two chapters, however – one on Asia and the Pacific region (Chapter 7) and one on the United States (Chapter 8) – present different paradigms, and wherever possible, information from non-African contexts has been added.

PARADOXES AND DILEMMAS

Researchers, practitioners, and advocates engaged with children's issues and HIV/AIDS find themselves facing some unsettling paradoxes. For example, the realities of the epidemic's scope are surely daunting – yet they ought not be interpreted so negatively that any intervention seems pointless. In the past it has been seen as necessary to emphasize only the worst in order to gain any attention at all. Now that there is at least a beginning of support, it is important to point out the positive side – that there are indeed many interventions, some requiring incredibly modest resources by American or European standards, that can make a substantial difference in children's lives. As in so many other areas, focusing on children's issues lays bare a society's problems but also reveals its strengths.

Another paradox is that while families are children's natural protectors (and in most cases do their best under extraordinarily difficult circumstances) it is also true that some households exploit and abuse children in their care. But some instances that appear to be – and may well be – exploitative (children taken out of school to work in fields, for example) might be the only means available for that family's survival. Other instances, such as the sexual exploitation of children, are clearly abusive and unconscionable. Families should not be romanticized, nor should they be demonized. The vast majority of children orphaned or otherwise made vulnerable by AIDS are living within families. The balance here is to find ways to support families so that they can more adequately meet children's needs, but also to protect children from being pressured into activities that contravene their best interests or subject them to outright abuse and exploitation.

Still other quandaries arise about language and definitions. Even "child" is defined differently in various contexts and for different reasons. This book is concerned with all children and young people below the legal age of majority. The term "AIDS orphan" still appears occasionally in the popular media, but it has become anathema to most professionals addressing the impacts of HIV/AIDS on children. This book avoids the term because it is stigmatizing, and suggests to some that children who have lost a parent are themselves "victims" (another unacceptable term) of AIDS, although most are not HIV-infected.

Even the term "orphan," despite its long religious associations (see Chapter 6) and its epidemiologic neutrality, is problematic because its meaning varies among cultures and is potentially stigmatizing. Focusing solely on children who have lost a parent fails to take account of those who are in similar or even greater need. It can result in the inappropriate categorization and labeling of children, and it may generate conflicts over resources and priorities at community and household levels. While orphans are often referred to in this book, this designation is not advocated as a criterion for individual eligibility for assistance. The unfortunate reality, though, is that some donors do tie funding to orphans, or specifically to orphans whose parents have died of HIV/AIDS. Programs often walk a fine line between telling donors what they want to hear and implementing services that serve other vulnerable children as well.

One of the solutions to this dilemma is the targeting of resources in two stages: first, to geographic areas seriously affected by HIV/AIDS; and second, to the most vulnerable children identified by communities in these areas (described in Chapter 10). Attempting to find another solution, many programs and national-level policymaking and planning agencies have begun to focus on "orphans and vulnerable children." Some donors and programs understand this specifically as children orphaned or otherwise made vulnerable by HIV/AIDS. Others, though, take the term at face value,

recognizing that the number of orphans and vulnerable children has been greatly increased by AIDS in countries with high HIV prevalence, but that other factors also contribute. Consequently, different people and agencies use the term "orphans and vulnerable children" to mean somewhat different things. In this book, the phrase is generally used to mean all children who are orphaned or are otherwise vulnerable in countries where the epidemic is having significant impacts.

"Orphans and vulnerable children" becomes problematic in another way when it is contracted to the label "OVC." Similar problems arise with the acronym "CABA", which stands for "children affected by AIDS." Those who use OVC or CABA as convenient shorthand in technical documents certainly do not intend any ill effects. Because these labels have been used frequently in official documents, however, people at the local level have begun to use them as well to show organizations with resources that they understand and share their commitments. The unfortunate result has been that one can now visit communities where particular children are identified (at least to visitors) using such labels. The debates on terminology issues undoubtedly will take new turns in the coming years. For this book, we have chosen to avoid the terms AIDS orphans, OVC, and CABA, except in quotations or organizational names, but we have not imposed a single terminology, thus acknowledging the fluidity of the discussion and the different contexts being described.

