Changing the Course of AIDS

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Changing the Course of AIDS

Peer Education in South Africa and Its Lessons for the Global Crisis

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Foreword by Charles Deutsch

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Foreword

A great deal has been written in the last two decades about HIV/AIDS, especially on the pandemic afflicting Southern Africa. What does this book add, not merely to our library of continuing tragedy, but to the hope that we can someday turn it into an archive helping us learn from the past?

In Southern Africa we are barely making a dent in rates of new infection. Prevention has always been grossly underfunded, and remains so. But now it is considered a priority to combine biomedical, structural, and social/behavioral prevention strategies. Two decades ago some virologists were confident that adequate investment in research would by now yield a vaccine preventing new HIV infection. Today, leading scientists say we may *never* have one. No one blames the scientists or the level of investment; science can't be forced. Similarly, structural solutions—alleviating poverty and providing equitable health care and education—are not things we can expect to happen quickly, in Southern Africa or anywhere else.

But expectations for social and behavioral strategies have been viewed through a different lens. The rhetoric of policymakers and donors is

"behavior change communication" (BCC) and its staples are "messages." It derives from economists who posit rational actors who will act in their self-interest if they can only be given accurate information. Its leading advocates are mass media specialists who claim they can sell anything with the right images, jingles, and spokespersons. From a very different direction, preachers spout fire and brimstone and tell people what behavior God insists on; teachers pronounce facts about biology from the front of the room. None of these, individually or in chorus, has worked yet; and the suspicion is dawning that prevention education needs its perspective adjusted for realism.

Behavior changes such as delaying sexual debut, encouraging secondary abstinence, reducing the number of concurrent partners, and consistently using condoms are largely dependent on deeper changes in norms that sanction violence against women, transactional sex, and men's right to (and pride in) multiple sexual partnerships. If we expect broad and quick changes in these and related behaviors (drinking and drug use, for example) that are freighted with pleasure, power, custom, tradition, and economic desperation, then we will try the wrong things, and everything we try will look like a failure.

Yet norms and traditions of all kinds do change, everywhere and all the time. Certainly technologies such as computers and cell phones provoke dramatic changes, but changes in norms concerning gender, race, and ecology, different across countries and cultures, are no less dramatic. Not so many years ago, the streets of U.S. cities were decorated with dog litter and no one would have believed they'd all soon be walking their dogs with a plastic bag at the ready. We can't always see change coming and pinpoint the reasons, but it usually happens through a dynamic interplay between laws and policies, technologies, and our conversations. Fire hoses were turned against relatively few civil rights activists, but as their news filled the media, churches and universities' conversations about them kept rippling outwards. The words we use, and the words we stop using, matter. Indeed, activists supporting each of these changes found various ways to stimulate and guide conversations at dinner tables and water coolers everywhere.

Because AIDS is most closely associated with sex and death among people whose traditions and institutions (including schools) refrain from mentioning either, we have not made good use of our conversations. Since

people of all ages usually talk, listen, think, and learn about sensitive issues such as sexuality on the quiet, with people like themselves, peer education is a leading social strategy to change the conversations and norms that surround behavior. What has been blurred by the myopia around BCC is that education is much more than information transfer and message transmission. Educators are better evaluated by the questions they ask than the answers they give. In this context, education is about *unsettling* the unexamined beliefs and traditional behaviors that are killing people, and doing these things, sometimes a little at a time, whenever the opportunity arises.

David Dickinson asks the question: How can we inject into the busy, distracted, difficult lives of the least educated and poorest among us the opportunity, and eventually the habit, to think critically about their social norms and behaviors; that is, about how to keep themselves and their loved ones healthy in a terribly dangerous environment? The answer is: Purposefully, persistently, with system and intent, through judicious infiltration of the social networks people live and act in. It requires intensive, sustainable face-to-face social strategies in which trusted people listen to what is being said and believed, and respond with stories that are not only accurate but also memorable and credible, and can compete successfully with the myths and beliefs that support dangerous norms. In some settings, such as schools, churches, mosques, and sports programs, peer education can be structured and scheduled. In other contexts, such as most workplaces, it is more informal and impromptu, but with many predictable opportunities to be prepared for.

It is the why, what, and how of these latter contexts that Dickinson so ably addresses. He is especially eloquent about the need to work below the surface and behind the scenes, where peer education has few rivals. He documents aspects of the struggle against AIDS that are not usually subject to disciplined scrutiny. He culls from the experiences and wisdom of hundreds of dedicated adult peer educators across South Africa, reconciling and contrasting their insights with theories that have been the basis of social strategies to contain and control new infection and test and treat those currently infected.

This book rests on a confidence in horizontal learning and a respect for what people who don't have much formal education can know and do for one another. Those beliefs are not widely and deeply owned by decision makers in the United States or South Africa. As we cast about for more

realistic ways to approach prevention, and settle on strategies that help people think and talk together about what they believe and what they do, these insights into peer education at the workplace will remind us that we have the resources in our midst to change our conversations, our norms, and our behavior.

