HIV Disease in Print

In this issue, we continue our tradition of sampling the huge amount of AIDS and mental health literature. Through book reviews written by knowledgable professionals, readers can glean a sense of what's out there and how to best use it.

This year, we have narrowed the number of books we cover—from seven to five—so we can provide a more comprehensive review of each book. Again, we have asked a group of AIDS Health Project staff and local experts to discuss these books: Therapists on the Front Line: Psychotherapy with Gay Men in the Age of AIDS (page 1); The Changing Face of AIDS: Implications for Social Work Practice (page 3); AIDS, HIV and Mental Health (page 5); Breaking New Ground: Developing Innovative AIDS Care Residences (page 6); and A Death in the Family: Orphans of the HIV Epidemic (page 7).

Of these books, the most notable are Cadwell, Burnham, and Forstein's Therapists on the Front Line and Lynch, Lloyd, and Fimbres's The Changing Face of AIDS. Both of these books appeal to therapists both new to HIV-related counseling and those steeped in it. Finally, while Lieberman and Chamberlain's Breaking New Ground is more distant from the psychotherapy experience, it offers an excellent overview of an issue that is affecting more and more clients: housing.

We will publish next year's book review issue in December 1995 and encourage readers to submit the titles (including names of authors and publishers) to us for possible inclusion.

Therapy with Gay Men
David Silven, PhD


Therapists on the Front Line is a treat for the novice as well as the seasoned, HIV-focused psychotherapist. Experienced clinicians summarize for readers their learning over the first decade of the epidemic in a broad range of critically important areas. The therapist just beginning to work with HIV-related issues will find comprehensive material to orient him or her to the work. The veteran therapist will be pleased to see many fresh perspectives.

The first section of the book lays out general issues pertaining to HIV-related psychotherapy with gay men. Here readers get an analysis of the genesis and therapeutic handling of common areas of difficulty for clients. These include the shame resulting from the double stigma of homosexuality and HIV infection, grief and mourning resulting from the loss of loved ones, spiritual confusion and inquiry, suicidality, neuropsychiatric dysfunction, risk-associated sexual behavior, and reactions to HIV antibody testing.

Chapter Two describes gay male development and the ways it can be affected by HIV infection at various points in the life cycle. This conceptualization is an important theoretical contribution that many readers will find novel. Likewise, Chapter Three offers a refreshingly atypical approach—this time from a self-psychological perspective—to the topic of grief and mourning.

The book's discussion of spirituality, though tending to focus on "God" to an extent that may be alienating to people with less traditional concepts of spirituality, provocatively explores the fundamental existential concerns for this population. Its examination of suicidality goes well beyond...
the expected discourse on ethical and legal issues to provide insight into the psychology of suicidality in this client population. It also details the potential pitfalls clinicians face in trying to assess and intervene. In contrast, Chapter Six deals with neuropsychiatric dysfunction and focuses primarily on ethical and legal considerations. Further discussion of how therapists can continue working with clients with neurocognitive deficits and how the nature of the therapy changes as a result of the deficits would have been helpful.

Therapeutic Modalities and Populations

The second section of the book covers therapeutic modalities, including individual, group, couples, and family therapy. Chapter Nine discusses the psychodynamics of AIDS from a self psychological view. Key psychological needs and vulnerabilities of HIV-infected individuals are described within a theoretical framework that will appeal to many readers because of its focus on the client’s subjective experience. It is disappointing, however, and somewhat of a mystery that this is the only chapter in the subsection “Individual Treatment.” Additional chapters on other psychodynamic as well as non-psychodynamic approaches would have made for a much more well-rounded presentation.

Chapter Thirteen focuses on the issues that arise when gay men with HIV disease return to live with their biological family in smaller urban areas. The emphasis on taking into consideration the developmental phase of the family alerts the reader to the complexity of intervening with the family system. An additional chapter in this subsection could have addressed family-focused interventions in the commonly encountered nonbiological “families” constituted by gay men’s friends and significant others.