THE HIV/AIDS EPIDEMIC: SCOPE AND TRENDS

Statistics cannot convey the individual human suffering created by the HIV/AIDS epidemic, but they are necessary to portray its cumulative effect. As the epidemic has evolved, so too have better methods of data collection and interpretation. Still, there are many gaps (see Chapter 9). In a report published in July 2004, the Joint United Nations Programme on HIV/AIDS (UNAIDS) estimated that about 38 million people around the globe were living with HIV/AIDS, 2.5 million of them children under the age of fifteen (UNAIDS 2004). Around 5 million people became newly infected with HIV in 2003 (4.2 million adults and 700,000 children), (and in that year an estimated 3 million people died (2.5 million adults and 500,000 children).

The epidemic is most severe where it emerged earliest – in sub-Saharan Africa, which has between 25 million and 28.2 million people living with the disease, with about 3 million newly infected in 2003. Over 2 million adults and children died due to AIDS in 2003 (UNICEF 2003). Beyond these hardest-hit countries, Thailand (where the epidemic is well established) is being joined by other Asian countries where HIV infection is spreading rapidly (particularly India, China, Indonesia, and Vietnam). HIV/AIDS is also growing in Eastern Europe and Central Asia among the countries

of the former Soviet Union (Field 2004). In Latin America the epidemic is entrenched in parts of the Caribbean (the Bahamas, Haiti, and Trinidad and Tobago) and in Brazil and Guyana. In the developed world – which has benefited from the advent of multidrug treatments called HAART (highly active antiretroviral therapy) – mortality has declined but new infections continue. In the United States this is particularly true among African American and Latino young women and men. Only a few countries, notably Senegal and Uganda, have succeeded in slowing the epidemic by early and large-scale prevention efforts.

In this global pandemic, each regional or local epidemic has a specific time frame, pattern, primary mode of transmission, and availability of resources. Injecting-drug use in Asia and Eastern Europe is a common mode of transmission but is much less prevalent in Africa. Heterosexual transmission occurs everywhere but is the primary mode of transmission in Africa and, increasingly, in the United States.

This is the broad picture. Three-quarters of the people living with HIV/AIDS are in sub-Saharan Africa, and the epidemic's impact on children follows the adult epidemic. In 1990, fewer than 1 million children in that region under the age of fifteen had lost one or both parents to HIV/AIDS (UNICEF 2003). By the end of 2001 the number had reached over 11 million children, according to the joint estimate of UNICEF, UNAIDS, and the U.S. Agency for International Development (USAID). By 2010 that number is expected to grow to 20 million. About 5.7 percent of all children in sub-Saharan Africa will be orphaned by AIDS by 2010 (USAID et al. 2002). The most recent estimates extend the age of "child" to eighteen, bringing the statistics in line with international definitions and recognizing that children of different ages have different problems and needs (USAID, et al. 2004). In fact, more than half of the orphans in sub-Saharan Africa, Asia, and Latin America and the Caribbean are aged twelve to seventeen, and a third are aged six to eleven.

According to UNICEF (2003), "The worst is yet to come." As increasing numbers of young adults with HIV infection progress to AIDS and die, they will leave ever larger numbers of orphaned children (see Figure I.1). Because there is such a long lag time between infection and illness, even if there were no new infections the numbers of affected children would still increase. Better access to treatment will delay but not stop this inexorable process. Prolonging the lives of HIV-infected parents and giving them a good quality of life will improve the educational, economic, and psychosocial outcomes for their children.

Ironically, however, the most effective medical methods of preventing transmission to newborns – the administration of antiretroviral therapy during pregnancy and delivery and then to the neonate through Prevention of Mother-to-Child Transmission programs (PMTCT) – can lead to an