CHARLES DEUTSCH, ScD
Harvard School of Public Health

Acknowledgments

This book was a pleasure to write. I learned a great deal. For that I am grateful to many people.

Above all, I would like to thank the many HIV/AIDS peer educators who appear in this book (under pseudonyms) or contributed to the research in so many different ways. It would be hard to find a kinder, more interesting, or more dedicated group of people to research and write about. That, however, is not why I wrote a book about peer educators. I wrote it because I believe that peer education is a critical component of any effective response to HIV/AIDS and, indeed, to changing behavior beyond the challenge of AIDS. As such, the peer educators in this book are not simply research subjects but colleagues with whom I have worked and from whom I have learned. One peer educator whom I will name, since we have worked and published together, is Duncan Kabelo Kgatea who has taught me more than any other individual peer educator. Duncan, *ke a leboga!*

In addition to peer educators, many others involved in peer education programs—medical doctors, managers, trade union officials, nurses, and

social workers—participated in the research; some appear (also under pseudonyms) in this book, and I am grateful to them all. The research would not have been possible without the HIV/AIDS managers at the companies I refer to as Autocircle, Autostar, Bestbuyco, Deco, Finco, and Mineco granting me research access—something that was not always easy for them given corporate fears over the reputational aspect of HIV/AIDS. I am also grateful to Brad Mears at the South African Business Coalition on HIV/AIDS (SABCOHA) for consistently and publicly supporting my research on peer education.

The research was funded from grants made by the University of the Witwatersrand (Wits) AIDS Research Institute and the Wits Faculty of Commerce, Law and Management's Research Committee. Professors Mukul Gupta and Mthuli Ncube at Wits Business School supported and approved the financing of working papers based on my research. Krish Sigamoney has consistently provided administrative support, while Gila Carter ably transcribed the many interviews.

The opportunity to take sabbatical leave during 2006–2007 greatly assisted in the production of this book. Grants from the Oppenheimer Memorial Trust and Wits' Anderson Capelli Fund allowed me to spend three months as a visiting scholar at the Institute of Industrial Relations, University of California, Berkeley. The opportunity to read and to reflect on my research was critical to the development of the arguments advanced. During my sabbatical I also spent two months living in a Free State township. There I conducted no research; my objective was to improve my Sesotho, but the experience of living in an African township helped me better understand the challenges faced by peer educators.

My exposure to the life of Africans started, long before I stayed in the Free Sate, in the township of Katlehong, southeast of Johannesburg. I am thankful to Daniel Morena Thulo and my many friends in Monise and other parts of Katlehong for accepting me as a part of their lives. The significance of African traditional healing plays a prominent part in this book. My understanding of this owes a great deal to Thapelo 'Touch' Hlahatse (Traditional Doctor Mosia) for which I am grateful.

My ideas on peer education have been both affirmed and challenged by Dr. Charles Deutsch of the Harvard School of Public Health/Centre for the Support of Peer Education (South Africa) who, in contrast to the "experts" pilloried in this book, is most certainly someone who understands the importance of peer-to-peer communication.

Pete Strauss and Karen Birdsall read and commented on earlier drafts of Chapter 1 and assisted in shaping my arguments into a comprehensible form. Suzanne Gordon, coeditor of Cornell University Press's Culture and Politics of Health Care Work series, took on what was still very much a work in progress. I could not have hoped for a better editor. The book is immeasurably more readable, and stronger, as a result of her input.

Finally, I dedicate this book to all peer educators and their fight for life. I hope that it contributes to their work and helps make AIDS everybody's everyday concern.

Changing the Course of AIDS

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"Empowered with Information I Have Influenced a Lot of People"

The Quest for Behavioral Change

Robert Mokwena is a forty-five-year-old African miner who works for Mineco—a fictitious name for a large South African mining company. Over the past decade he has watched family and friends die. His best friend of many years, Benny Modise, died shortly after telling Mokwena that he was HIV-positive. At the time of his friend's death, antiretroviral treatment was unavailable. As he became more and more debilitated, Modise was unable to work and was put on medical disability. Admitted to hospital he grew increasingly despondent. Finally, Modise hung himself from a tree in the hospital grounds. Soon after this tragedy, Mokwena's niece died of AIDS and her infant daughter soon followed. Mokwena could do nothing for them but stand by helplessly and watch them die.

At work, after over twenty years underground, Mokwena had been promoted to a surface job as a training instructor for new recruits to the company. Part of his orientation program included a module on HIV/AIDS. People asked questions. Questions he couldn't answer.

So when the opportunity arose to enhance his knowledge of this epidemic, he took it. He became what is known as a *peer educator*—a commonly

promoted communication channel that, in the context of AIDS means a lay person who helps educate coworkers, community members, and family and friends about HIV/AIDS, how to prevent infection and how to deal with the disease. "I became a workplace peer educator because I wanted to help my brothers and sisters," Mokwena explains. "Most of my colleagues cannot read and write. They need someone who knows their language and culture, someone with good communication skills." He wants to give his coworkers, family, and community not only education but also hope. There was no hope for his best friend, and that's why he believes Modise took his own life. "I think I would have convinced him to live if I was trained as a peer educator by then." On the death of his niece and her child he explains, "All the family was affected by this. I still believe I could have done something as a peer educator."