The book’s third section deals with specific treatment populations: men of color, men in rural areas, adult survivors of sexual abuse, men with a history of substance abuse, and seronegative men. The editors’ decision to focus on only two ethnic minority communities—African Americans and Latinos—seems unnecessarily exclusive. Despite this flaw, the chapters on those two communities are informative. Chapter Fifteen is particularly successful in avoiding overgeneralizing about African Americans, alerting readers to the tendency to view individuals through the lens of cultural stereotypes. Chapter Eighteen on adult survivors of earlier sexual abuse presents a sophisticated and thought-provoking analysis of how having HIV disease and dealing with care providers can trigger disturbing somatic and affective responses rooted in earlier sexual abuse.

Empathic Challenges

The fourth and fifth sections of the book deal with empathic challenges and countertransference issues, including considerations that emerge when the therapist him or herself has HIV disease. Especially evocative is Chapter Twenty-Three on countertransference, in which the author gives a highly personal and revealing account of his own struggles as a therapist with survivor guilt, fears of abandonment by clients who are dying, anguish over clients who die, the use of defenses such as numbing and pathologizing clients, feelings of helplessness, and confusion about his role.

The final chapters address the sensitive issues that arise for the HIV-infected therapist with respect to disclosure of serostatus to clients and the timing of closing one’s clinical practice. The issues are poignantly presented in the context of personal responses of therapists. The extreme professional challenge to the therapist with HIV disease is illustrated well by the experience of the therapist chronicled in Chapter Twenty-Seven. Despite having multiple avenues of support and peer consultation, this therapist handled disclosure to his clients and the closing of his practice in ways that seemed dictated more by his own needs than those of his clients.

Conclusion

As the editors acknowledge in the preface, there are certain key HIV-related topics that the book does not cover in any depth: epidemiological and medical aspects of HIV disease, and political and psychosocial issues. Therapists will need to consult other resources in order to round out their knowledge base to include these subject areas. Also missing from the book are discussions focused on the management of boundary issues: for example, how should seronegative therapists handle being asked to disclose personal information about their serostatus or sexual orientation? What issues should be considered in regard to making home- or hospital-visits when clients become ill? And, how do the client’s prognosis and fluctuating health influence the goals and focus of therapy?

Still, the book is quite broad in its scope, and, despite this breadth, succeeds in treating issues sensitively and thoughtfully. The chapters encompass a wide range of theoretical and personal perspectives that are presented in a candid manner.

Social work as a profession suffers from chronic low self-esteem. Therefore, it is delightful to review a work written by social workers about our profession’s extraordinary work in the forefront of HIV research, planning, and service delivery. The Changing Face of AIDS, which focuses on social work philosophy and efforts, is edited by the three organizers of the International Conference on Social Work and AIDS, and the chapters are based on presentations from the 1991 conference. The text is divided into four sections: "HIV/AIDS and Social Work: An Overview," "Service Delivery Issues," "Special Populations: Approaches to Interventions," and "A Synthesis." A huge amount of material is presented here, including key chapters on substance abuse and chronic mental illness as well as comprehensive service delivery, case management, and policy planning.

This is an academic text, and readers should expect sound research and statistical analyses. But the majority of HIV social workers are in direct service, dealing every day with individuals and families affected by the epidemic. Therefore, a social work text should be readable, compelling, and practical as well as scholarly. The Changing Face of AIDS generally achieves this balance. It is not possible to address all 12 chapters here; rather, I have chosen to discuss several chapters, which, because they deal with special populations, address more of the day-to-day issues faced by most HIV social workers.

Women and Children

The most compelling chapters are those focusing on women, children, and families. The authors provide information needed to make the transition to treating the growing number of women and children who are becoming infected. They also manage the difficult balance between academic responsibility and humanity, citing key research and offering practical information while eloquently addressing the personal stories, and pain, of their clients.

In “HIV Infection in Infants, Children, and Adolescents: Implications for Social Work Practice,” Lori. S. Wiener and her co-authors illustrate the impact of HIV disease on children with poignant examples of children’s writing and art. They pay particular attention to the developmental issues of children at different ages. Perhaps most useful are the practical guidelines the authors include for providers—and parents—in extremely difficult, and little discussed, situations. For example, Wiener addresses who should hold a child during a painful procedure and how to help children learn to take medication at school, and she discusses the impact of disclosure—for example, what does it mean for a 6-year-old to know she has the same disease that just killed her sister?