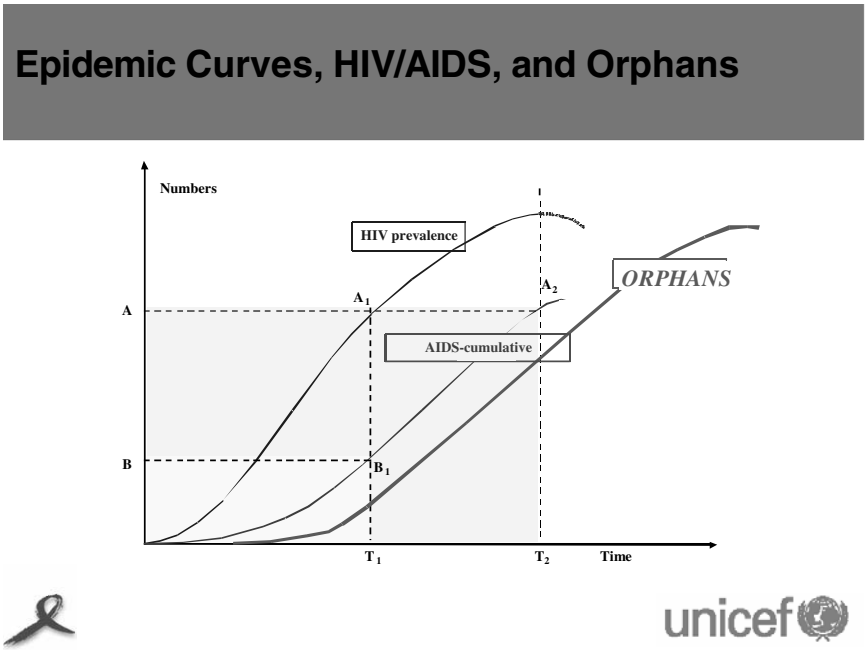

FIGURE I.1. The worst is yet to come. (Reprinted from UNICEF 2001, 27.)

increase in orphans. HIV-positive women in PMTCT programs are more likely to have uninfected babies. If they do not receive drug therapy themselves after giving birth, however, they are more likely to sicken and die, leaving their children as orphans. Some agencies are establishing "PMTCT-plus" initiatives to provide life-prolonging interventions to HIV-positive parents identified through these programs. Programs to provide antiretroviral treatment to HIV-infected children in developing countries are still in their infancy, with some agencies targeting HIV-infected orphans. As important as these programs are for reducing child mortality, they will have only a minimal effect on reducing the number of orphans because more children will survive the death of a parent. Preliminary estimates suggest that the number of orphans may be reduced by about 3 percent if anti-retroviral treatment and PMTC+ are fully implemented (Neff Walker, personal communication, April 2005).

Just as HIV/AIDS is a dynamic pandemic, its impacts on children, families, and households unfolds gradually and in many directions. Beginning with a parent's HIV infection, and then through the more serious illnesses of AIDS and ultimately death, children's lives are increasingly circumscribed by the economic problems that beset the family, by their lost or limited educational opportunities, and by psychosocial distress and other

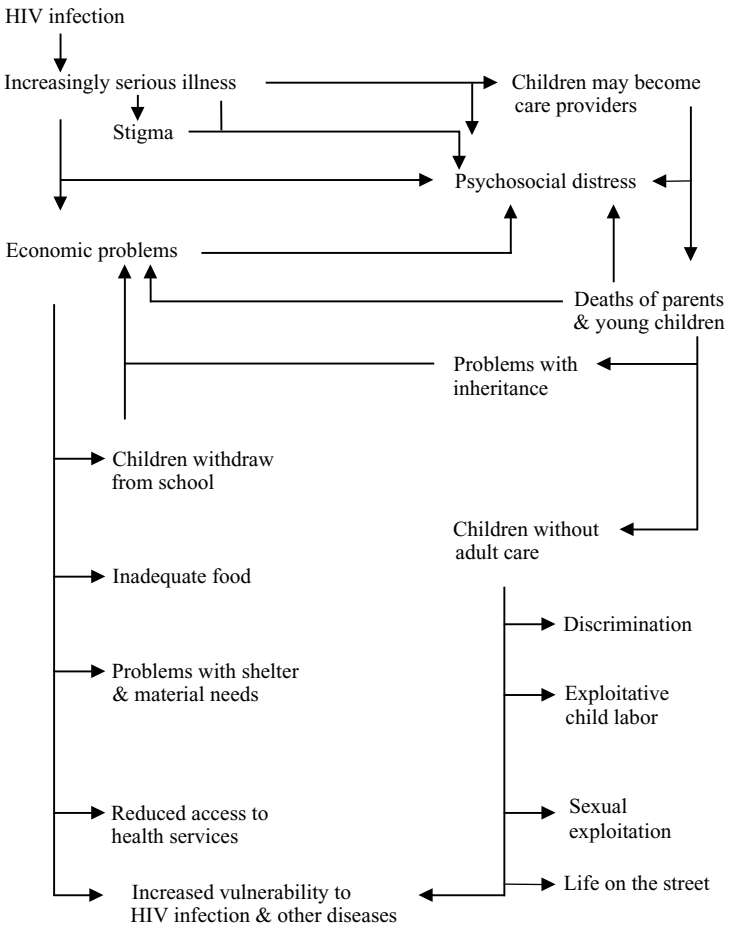

FIGURE I.2. The cascading impacts of HIV/AIDS on children.