Becoming a peer educator was Mokwena's way of responding to the AIDS epidemic. "Fortunately I was chosen to be among the first volunteers to be trained [by the company] as a peer educator in the year 2000. I received a four-day course and a certificate. Empowered with information I have influenced a lot of people."

This book is about what happens when people like Mokwena decide to help those around them to deal with a catastrophic disease. It tells the story of South African peer educators and their quest to encourage behavioral change. The subject of this story—how to help other human beings change dangerous and destructive behaviors—is a very old one that has existed as long as there has been concern for others. Today, it is particularly urgent, acute, and pressing: a matter of life and death for millions of South Africans as well as for many millions more across the globe at risk or already infected with HIV.

In its sub-Saharan African epicenter, the AIDS pandemic presents a socially debilitating loss of life and a seemingly bottomless well of human suffering. Perhaps one in five adult South Africans is infected with HIV, and there is little evidence to show that the rate of new infections is slowing (Rehle et al. 2007). Only a fraction of those infected with the virus are aware that they are HIV-positive, and only a fraction of this fraction openly comes to terms with their status. Treatment, while increasingly available in South Africa, remains underutilized. Many people who are infected access treatment only when desperate and it is too late. To stem the epidemic, individuals at risk need to take steps to prevent infection, get tested for HIV,

and, if infected, live openly with the virus and access available treatment. These are matters of individual behavior. Given the record so far, it is clear that, despite vast sums spent in combating the epidemic, there has been little progress. In the absence of a decisive medical response to AIDS, the quest to change individual behavior remains.

Although AIDS is an African tragedy, Africa is only one chapter of the pandemic. Beginning in San Francisco, its discovery in the early 1980s among the gay populations of world cities is well known. As are its transmission to hemophiliacs via contaminated blood and its spread into a range of vulnerable groups in developed countries: intravenous drug users, sex workers, and the inner-city poor. The pandemic continues. There are chapters still being written: on how the virus is entering into the vast populations of India and China and on how infection among drug users in the former socialist countries of Eastern Europe threatens the wider population. Given this, the quest for behavioral change in the era of AIDS is a matter of importance not only in South Africa, not only in Africa, but also globally.

Out of Africa, this book argues, comes something new. Something needed by all of us. The lessons we can draw from South African peer educators is relevant to stemming the AIDS pandemic beyond Africa. Preventing infection requires individuals to address and change the least manageable of human behaviors. For HIV infection is, for most, a question of sex: sexual behaviors that infection starkly exposes. Sexual behavior is embedded within beliefs about gender, faith, status, morality, identity, and more. Preventing infection, or coming to terms with being HIV-positive, requires individuals to take responsibility for themselves. Yet, this is not straightforward. Their actions and the actions of others with whom they coexist are enmeshed within a web of social understandings and responsibilities that can neither be ignored nor thrown out wholesale. The social worlds that we inhabit are shaped by the past as well as our own actions. In the story this book tells, a history of colonialism and apartheid have molded the life of individuals in South Africa, but many other institutions—such as churches, unions, and government—also play a role in shaping and reshaping the terrain of everyday life, and everyday sex. This book has lessons for regions as diverse as Asia and Eastern Europe where the epidemic is unfolding with, it would seem, little cognizance of what has happened elsewhere. Even in the advanced countries with their

low rates of infection, there is much to learn from what peer educators are doing. For it may well be that the limits of managing this disease from above have been reached, and it is time to learn from below—where the parameters of risk are determined.

South African lessons are also relevant to other health-related problems, not just to HIV/AIDS. The quest for behavioral change is not, after all, confined to the AIDS pandemic. We are all acutely aware, from our own experiences, just how difficult it is to change what we do. Seemingly small decisions—what we eat, how much we drink, whether we light up a cigarette, how much exercise we get, or how fast we drive—make for big problems. Many of us manage, with only the occasional regret, miscalculation, or sense of guilt, lives not as well lived as we would like. For others, behaviors result in obesity, addiction, abuse, broken lives, illness, and premature death. We know all this, but we often stand powerless. *Telling* people what they should do to help themselves does not stop unhealthy eating, smoking, drinking, or reckless driving. Nor is it stopping AIDS.

In exasperation at our own stubbornness, we may resort to legal penalties. We may try to force people to change. That may moderate some behavior, perhaps speeding, but many choices lie beyond what we feel comfortable about legislating, are not amenable to legislation, can be legislated only at the margins, or will be driven underground by legal penalties. We remain with the problem of what to do after we admit that, for all the logic of our messages, individuals seem to be chained to behaviors that detract from their own and others' well-being.

