The last two decades of the twentieth century witnessed unprecedented numbers of children eighteen years and younger in the United States residing in homes headed by a grandparent. Of the nearly four million children living in grandparent-headed households in 1997, 1.5 million had neither parent present (Lugaila 1998). “Skip-generation parenting” includes thousands of grandparents and older relatives such as great-grandparents and great-aunts who are raising children and adolescents because HIV disease has killed or disabled the parents. Where custodial responsibility has been documented, grandmothers are most often the surrogate parents to children of HIV-infected parents (Schuster et al. 2000; Draimin 1995; Schable et al. 1995; Cohen and Nehring 1994). The AIDS epidemic in the United States was projected to have orphaned more than 150,000 children by the year 2000 (Michaels and Levine 1992), leaving as many as 40,000 older adults as surrogate parents. Thousands more are now caring for children whose parents are infected but living with HIV disease. By 2010, hundreds of thousands of grandparents and other family elders will be raising children in the wake of HIV/AIDS around the globe. Despite this unprecedented caregiving responsibility, the older adults themselves are relatively invisible, hidden in the shadows of HIV care and the demands of raising a child.

Although surrogate parents in the HIV epidemic face problems shared with those raising children of incarcerated or drug-addicted mothers, HIV disease poses unique problems for both child and caregiver. To which friends and family members can a grandmother disclose the reason for her daughter’s death? Should she also tell them of her four-year-old grandson’s seropositive
status? How does a seventy-six-year-old widowed grandmother handle the rage of her infected sixteen-year-old grandson who had watched his mother die from the disease seven years earlier? A fifty-three-year-old grandfather with primary responsibility for five young grandsons of a drug-using, infected mother has a bleeding ulcer that has already hospitalized him. Where can he find childcare, transportation, and health insurance so that he can seek medical attention? To whom does a sixty-four-year-old grandmother turn for guidance in discussing safer sex when her fifteen-year-old infected granddaughter begins dating?

Although older adults find comfort, satisfaction, and meaning in surrogate parenting in the wake of HIV/AIDS, caregiving imposes harsh and persistent threats to their own well-being. A grandmother in her thirties or forties defies classification as “older.” However, the typical parental surrogate to HIV-affected children is a woman or couple in the mid- to late fifties, with some grandparents, great-grandparents, and great-aunts in their late seventies or early eighties. Parental surrogacy is thrust upon the elder generation when age-related chronic health problems surface and financial, emotional, and physical resources must be stretched to meet this new family responsibility. Given an extended period of child rearing for eighteen years or more, financial strain, social isolation, emotional stress, and neglected health problems may increase an older caregiver’s risk of poor health, disability and dependency as he or she continues to age. From the vantage point of parental surrogacy, threats to a caregiver’s physical and psychological well-being affect his or her capacity to serve as the primary parent until the child reaches maturity.

The implications of older adults raising children orphaned and affected by HIV disease are profound and complex, not only for individual caregivers and their families but also for professionals across a wide range of disciplines and service sectors. Entire communities and societies also feel the impact as their elder generation assumes the parental role of a generation lost to HIV/AIDS. Over the coming decade, HIV-determined parental surrogacy will have important implications for public policy, health and family service agencies, the “aging network,” child welfare, and legal and educational systems. Service professionals, administrators, clergy, and educators will continue to meet caregivers in a variety of settings: as they escort infected family members to clinic appointments, apply for public benefits, learn from home-care staff how to adjust intravenous morphine injections and suction tracheal tubes, visit ill and dying children and grandchildren in hospitals, bury loved ones, and cope with children’s behavioral and academic problems.
Caregivers, of course, are not the intended focus or identified patients of HIV and social-service programs. In most situations where elder parental surrogates are visible, it is only in their role as a child’s caregiver. The mission of a pediatric AIDS clinic or Head Start Program, for example, is to serve the child, not the older caregiver. Older adults raising orphaned and affected children exist in the background, and in their commitment to care for the children they are reluctant to make their own needs known. Because most communities lack a service-delivery system designed to assist older parental surrogates, professional staff are often unable to identify caregiver needs, especially in HIV-affected families.