Susan Taylor-Brown’s chapter, “HIV-Positive Women: Finding a Voice in the AIDS Pandemic,” is also successful emotionally and didactically. The chapter addresses many now familiar concepts about HIV disease and women—such as the tendency of women to seek medical care late in the disease process and their lack of power in sexual relationships with men—but it does so with some critical new twists. Taylor-Brown observes that most HIV-infected women are unable to identify their mode of transmission. She states that while women have significantly higher risks of being infected by men than vice versa, “The tendency to leave the responsibility of partner notification to the HIV-infected individual appears to be working against the notification of women who are at risk.”

Gay Men

Two chapters address HIV infection in the gay community but from very different...
perspectives. In “Gay Men and HIV: The Band Plays On,” Steven Cadwell, a social worker and scholar writes passionately, with justifiable anger, about the trauma that the epidemic and society’s response to it has wrought on the gay community. The expression of his anger and some sweeping generalities make this chapter less effective than it could have been. For example, Cadwell states: “Most gay clients with HIV-related problems also suffer from chronic traumatic stress syndrome.” Is Cadwell making reference to a psychiatric diagnosis of post-traumatic stress disorder or using this concept figuratively? Cadwell also writes, “No one in the gay community is spared: Everyone is a survivor of the epidemic.” “Everyone” is always a dangerous term to use, and Cadwell seems to assume that all infected gay men consider themselves to be a part of the “HIV community.” Finally, while Cadwell’s focus on psychotherapy—particularly on Erikson’s developmental model—is useful, he ignores gay men who, for psychological, cultural, or economic reasons, might not be psychotherapy candidates, and in general pays minimal attention to gay men of color and those outside of the middle class.

Manuel F. Fimbres’s chapter, “HIV/AIDS Prevention in Communities of Color: Strategies for Collaboration and Coalition Building” also examines the role of the gay community, providing a fascinating and detailed history of the San Francisco experience. He gives credit to this community’s mobilization in response to AIDS, and he suggests that communities of color can build strategies of response based on this model. This is an intriguing comparison of “dependent” versus “interdependent” communities. Fimbres observes that while both the gay and the Hispanic communities in the Bay Area are separate from the “dominant” community, the gay community has developed a comprehensive HIV response and network of services while the Hispanic community has not. He explores this difference and suggests how the experience of the San Francisco gay community might be adapted within the Hispanic community of San Jose and other communities of color.

Fimbres also outlines a successful coalition model for prevention. He grants both enormous respect and affection, effectively modeling how one HIV community could learn from another in a way that could potentially heal, rather than split, HIV services.

Social Work as a Conduit

In his synthesis, Gary A. Lloyd discusses how the social work profession has been forced to challenge our biases, our ethics, and our professional standards in light of the HIV epidemic; in fact, these issues affect all disciplines working in the field. We need to remind ourselves that social workers alone cannot provide all the services necessary to respond to the epidemic. And although the book addresses the role of social work as a conduit between clients and other providers, it omits a specific discussion of this interdisciplinary focus. Despite this omission, I highly recommend The Changing Face of AIDS, especially for social workers. Reading chapter after chapter about social workers working effectively is frankly uplifting, a reminder of the potential for excellence in our much maligned profession.

Clearinghouse: HIV-Related Books

We could not review every HIV-related book published recently. We include this listing to offer readers a survey of additional books of interest.


An Overview of the Literature

George Harrison, MD


AIDS, HIV and Mental Health is like one of those small triple chocolate truffles: just enough chocolate for some tastes and for others, a bit overwhelming. As a researcher, King is familiar with viewing the world through the papers that fill the journals. It is from this perspective that he reviews this topic, an approach that is informative but clinically dry.