This problem confronts us when we try to do something as seemingly innocuous as getting people to cut down on fat and salt in their diet—things that we know may add years to their lives and enhance their quality of life. If this is true, then the problem of getting people to change their behavior when it comes to AIDS is clearly enormous. Which is why the subject of this book—what has happened when HIV/AIDS peer educators try to get people to change their behavior—has much to teach us about getting people to change behaviors that have little to do with the HIV/AIDS epidemic. Even the slightest advances around AIDS can help us make progress in influencing the choices that have an impact on peoples' health and well-being and, by extension, escalating health care and social costs.

The choices people make are not simply individual ones. They exist in a web of social, workplace, family, and community relationships. Their

individual choices are constrained by contexts in which they live and work. Typically, in thinking about the context of people's lives, we often focus on material conditions. There is a good reason for this. We know that many social and health problems are concentrated among the poor, and that their choices are restricted by difficult material conditions. Nonetheless, poor people can and do make choices. What we need to understand are the social factors that make it hard to enact these choices. A lack of resources is part of any answer, but not the only one. Consider, for example, the issue of alcohol abuse; we know that alcoholism is a major problem in many poor communities, but not all poor people are alcoholics and not all alcoholics are poor. This book looks at the psychological terrain that people inhabit and how the ordering of this psychological space can hamper attempts to change behavior. By this I do not mean probing the id, ego, and superego of South Africans but instead looking at the web of social relationships that influence behavior. Through an analysis of peer educator activity, we examine the texture of the social spaces of South African workers, their families, and their communities and how this constrains individuals' ability to respond to the epidemic. We will also see how peer educators, under the most difficult of contexts and with the most difficult of issues, labor to bring about behavioral change.

HIV/AIDS and Behavioral Change

Changes in sexual behavior could prevent most HIV infection and dramatically undercut the potency of the pandemic. Change in beliefs and behavior also play an important part in the effectiveness of providing antiretroviral treatment and in mitigating the impact of the disease, including the stigmatization of those who are infected or affected.

Early responses to AIDS assumed that knowledge about HIV/AIDS would be sufficient to change beliefs and bring about behavioral change (UNFPA 2002). This assumption promoted *top-down* or *vertical communication programs* that disseminate information from centers of expertise to target audiences. In short, the assumption was that information = knowledge = belief = behavior. Enough lectures, charts, illustrations, and graphs would change peoples' beliefs about the disease, which would, in turn, lead to lasting changes in their behavior. The general failure of such

programs, evidenced by continued HIV infection and persistent stigmatization of those with the disease, has prompted a rethinking of such communication strategies (UNFPA 2002). Where success in changing sexual behavior and lowering infection rates has been observed, a number of authors have pointed to the contribution of horizontal, rather than vertical, communication processes (Low-Beer and Stoneburner 2003, 2004; Parker 2004; USAID 2002). A number of features characterize *horizontal communication processes,* including: embeddedness in local cultural contexts; dialogue, especially among similar individuals, rather than information delivered by experts; individuals as change agents, rather than as targets for change; and the importance of face-to-face, personal communication channels (Low-Beer and Stoneburner 2003; Panford et al. 2001; Parker 2004; USAID 2002).

Despite the potential of horizontal communication processes in changing beliefs and behavior around HIV and AIDS, Daniel Low-Beer and Rand Stoneburner (2003) point out that their value is rarely recognized. One important consequence of this neglect is that, beyond broad principles, we understand relatively little about horizontal communication processes around HIV/AIDS. This is not surprising. Apart from the vested interests of AIDS experts, who dominate vertical programs and are unlikely to voluntarily relinquish their role, horizontal communication throws up barriers to external observation because it is framed within local cultures and consists of face-to-face interaction between peers. Thus, even if the value of horizontal communication in changing beliefs and behaviors is acknowledged, how such communication takes place and why it works, if it works, remains opaque.

Workplace peer educators in South Africa operate within programs set up by companies that have become concerned about the impact of the AIDS epidemic on their public image and their ability to maintain a healthy workforce. Largely pushed by grassroots concern and activism—as well as frustration with the South African government's failure to come to grips with the epidemic—these companies have initiated workplace behavioral change programs in an attempt to stem the epidemic. Although workplace peer educators formally operate within vertically oriented company AIDS programs, they are best understood as grassroots change agents who operate within the specific cultures of their peer groups and utilize personal communication channels. Workplace HIV/AIDS peer educators are, thus,

attempting, through horizontal communication processes, to change beliefs and behaviors around HIV/AIDS. Studying their activity provides insight into the process of peer-to-peer communication around HIV/AIDS and the challenges that this entails. This is important: There is much to learn about AIDS beliefs and behaviors from what is unfolding on the ground. This is perhaps especially so in South Africa where a colossal failure of leadership—across state, business, unions, and academia—in the face of AIDS has contrasted with responses from below.

HIV/AIDS in South Africa

AIDS presents a major challenge to South Africa. The primary means of HIV transmission in sub-Saharan Africa is unprotected heterosexual sex (UNAIDS 2003). Unless treated with antiretroviral drugs, the virus's destruction of the immune system results in increased illness and eventual death within nine to eleven years of infection (UNAIDS and WHO 2007). Antiretroviral drug treatment can control but not eliminate the virus for periods not yet established. The continuing incidence of HIV infection draws attention to the difficulties of responding to this disease. Stigmatization, fear, and discrimination—linked to sexual transmission and the disease's incurability—hamper efforts to promote prevention, testing, and treatment.

