

EDITOR'S NOTES

Water seeks its own level; so too do injustice, marginality, and ill health. It is no coincidence that Acquired Immune Deficiency Syndrome (AIDS) disproportionately affects gay men, African Americans, injection drug users (IDUs), and others whose access to civic entitlements—and human dignity—has been undermined. Although we often talk about the risk of acquiring HIV (the human immunodeficiency virus, which causes AIDS) in terms of *vulnerability*, we must be mindful that although certain behaviors are more likely to facilitate HIV transmission (anal or vaginal intercourse without a condom and sharing drug-injecting apparatus for adults; during childbirth and through breastfeeding for infants), these sorts of risk occur in the context of people's lives. Such "risk taking" is more likely to occur in those communities that are marginalized: socially, economically, and in terms of wellness.

The dominant discourses about HIV/AIDS are medical. There are rich, important bodies of literature about public health (epidemiology and health services administration), basic science (virology, physiology, and pathology), and pharmacotherapy (drug treatments). Public health has to a large extent situated behavioral analyses in specific "at-risk" communities: most often gay men, IDUs, sex workers, and the sexual partners of IDUs. From a public health perspective, focusing on specific categories of "risk takers" makes sense: the traditional goal of public health is to contain disease to prevent its affecting society at large. Regardless, basic science has allowed education and prevention campaigns to focus on the detailed specifics of transmission and infection, enabling much more precise (and therefore effective) educational campaigns to be launched. Similarly, this knowledge has been integral to the development of pharmacotherapeutics to slow the progression of AIDS and treat AIDS-related opportunistic infections. Without the contributions of medicine, effective educational campaigns (in terms of HIV prevention or living with HIV) would be impossible to develop.

However, for all the important medical findings, profound limitations remain. The reasons why people engage in risky behaviors, and the meanings they ascribe to such behaviors, don't fit very well in the medical paradigm. Instead, such behaviors are often presented as burdensome to the rest of society—even when the motivation behind the behaviors is positive and affirming, or despite society's bearing an often substantial burden of responsibility for creating the conditions that lead to the "risky" behavior in question.

This notion of risky behavior operates differently in specific communities. Gay men, while remaining socially and politically marginal, have also had access to economic and human capital—powerful tools that quite literally saved many lives when the public health sector deemed "gay cancer"

unworthy of its attention (Egan, forthcoming; Shilts, 1987). The concomitant community-based educational response remains an archetype of effective community education—for communities where capital is plentiful. Part of this educative process has been to humanize gay male sexual expression (in mainstream society, but also within the gay community itself) as a natural, healthy manifestation of love and desire, rather than a problematic health behavior.

Clearly the dominant discourse regarding injection drug use—that injecting drugs is wholly problematic, for the user and society—is less likely to shift as dramatically. Among African Americans, reticence to acknowledge the seriousness of the HIV/AIDS epidemic in the community (outside of IDUs and gay men) too often impedes any community-driven or public health response. Despite African American women being one of the groups for which HIV rates are growing fastest (Centers for Disease Control, 2002), many AIDS NGOs are focused on gay men, making culturally appropriate education programs for African American women quite difficult to access (Archie-Booker, Cervero, and Langone, 1999).

The contributors to this volume—from the United States, Canada, and Australia, working in university-based and community-based environments and for divergent communities—bring to the fore their specific experiences in the fight against HIV/AIDS. They share stories of shifting paradigms and challenging norms, and of seeking and finding innovation. Ronald Cervero contextualizes adult education's role in HIV/AIDS, both in the United States and internationally. In Chapter Two, Lisa Baumgartner reviews how persons living with HIV/AIDS (PLWHAs) reconstitute their sense of self as they live with an HIV-positive diagnosis. These women and men were all diagnosed before the advent of antiretroviral therapy (ART); thus they have faced AIDS before and after the idea that HIV/AIDS could be (at least for some) a manageable chronic condition. In Chapter Six, Brent Allan and William Leonard argue that PLWHAs not only need to be involved with HIV prevention but also already play an integral, though often silenced, role in stemming the spread of HIV.

Success in HIV/AIDS education is often dependent on challenging the status quo. In Chapter Eight, Robert Hill discusses how public health responds better to persons with simple, solitary identifications and affiliations, leaving such groups as transgender sex workers doubly marginalized—yet nonetheless resilient. In Chapter Seven, Donovan Plumb challenges the predominance of individualistic learning theories and explicates how the HIV/AIDS community in Nova Scotia, as a community of practice (Wenger, 1999), has created shared knowledges. In my chapter about IDU-targeted HIV prevention, I underline how notions of practice constricted by disciplinary or professional affiliations neither reflect the genuine field of practice nor represent how IDUs themselves seek and access services. Each chapter demonstrates how important innovation is in AIDS education—and how adult educators often lead such innovations.

One of the more interesting outcomes from community-based responses to HIV/AIDS is to be found in the area of research. Terry Trussler and Rick Marchand (Chapter Five) are leaders in community-based HIV/AIDS research development. They have trained researchers for NGOs and other grassroots organizations around the world. By bringing research capacity into the hands of community—instead of relying on partnerships with public health or university-driven researchers—their work brings knowledge production into the hands of those at the heart of the research questions. Their work is revolutionizing how the research enterprise operates—both in adapting existing methods and resources and in bringing new ones to the table. Kimberly Sessions Hagen (Chapter Four) is working from similar principles, but in the (ostensibly) opposite direction. Her work in recruiting participants for HIV vaccine trials seeks to shift the medical research paradigm from the inside, toward a more humanized, community-centered approach.

Why is adult education, as a discipline, making an increasing contribution to the body of knowledge about HIV/AIDS? Certainly as social scientists we bring a unique set of tools for both determining research questions and collecting data. As an applied field, adult education focuses on what really happens, what it means, and what the ramifications of practice are in real terms. Our focus on adulthood, when people are most likely to be engaging in such “risk” behaviors as sex and drug taking, is also important: embedded within most medical discourses is the notion that adults always exercise choice when engaging in risk behaviors. As adult educators we know that the context of people’s lives can both limit and coerce the “choices” they make.

It is perhaps our emphasis on criticality—a willingness to take on notions of power and difference, infused in all the chapters here—that drives this emergent body of literature. So too does the willingness of more and more departments of adult and continuing education at universities and colleges to participate in more equitable community-university research partnerships with frontline HIV/AIDS workers. For activist-educators in Canada, Australia, Africa, Asia, Latin America, and the United States, the works of Freire (1983), Mezirow and Associates (1990), and Foley (2000)—among others—already figure prominently in both the principles and specifics of HIV/AIDS education.

HIV/AIDS is a relatively new phenomenon, not known to have affected people before the 1970s. It presents a unique opportunity to examine community responses to such a crisis throughout the lifespan of the epidemic. With regard to the “developed” world, we know that AIDS’s impact began to be felt in earnest in the last twenty-five years. We have, alongside the challenges of HIV/AIDS, been given an opportunity to see how different communities respond to the AIDS crisis. By examining HIV/AIDS through an adult education lens, we gain insights into how communities (and governments) can respond quickly and effectively to emergent health issues—

and other issues linked to marginalization. The potential for transferability is enormous.

We've already learned so much. But there is so much more to learn.

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