The book begins with a brief biomedical overview. It then covers aspects of mental health in a series of chapters on: newly diagnosed patients; the assessment, diagnosis, and management of the HIV-related psychological and neuropsychiatric conditions; and the incidence of psychiatric illness among HIV-infected individuals. The majority of the book discusses the impact of the disease on a variety of subgroups including substance users, women, children, transfusion-exposed individuals, and the people who support patients including extended family and professionals. The last chapter looks at the knowledge base in the field of stress, mental health, and the immune system.

A Data-Friendly Approach

King disavows his intent to write a definitive text reviewing the HIV-related psychiatric literature or even a primer on the management of psychiatric issues. His stated goal was to write “a brief, critical account of the mental health aspects of HIV infection as it impacts on patients, professionals and other carers.” To do so, he knowledgeably sorts through frequently conflicting studies to generate a frame of the salient issues of HIV-related psychiatric care.

King presents this frame in the form of a distillation of the research studies. It is a failing of the book that the ultimate synthesis of the material is left to the reader. This shortcoming is exemplified in his chapter on persistent psychological disorders. He organizes this chapter around studies of psychosocial issues and the incidence of psychopathologic disease states. While King’s observations are careful, conservative, and demonstrate a clear understanding of the research, they offer little indication of his opinions about these topics. King does himself and his readers a disservice by failing to provide an explicit personal analysis of the material. Instead, he lets the arid data speak for him.

This sense of reserve also extends to the minimal use of clinical material. The result is a particularly dense book which is data rich and clinically poor. Case material—when presented at all—includes little development and provides the only glimpse of King’s clinical experience. King recounts a case of a middle-aged injection drug user who is in obvious need of better social support but refuses follow-up. Although this vignette successfully gets beyond the impersonal when King alludes to the frustrations of being unable to deliver appropriate services, he never directly addresses this issue. He also offers no indication of what strategy his team uses to respond and no discussion of the larger countertransference issues.

The strength of King’s approach is his obvious ease with research data. Researchers and clinicians who are comfortable with scientific literature and who seek to understand the rudiments of HIV and mental health may be the most comfortable with this approach. King concisely summarizes large amounts of data and comments on the appropriateness of the methodology and conclusions. Because of his own involvement in the field, he has the ability to place the research in context of time, place, and politics. This is a critical skill in a field that is young and frequently changeable. King also makes informed suggestions regarding alternative research structures or future studies crucial to the field as he sees it unfolding.

A discussion of HIV disease raises, by its nature, the issue of disenfranchise-ment. The impact of HIV-related stigma on different sub-populations is key to King’s presentation, and he is clearly attentive to its impact on the mental health of particular segments of society. Because of the difficulties inherent in social research, it is remarkable that King is able to set high critical standards and still define a coherent body of literature on this topic.

In one area, King fails to be thorough. His summary of research on HIV-related psychiatry includes very little work outside of the United States and Britain.

An Ambitious Book for a Limited Audience

AIDS, HIV and Mental Health is an ambitious book, and it succeeds in distilling King’s understanding of the field and conveying it in terms of research results. It is a densely informative text for scientifically

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A Blueprint for Housing
Stephan M. Peura


Breaking New Ground: Developing Innovative AIDS Care Residences chronicles the development of the Bailey-Boushay House and the Rosehedge Houses in Seattle's King County. Lieberman and Chamberlain have written the definitive "how to" book, a blueprint, applicable not only to HIV-specific housing, but also to housing facilities for all special populations. The book is also a resource for HIV counselors, providing them with information on how to meet their clients' housing needs.

The Planning Process and Its Pitfalls

Breaking New Ground is organized into four sections covering planning, organizing, financing, and constructing housing facilities for special populations. The first section offers a history of the HIV epidemic and its impact on homelessness, and accurately portrays the need for specialized housing. This section also includes a thought-provoking discussion of philosophical questions regarding HIV-specific housing and its role in long-term care. Finally, the section ends with a good profile of the continuum of housing types, and the populations and needs that are best served by various types of facilities.