South Africa's antenatal HIV sero-prevalence surveys, measuring whether the person's immune system has "sero-converted" (i.e., produced antibodies) in response to the HIV virus, at public sector clinics have shown a rise in HIV prevalence among pregnant women from 0.7 percent in 1990 to 28.0 percent in 2007 (Department of Health 2008). A national sero-prevalence survey (Human Sciences Research Council [HSRC] 2005) indicated a wide difference in infection rates between the four racial categories used in South Africa: Africans, coloreds, Indians, and whites. These four racial categories were inherited from apartheid. They continue to be used in South Africa both for official purposes, notably Employment Equity legislation, and, with some variation, in popular discourse. Employment Equity legislation additionally groups Africans (indigenous people), coloreds (people of mixed origins), and Indians (people originally from the Indian subcontinent) as "black." All black people are regarded as being

"previously disadvantaged" in comparison to whites, though it is recognized that the apartheid racial hierarchy resulted in greater discrimination against Africans than coloreds or Indians.

Among those two years and older, 13.3 percent of Africans, 0.6 percent of whites, 1.9 percent of colored, and 1.6 percent of Indians were found to be infected. While there is room to doubt the precise levels found in this survey, it is clear that HIV prevalence is much higher among Africans than other racial groups. Magnifying this racial dimension of the disease's distribution is the overwhelming numerical domination of Africans within the country's population. Statistics South Africa (2008a) estimated that of a population of 48.7 million, 79.2 percent were African, just over 9 percent white, 9 percent colored, and 2.6 percent Indian. Given the close correlation between race and socioeconomic status in South Africa, high prevalence rates among Africans equates to high HIV prevalence rates among the poor and poorly educated. The racial distribution of the disease, its causes, and its consequences are important issues that this book returns to a number of times.

There are also marked differences in the burden of the epidemic by gender. The HSRC survey found that while 8.2 percent of males (of two years and over) were HIV-positive, the rate among females was 13.3 percent. The intersection of race and gender leads to the highest infection rates among African women estimated at 24.4 percent of those between fifteen and forty-nine years of age. Perhaps the most frightening statistic, and the one that gives the best insight into how HIV/AIDS is affecting South Africa, is looking at the distribution by age. Since HIV is transmitted primarily by sex, prevalence peaks among people of working age: 33 percent among women aged twenty-five to twenty-nine and 23 percent among men aged thirty to thirty-nine (for all races). Among African women between twenty-five and twenty-nine, this peak spikes to 38 percent. Such peaks are disguised by much lower rates of infection among children, who are at little risk of infection until they become sexually active and older people whose most active sexual periods were before HIV was widespread. In the absence of behavioral change to reduce infection, over time the disease will be infecting approximately one in three women and one in four men in their twenties and thirties.

A plateauing of prevalence rates, which may now be occurring, does not indicate a slowing of the epidemic but rather that the number of new

infections is offset by the deaths of those infected earlier. Demographic models predict that average life expectancy will drop to forty-six years in 2010, twenty-two years lower than it would have been in the absence of AIDS (Rehle and Shisana 2003). The effective provision and uptake of antiretroviral treatment will mitigate this drop in life expectancy. It will also increase the percentages infected with the virus because HIV-positive people will be living longer. Along with this will be the need for individuals and society to deal with the implications of a large proportion of the population relying on expensive, chronic antiretroviral medication.

The South African Context

An epidemic needs to be understood within the context that shapes the terrain on which the pathogen, and its host, exists. South Africa's HIV prevalence rates are not unique. However, it stands out as the most industrialized and most highly developed country with such high levels of infection.

It is impossible to tell the story of HIV/AIDS in South Africa without understanding the history and impact of *apartheid*—a legalized system of racial discrimination—and the transition to democracy that took place in 1994. In South Africa, Dutch and British settled the territory they occupied and thus the country was not, unlike many other imperial territories, governed only by means of a small colonial administration. These settler colonialists divided the country into a rich, white minority and an impoverished black majority. The story of South Africa's political miracle—the avoidance of an all-out race war—speaks to the eventual pragmatism of the white elite in stepping down from political power before the country descended into chaos. It also captures the agreement from leaders on both sides of the racial divide as to the desired future direction of the country: a modern, prosperous African state with legal equality for all and a transformation process designed to redress past discrimination.

This narrative of South Africa's apartheid era and democratic transition, however, misses important historical stages pertinent to understanding the country and its peoples today. Prior to European conquest, South Africa was populated by several Bantu-speaking societies. The term Bantu has picked up negative connotations in popular use. However, as a linguistic categorization of the majority of Africans in southern Africa, it remains

a valid and useful category. These groups, as well as smaller populations of Khoe-San or Bushmen, were organized along family, clan, and tribal lines that in some cases solidified into larger nation polities. These indigenous societies had distinct political, military, economic, and social structures. The long process of colonization, which is usually dated with the arrival of Dutch settlers in 1652, subjugated these political entities. Thus, the construction of apartheid following the electoral victory of the Afrikaner (settlers of Dutch origin) National Party in 1948 was not the introduction of racial domination in South Africa but its brutal and open codification as an ideology subscribed to by the majority of whites and its systematic implementation through racist laws.