Multiple systemic barriers to case management and other services frustrate professionals who attempt to link caregivers to available resources. Barriers include professional ignorance about or denial that HIV disease affects older adults, eligibility restrictions on services funded through the Ryan White Comprehensive AIDS Resources Emergency Act of 1990 (CARE), limited funding and age restrictions of Older Americans Act (OAA)-funded services, and a fragmented health and human service system. The needs of elder HIV-affected surrogate parents are overlooked by public policies for HIV-infected persons and for older adults.

At the community and societal level, the implications of a lost generation of parents are unprecedented, yet this is the demographic profile of countries and communities hardest hit by the HIV pandemic—largely poor communities and nations of color. In policy reports and the popular press, the magnitude of this crisis at the community, national, and global level has been cast in terms of only orphaned and affected children, not the generation of elder caregivers. How communities will be affected by a generation of elders whose financial, social, and emotional resources are diminished by parental surrogacy and who have lost the caregivers for their own later lives remains to be seen. What national and global policy initiatives and strategies will be needed to address the greater vulnerability of these older adults? Two decades into the pandemic, these questions still have not been asked.

Nearly invisible, HIV-affected surrogate parents are a distinct group within two other groups that have received scholarly attention: those providing help to an HIV-ill family member or partner and those grandparents who are acting as parents. Although nearly 11 percent of grandparents in the United States report having assumed primary child-rearing responsibility for at least six months (Fuller-Thomson, Minkler, and Driver 1997), the number that has done so because of parental HIV disease is unknown. To
date, there are no book-length studies of older adults raising children in the
wake of HIV/AIDS, despite attention to AIDS orphaned children (New
Jersey AIDS Partnership 1997; Boyd-Franklin, Steiner, and Boland 1995;
Geballe, Gruendel, and Andiman 1995). This collection is intended to ad-
dress an area virtually ignored by current policy and programs and to fill a
vacuum in the practitioner-oriented and academically oriented literature on
families and caregiving.

Because the issues affecting elder caregivers extend beyond a single area,
this collection assembles a group of contributors with expertise in aging, HIV
services, community health, child welfare, mental health, education, and pub-
lic policy. The authors’ professional disciplines include social work, nursing,
medicine, health administration, gerontology, special education, and coun-
seling. The book’s primary goal is to generate, support, and guide program
and policy initiatives that can address the complex issues embedded in the
daily experience of these families and the professionals who work with them.
Some readers may want to consider clinical and other “practice” issues with
caregivers and families, others program design and service delivery, including
outreach, staff training, and interagency coordination. Public policy profes-
sionals and attorneys will find the collection helpful in advocating the cause
of their clients and in effecting systemic reforms. It is hoped that students and
scholars will consider how academic resources can be harnessed through ap-
plied research to support these invisible caregivers and their families so that
raising children in the wake of HIV/AIDS does not continue to compromise
the older generation’s well-being as it ages.

In the early 1990s the concept of “secondary survivor” was introduced to
underscore the intergenerational impact of HIV/AIDS, notably in poorer
African countries where “these survivors [bear] the full weight of sustaining a
decimated, confused and demoralized community. . . . The surviving respon-
sible person in the family is likely to be drawn from the older generation”
reflect the global impact of HIV/AIDS and the transformation of orphaning
“into a long-term, chronic problem” (Hunter and Williamson 2000:4) for the
twenty-first century. In sub-Saharan African, Southeast Asian, Latin Ameri-
can, and Caribbean countries and U.S. urban areas hardest hit by the epi-
demic, the loss of the young adult and mid-life generation imposes harsh bur-
dens on elderly caregivers. Yet, as the world’s nations begin to cope with the
estimated thirty million AIDS-orphaned children and the millions more who
are living with infected parents (Hunter and Williamson 2000), the older
parental surrogates may be further neglected. The aim of this book is to bring them out of the shadows and, in making them visible, contribute to their well-being and empowerment.

References