Section II describes the planning process and its pitfalls. It covers the steps in planning, the need for public and community relations, and needs assessment of target populations. Also in Section II is a comprehensive review of the various types of state-regulated licensures established for specific housing programs, for example, group home, personal care, assisted living, and skilled nursing. It includes a useful table of facilities by state and type of licensure for people with HIV disease.

Section III describes step-by-step the tasks involved in planning and developing a capital project. It relates in detail the process of developing the Seattle-based projects, and it succeeds in educating prospective housing developers about potential obstacles and the planning necessary to move through them. In their discussion of financing methods, the authors include an especially good guide to federal grants available to support HIV-related housing. Their experiences offer a practical model for a successful capital campaign.

The final section deals with the challenges involved in constructing a facility, including the necessity for routine construction meetings, regulatory inspections, and permits. It also describes the difficulties of building changes and additional expenses. The authors offer ideas about interior design, and recommendations regarding operating, staffing, and evaluating projects.

The book also incorporates a series of vision statements—comments by HIV housing providers across the country—that discuss the seriousness of housing problems and the philosophical reasons for such programs. The authors supplement the book with several appendixes, including a list of governmental financing resources, the Bailey-Boushay program plan, the Rosehedge development budget, and a glossary.

A Thorough Guide

Breaking New Ground is a thorough guide to the philosophy, planning, and development of specialized residential facilities—one of the most comprehensive HIV-related texts on the subject. Its organization is logical and accessible, and it functions well both as a good, thorough read and as an off-the-shelf reference guide. Lieberman and Chamberlain successfully weave together a description of the major events of a housing undertaking with their actual experiences—and, yes, successes—without over-emphasizing their own projects.

Historically, it has been front-line service providers advocating for the needs of their clients who have marshaled the forces to finance and develop programs for their constituents. As counselors document the housing-related needs of their clients, it is important for them to know what resources are available to meet those needs, and the individuals and organizations necessary to access them. Breaking New Ground provides HIV counselors with a guide to the players, resources, and organizations that they may call upon on behalf of their clients.

What is missing from this "how to" book falls within the realm of "and now what?" Now that one has successfully built and opened a specialized HIV residential facility, what next? How does one invent, establish, sustain, evaluate, and fine-tune programs for the inevitably diverse and challenging community they are certain to encounter in their facility? In defense of the authors, these questions probably require another book in and of itself. A book begging to be written for—if not by—those of us who are currently providing such residential programs!
Orphans of the Epidemic
Robert Tufel, MSW, MPH


Children and adolescents with HIV-infected siblings, parents, or both are profoundly affected by the disease in their families but are often overlooked as attention focuses on infected individuals. Responses such as grief, fear, anger, and sadness and issues such as disclosure, confidentiality, and abandonment are difficult enough for adults living with HIV infection but can overwhelm children and adolescents.

A Death in the Family: Orphans of the HIV Epidemic details the needs of surviving children and adolescents, their families and new guardians. It describes the issues raised by the increasing numbers of “AIDS orphans” from a variety of perspectives including epidemiology, law, mental health, program development, and advocacy. The book is the outgrowth of a conference sponsored by the Orphan Project and the United Hospital Fund, and it brings together writings by providers working with HIV-affected families as well as personal essays by HIV-infected parents and affected family members.

By outlining common concerns and issues, A Death in the Family offers service providers, especially those just beginning to work with this population, a framework for approaching their clients. The book is also useful for policy makers and program developers who can create systems that are responsive to the needs of families.

An Effective Overview
A Death in the Family is divided into five sections containing essays written by attorneys, program directors, academics, social workers, and family members. The first section describes research on surviving children and adolescents and contains two notable essays, one by Carol Levine and the other by Barbara Draimin. Levine’s essay presents her research on the numbers of AIDS orphans in New York City and the United States.

Draimin’s essay presents data from a study she conducted on the mental health needs of HIV-affected adolescents living with HIV-infected parents. It offers a disturbing look at the isolation these adolescents face and the lack of services set up to assist them. Both these essays present data on a population that has been overlooked by most researchers. They represent some of the first systematic attempts to determine the number of AIDS orphans and describe their mental health needs.