Yet despite centuries of colonialism and decades of apartheid, much of pre-colonial society remains—albeit often fragmented, devalued, and hidden. Belief in traditional African values often oscillates between pride and embarrassment. The truth is that these legacies are complex. In presenting itself as a modern organization, the African National Congress (ANC) has consistently striven to overcome tribalism as a division of black unity and a danger to its founding vision of a diverse but harmonious society. In part this was because of the apartheid government's deliberate policy of highlighting and supporting ethnic differences as a strategy of divide and rule. Precisely mapping ethnic groups is not possible (as the apartheid ethnographers found out). The fact that there are eleven official languages (two of European origin and nine indigenous), and that each of these are associated with a particular group that may itself be subdivided, highlights the complexity of ethnicity in South Africa. For all the ANC's ideal of racial unity, the question of ethnicity is of great significance to individuals' identities and loyalties, to social networks, and to the political need to craft not only a racial but also an ethnic balance of political power. However, beyond a public celebration of linguistic diversity, the legacy of the old within the modern is played out furtively.

To understand the context of the AIDS epidemic, we need to recognize how South Africa's difficult historical legacy shapes every facet of life. Given the subject of this book, we will need to bear in mind not only why the country's population has been particularly vulnerable to the transmission of the HIV virus but also how health care systems and access to those systems has been shaped by the broader processes that have constructed South Africa.

Pre-colonial Africa had extensive systems of indigenous healing. These attempted to address individual's health problems and were also responsible for public health and social stability though their influence on rights of passage to new social status and for maintenance of public health through prescribing and maintaining social and sexual relationships. These roles were (and remain) deeply linked to an African cosmology in which ancestors play a significant role for the living. Offending the ancestors—by failing to adhere to appropriate standards of behavior—brings problems to individuals and society. But these ancestors can also be used by traditional African healers to restore balance though processes of divination. Most commonly this is done by means of "throwing the bones" (tossing a collection of objects, including small animal bones, which are then interpreted). Mediating between the living and the ancestors, traditional healers seek to identify the root cause of problems and prescribe necessary corrective action. Typically, this combines paying attention to the ancestors and restoring, at least for a period, strained social relationships. Ceremonies in which an animal is slaughtered and eaten and traditional beer consumed are the most common way of rectifying ancestral neglect.

Steven Feierman (1985) describes the suppression of these indigenous systems of health care by colonial authorities across Africa who stripped away any serious roles of political or social control from subjugated populations. Witchcraft acts promulgated throughout the nineteenth and twentieth centuries in most African colonies eliminated the role of traditional healers in any form of social regulation. This change had public health implications. For example, traditions such as a cleansing period after the death of a spouse before resuming sex became a practice that relied on family subscription rather than a necessity backed by traditional healers forming part of the polity. This reduced the role of traditional healer to the provider of individual healing services—typically out of view (Chavunduka 1986). Alongside this suppression of traditional medicine, colonialists, notably in the form of missionaries, introduced Western medical practices. This kind of medicine has been of limited value across Africa for several reasons. Whether under colonial rule or after independence, insufficient resources have been available for doctors, nurses, hospitals, and clinics. Moreover, the narrow scope of Western medicine, even when available, largely ignores spiritual and social aspects of health. One result is that plural medical systems now exist in most African countries (MacCormack

1986) including South Africa. In such plural systems, people use different healing systems—such as Western, traditional, faith, and patent medicine—depending on accessibility, respectability, sympathy, cost, and perceived efficacy. Often, given doubt over efficacy and the multiple dimensions of health, more than one system is simultaneously consulted.

As the South African network of Western-based medical care extended, it did so in an uneven way. Health resources tend to be biased toward urban areas and to provide better service to richer sections of the populations. In South Africa, racial segregation reenforced this inequality with modern health care available, through public and private systems, for whites and limited poor-quality care available for blacks. Where health care was available for Africans, this was often based on economic expediency, as in the mining industry where an extensive system of health screening and interventions aimed at maintaining healthy workers was introduced with little regard for their families or, indeed, for workers beyond their period of service. Packard (1990) provides a detailed account of such a response in South Africa to tuberculosis among black migrant mine workers.

After the end of apartheid in 1994, the new government had to integrate a fragmented health service that had been divided both on racial and national (i.e., notionally independent, ethnically defined, black "homeland" states) lines—much of it squalid and underresourced. What it also inherited was a private health care system to which the richest 15 percent of the population had access via private insurance. While spending on health has been a priority for the ANC government, the public health care system remains distinctly second-class in relation to private care with limited facilities and poor services. Not surprisingly, despite the existence of extensive Western health care facilities, accessing plural health care options remains common in South Africa. While accessing what services are available from public-sector hospitals and clinics, Africans, in particular, consult traditional and spiritual healers or buy patent, often quack, medicines based on herbal formulas, which are available almost anywhere from street corners to large pharmacies.