difficulties that can ultimately lead to the worst outcomes. (See Figure I.2 for a schematic presentation of this downward spiral, and see Chapter 2 for more details.)

The staggering level of suffering that HIV/AIDS is causing should be sufficient to motivate an adequate collective response to this situation. Moreover, the almost universally agreed upon rights of children defined in the United Nations Convention on the Rights of the Child (see Chapter 5) should be sufficient to generate the action needed. However, to date such considerations have been insufficient motivators of national and international agencies. Perhaps the additional stimulus needed can come

from greater attention to the consequences of failing to make an adequate response.

Clearly, the number of children and families made vulnerable by HIV/AIDS is massive and will remain so for decades. AIDS is causing unprecedented child and family welfare problems, but the collective response in every country seriously affected by the pandemic falls far short of what is needed. What affected children and their families require, and what their own countries and the international community owe them, is a combination of efforts, large and small, that together match the scale and duration of the problems that AIDS is causing. Only a small minority of children and families affected by HIV/AIDS are currently benefiting significantly from assistance coming from outside their extended family and neighbors (USAID et al. 2004). While there are many effective programs and funding has increased, the gap between the impacts of these initiatives and what needs to be done remains huge (World Vision 2005). More resources are desperately needed, but there is no solid consensus on just where this might come from, how it can be sustained for decades, or how it should be applied (see Chapter 10).

BUILDING AN EFFECTIVE RESPONSE

The way a problem is understood influences what is done about it. The starting point for developing effective responses to the impacts of the pandemic on children is recognizing that families and communities are the first line of response (see Chapter 1). Whether or not outside bodies intervene, families and communities will be dealing with the impacts of AIDS, often with great difficulty. Consequently, governments, international organizations, nongovernmental organizations (NGOs), religious bodies, and others will have significant, sustainable impacts on children's safety and well-being to the extent that they strengthen the ongoing capacities of affected families and communities to protect and care for their vulnerable children. Special efforts are needed for the care and protection of children on the street or in child-headed households.

A global consensus has emerged on the necessity of a collaborative international response of building family and community capacities, ensuring that children benefit from essential services, and establishing appropriate and meaningful governmental and societal responses. This consensus is reflected in a recent and very important document: *The Framework for the Protection, Care, and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS* (2004). The *Framework* was developed through an extensive global consultation process and reflects a broad, international consensus on the actions needed to address the needs and rights of orphans and vulnerable children. By July 2004, when it was released, it had been endorsed by twenty-three international, governmental, and

nongovernmental organizations. While UNICEF took the lead in developing the document, the *Framework* incorporates the contributions of many organizations. It was issued by all the endorsing organizations, rather than any specific one.

Developing programs that significantly improve the lives of individual children and families affected by HIV/AIDS would be relatively easy if there were enough resources, organizational capacity, and political will. Vulnerable children and households can be identified, health services provided, school expenses paid, food distributed, and supportive counseling provided. The reality, however, is that the funding either currently or likely to become available will be too limited to sustain such an intensive direct service delivery approach for the duration required. The challenge, then, is to implement approaches that:

- improve substantially the safety and well-being of vulnerable children and families,
- make maximum use of all available resources,
- match the massive scale of the impacts of AIDS, and
- can be sustained for decades.

Creating an adequate response will require careful consideration of the spectrum of the epidemic's impacts. On the one hand, it is necessary to recognize the problems on a human scale – what happens to parents, children, and orphans' guardians. This perspective by itself, though, is inadequate to guide the scaling up of responses to these problems. Thus on the other hand, it is also essential to keep in mind the magnitude and duration of the HIV/AIDS pandemic and its collective impacts. The authors in this volume provide not only essential information and perspectives, but also critical recommendations for action that, taken together, point a way forward.

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