The second section of the book gives voice to the experiences of family members, including children, grandmothers, siblings, and parents. It describes in their own words the issues they face: loss, stigma, living with an ill parent, disclosure, confidentiality, and guardianship planning. In many ways, these essays are also “coming out” stories for children and adolescents who, for the most part, must confront a parent’s and sibling’s illness in an atmosphere of secrecy and fear.

The third section of the book describes the epidemic from the perspective of providers who are working with HIV-affected families. The four essays in this section define the complexity of the situation and focus on psychosocial issues, mourning, confidentiality and disclosure, and guardianship planning. Particularly informative is an essay by Richard G. Dudley, who describes some of the common characteristics of HIV-affected children in terms of age, prior psychological state, cultural background, and HIV infection status.

The last essay in this section, “Custody and Placement: The Legal Issues” by Mildred Pinott, presents an overview of options for HIV-infected parents planning for their children. Pinott discusses how and when to talk to parents about planning for their children and describes the psychological implications of planning for HIV-infected parents. This essay, in particular, highlights the overlap between the law and social work inherent in work with HIV-affected families. It demonstrates the need for social worker-lawyer teams to collaborate in guardianship planning.

Comments and Submissions
We invite readers to send letters responding to articles published in FOCUS or dealing with current AIDS research and counseling issues. We also encourage readers to submit article proposals, including a summary of the idea and a detailed outline of the article. Send correspondence to:
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This is one of the first books to document in a systematic manner the complex issues facing HIV-affected families.
The fourth section describes four model programs developed to meet the specific needs of HIV-affected families: education, medical care, and foster care and guardianship. Notable in the last essay is the role the New York City Child Welfare Administration has played in identifying foster homes for children of parents with HIV disease while the parents are alive and able to be involved in selecting appropriate guardians.

In the final section, Levine offers recommendations regarding services, research, education, and training. While stressing the need for more programs to ease the guardianship transition, Levine omits mention of the importance of changing funding guidelines so that support of families continues even after infected individuals die.

New York Focus

The major drawback of the book is its frequent occurrence in those who are marginalized, generally despised, and considered disposable in our society—homosexual men and drug users.

The author is an anthropologist. . . .His recommendations are: allow unrestricted, over-the-counter acquisition of needles and syringes, and decriminalize the possession of injection paraphernalia.

Brief Reviews


This comprehensive, practically oriented book should serve the large population of hidden AIDS grievers well. The main body is a series of chapters about intervention with children and adolescents, women, families of homosexual and bisexual men, inner-city survivors of AIDS, gay lovers and friends, and practitioners. It provides many case examples and chapter sections on “implications for practitioners” that could apply to social workers, psychologists, psychiatrists and other mental health workers. For those who are unfamiliar with cases of HIV disease, this book provides an important perspective and concrete examples of the types of problems they may find themselves facing.


This book raises valid and urgent questions concerning the profoundly harmful and even lethal neglect of IVDDUs by social scientists, public health professionals, and political leaders. The author describes the failure to adequately deal with AIDS as a morbid illness because of the moral implications projected on it by its frequent occurrence in those who are marginalized, generally despised, and considered disposable in our society—homosexual men and drug users.

The recommendations are: allow unrestricted, over-the-counter acquisition of needles and syringes, and decriminalize the possession of injection paraphernalia.

Next Month

HIV-related therapy has always made special emotional demands on counselors, forcing practitioners to confront their own feelings about loss and death. These issues are easily reflected in the counseling session, where already fragile boundaries can give way under the weight of a client’s HIV progression. In the January issue of FOCUS, Thomas C. Rosica, CSW, a New York City therapist, offers insights about balancing boundaries with client and practitioner needs, and focuses on a particularly challenging case.

Beyond the consultation room is the far messier world of case management, a world where boundaries are harder to define and harder to maintain. Also in the January issue, Laurie C. Curtis, MA, a mental health consultant at Trinity College of Vermont, and Martha Hodge, MS, Director of Adult Services at ComCare in Phoenix, discuss the issue of boundaries for providers who work in the community.
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