The AIDS epidemic as a new health concern entered into this complex set of health systems operating in South Africa. Understanding the South African government's response to the epidemic, which we review shortly, requires placing the arrival of the disease within the wider tensions held within this complex system. The aspiration that all should have access to

health services is undermined by the reality of limited and unequally distributed resources. Any hope that Africans, freed from colonial bondage, could draw on their own indigenous healing knowledge has not been fulfilled because of a fragmented and chaotic traditional health care system.

The story of AIDS in South Africa is, as this book emphasizes, much more than one of the state's response. It is also about how individuals, families, and communities have responded to the epidemic. In this regard, it is a question of understanding not only the legacy of publicly devalued traditional healing systems of Africans but also other dimensions of the African population. This is not to downplay the presence of other racial groups in South Africa. But the overwhelming majority of South Africans are Africans, and it is among this population that the epidemic is, at least currently, disproportionately concentrated. In South Africa there has been a long and deeply harmful process dehumanizing Africans. In response, Africans have, as oppressed people do everywhere (Scott 1990), learned to hide their true feelings, to dissemble, to steal advantage by stealth, and to undermine by petty, calibrated acts of sabotage what they dare not openly challenge. The need to overcome this public subservience to domination was the key to Steve Biko's call for black consciousness.[1] To the extent that this project remains unfulfilled, it feeds into typical responses to HIV/AIDS in which mostly white experts tell black Africans what they should be doing to protect themselves from AIDS, make sure they know their HIV-status, and, if infected, live healthfully and, when appropriate, start antiretroviral therapy. Many in the assembled audiences display a polite public reception, learn the correct responses, but do little more once the lecture is over. Away from such public performance, many rely on the alternatives explanations of HIV/AIDS that draw on African experience of their dehumanization with expert pronouncements commonly contradicted by a range of AIDS myths involving racial conspiracies that reflect a colonialized past as well as continued underdevelopment.

1. Steven Biko (1946–1977) founded the Black Consciousness Movement in South Africa. This movement stressed the need for blacks to take pride in themselves. Although black consciousness never rivaled the ANC as an organized opposition to apartheid, its influence in reshaping the cultural landscape of racial oppression and resistance was enormous. Biko was killed by police while in custody.

This book will explore not only the gulf between a handful of educated experts and an underdeveloped and undervalued African population but also the divisions within this population—divisions that have significant implications for any response to HIV/AIDS. Race dominates any evaluation of what divides South Africans, but within the four racial categories—Africans coloreds, Indians, and whites—there are further subdivisions. The African majority is divided by ethnic differences the salience of which depends on the situation, but which are readily available to justify actions or explain grievances that race alone cannot explain.

The gendered culture of South Africans, black and white, sets up another tension. While the South African Constitution is not infrequently referred to with pride, this coexists with widespread resentment among African men (and often women) of the rights that it gives to women and children. Religion further exacerbates divisions within the country. Although an overwhelming Christian country, South Africa has minorities of Muslims (among Indians and coloreds), Jews (among whites and the Lemba—a small African Jewish community found in South Africa and number of neighboring states [Le Roux 2003]), and Hindus (among Indians). Christians in South Africa are divided among a host of denominations, some linked closely to race. While almost 80 percent of South Africans describe themselves as Christians, they attend a range of mainline churches (e.g., Dutch Reformed, Catholic, Anglican, Methodist), as well as African Initiated, or Zionist, and Pentecostal churches. While very few Africans report that they subscribe to African traditional beliefs, in reality such beliefs coexist alongside Christian teachings and practice in most Zionist churches and, frequently, among the congregations of mainline and even Pentecostal churches despite hostile official stances.

Despite these differences within the African population, which the more public tensions of race conceal, there is a strong social ideology of unity—often expressed in the concept of *ubuntu* or the idea that people can only be people (that is fulfill their potential) with the help of other people. But while this ideal of unity is frequently espoused, any close observer sees what everybody knows: It is largely absent. While African children may grow up with the entire neighborhood acting as surrogate parents, the adult world of Africans, and South Africans generally, is a much harsher and individualistic competition for advantage and control. High levels of rape and child sexual abuse highlight the disregard for the welfare and dignity of others in South Africa. Africans often express nostalgia for what they claim to be the

authentic social norms that prevailed in a pre-colonial golden age. At that time, neighbors supposedly rallied to help and care for one another. Today, the reality is that—with exceptions—below a pervasive culture of polite cheerfulness, there is frequent mistrust of neighbors' and even family members' real intentions. All this is, as we shall see, highly pertinent for how peer educators work in South Africa.

Poverty aggravates all these tensions and reduces opportunities for generosity or even reciprocity. It is hard to care for others when you are hungry. In post-apartheid South Africa hunger is not unknown, but the widespread provision of social security means that most families can put food, even if it is only pap (maize porridge) on the table. What constantly corrodes social fabric in South Africa is less absolute poverty than inequality, within families, within communities, and within the country. Despite a widened social security net, inequality is increasing (South African Institute of Race Relations [SAIRR] 2008). Using the internationally used Gini coefficient measure of inequality in which a score of zero reflects perfect income equality (everybody has the same level of income) and one complete inequality (one person receives the country's entire income), South Africa is one of the world's most unequal countries. South Africa's Gini coefficient of 0.7 reflects the reality of the top 10 percent of households enjoying 50 percent of national income while the bottom 40 percent of households received just 7 percent of income (Statistics South Africa 2008b). By comparison, Scandinavian countries (some of the world's most equal) have Gini coefficients at around 0.25, while the United States (one of the most unequal developed societies) has a Gini coefficient of 0.4. Inequality in South Africa stems in large part from a distorted labor market that has an intense shortage of skills, allowing a minority to earn high salaries, while a vast army of poorly educated, mainly African and colored, adults search unsuccessfully for employment. Although mitigated by extensive but largely unrecorded informal activity, South Africa's employment rate stands, depending on how it is measured, at between 20 and 40 percent.

Five Companies

Macroeconomic variables help us understand the broad terrain on which AIDS operates, but local conditions also shape the epidemic and responses.

This book focuses on workplace peer education. As well as having their own internal cultures, companies help shape the context of peoples' lives in many ways. In this book, we draw on the work of peer educators in five large South African companies: a mining company, two automobile manufacturers, a retail group, and a financial institution.

Above all other industries, the mining sector has shaped South African economic development and the country's social structure. Extracting the countries vast mineral wealth—gold, platinum, diamonds, and coal—has been the country's economic backbone. Much of this mining continues to use labor-intensive methods with profitability maintained by cheap labor. To achieve this, the mining industry has relied on migrant workers, both from neighboring states and within the country's borders. The flow of migrant workers set in motion by South Africa's mines endures to this day. Mining remains a high profile component of labor migration, but is now only the tip of the iceberg. Many apparently urbanized workers retain strong links with rural areas, or, looked at another way, many young men and women growing up in rural areas or small towns have little choice but to migrate to the urban areas if they are to find work. Approximately 55 percent of South Africa's population lives in urban areas. However, given widespread mobility, this is a gross simplification of where people live and work beyond providing a snapshot on census day.

A permanent system of labor migration provided a mechanism for the mining companies to de-link the costs of social reproduction and economic production. Without migration, companies must pay for the education, health care, and pensions of their workforce, either directly by salary levels that allow workers to pay for these themselves or indirectly though the state and taxation. With labor migration, workers could be superexploited because the cost of social reproduction—of raising families, of old age, and of disability—were transferred onto neighboring states and black homelands within South Africa. Not surprisingly, this system was resisted. Today the National Union of Mineworkers (NUM), one of the country's largest unions, still seeks to improve the working and conditions of black mineworkers—including campaigning for health and safety, an end to single-sex hostels that accommodate migrant workers, and the elimination of racial disparities within the workforce. White miners, long privileged by job and training reservation, are represented by separate unions that historically had been accommodated within the industry, at least from the

1930s onward. In 1922, white miners engaged in a violent insurrection on the Witwatersrand, known as the Rand Rebellion, in defense of privileges that management sought to undermine using cheaper black labor.

"Mineco," the mining company researched for this book, has 44,500 employees (out of an industry total of some half million). Like most large mining companies in South Africa, it is a rigid bureaucracy with a vast network of operations—including hostels, hospitals, management clubs, maintenance yards, and its own security force—supporting approximately ten mines, many with multiple shafts, and processing facilities spread across three of the country's nine provinces.

As we will see in Chapter 2, the mining industry was the first to respond to HIV/AIDS, and Mineco has a highly developed, though overstretched, HIV/AIDS program that includes a network of four hundred peer educators, testing facilities, and the provision of antiretroviral drugs for HIV-positive employees (but not their families). (Since the research for this book was conducted, Mineco has redesigned and greatly expanded its peer educator program with a target of over two thousand active peer educators.) The mining industry responded early to HIV/AIDS for a number of reasons. Given the extensive sexual networks created by the migrant labor system and single-sex hostels, there is a high level of HIV prevalence among mineworkers; this was detected relatively early as a result of annual medical checkups that all miners must, by law, undergo if they are to work underground.

Miners, whose families may live thousands of kilometers away from the mines, typically live in compounds while working. They may come from a neighboring country such as Mozambique or a former South African homeland such as the Transkei, the Xhosa-designated territory in what is now the Eastern Cape Province. Rather than living in homes or apartments, they live in single-sex hostels, where they bunk with many other miners. Previously, rigid social control limited their access to women, and homosexual relations (typically engaging in thigh sex rather than penetration) between older and younger mine workers were common (Moodie and Ndatshe 1994). Such homosexual relationships continue (Dickinson, Phillips, and Tau 2008) though almost certainly less commonly now that access to women is largely uncontrolled. In the past, miners returned home on an annual basis for perhaps six weeks between contracts. The workforce now has more permanent contracts, but frequently remains migratory.