
LEARNING

by

HEART

*AIDS and Schoolchildren
in America's Communities*

DAVID L. KIRP

WITH STEVEN EPSTEIN, MARLENE STRONG FRANKS,
NATHAN SIMON, DOUGLAS CONAWAY AND JOHN LEWIS

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B Y H E A R T

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Learning by Heart

To

Ndebe Jackson of Ocilla

Jamie McCardle of Wilmette

Marcus Robinson of Lorraine

David Swenson of Chicago

Ryan Thomas of Atascadero

Ryan White of Kokomo

To the memory of Mark Hoyle of Swansea

*And to all the other children whose lives have been touched
by AIDS*

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P R O L O G U E

Late at night on Friday, August 28, 1987, the Arcadia, Florida, house of Louise and Clifford Ray burned to the ground. By the next day, all America knew the story, even if most people did not fully sense its portent.

The Rays had fought to get their three sons, hemophiliacs infected with the AIDS virus, into the grade school of the small farming town where the family had lived for generations. They had tried unsuccessfully to convince the superintendent and school board that their boys posed no risk to classmates, and then they had gone to federal court and convinced a judge.

But Arcadians were not reconciled. They formed a Citizens Against AIDS in Schools Committee to pressure the Rays into changing their minds and, when that approach failed, they organized a boycott of the school the Ray children attended, which kept half the students home. The mayor took his own son out of the school and enrolled him in a public school in another county. A handful of Arcadians telephoned the Ray household with death threats. And one or two among them torched the Rays' home.

It was easy for the rest of us, watching these events unfold on the nightly TV news, to dismiss the people of Arcadia as ignorant bigots—easy and wrong. The people in this central Florida community, with its shopping mall and rodeos, think of

themselves as decent and ordinary, no different from anyone else. Likely enough they are right, which is what makes their story so hard to shrug off. That burning house is part of our lives, even as AIDS has become part of our lives.

Imagine for a moment that your own eight-year-old came home from school and told you that a classmate had AIDS. How would you react?

By now, there is durable scientific evidence on what is called casual transmission of AIDS: it says that the risk of spreading AIDS in the classroom or the schoolyard is infinitesimally small, far smaller than risks we expose our children to daily. But infinitesimally small is not zero. And the news your child is bringing home means you are being asked to make your own risk assessment, with the risk borne by your own child.

"I'm kind of glad my grandkids won't be around them. There's enough risks in this world without taking them deliberately," one Arcadian told a reporter. It is understandable that wise and caring parents would not want to invite even the remotest possibility of death into their children's lives, that they would imagine themselves responsible for preserving childhood as a kingdom where no one dies. It is understandable too that such parents could criticize a family like the Rays, as the Arcadia school superintendent did, for "parading their children in front of TV . . . not protecting them." To the superintendent and to many people in the town, it seemed that the Rays had forgotten to care for their own children, that instead they had turned them into a cause.

Arcadia, Florida, reveals just one aspect of the drama of AIDS among the young. Days later, in another Arcadia—this one in Indiana—Ryan White, a fifteen-year-old hemophiliac with AIDS, enrolled at the local high school. Ryan's new classmates went out of their way to greet him and made sure to invite him to a dance after the first home football game of the season.

Two years before, when the Whites lived in nearby Kokomo, they had taken on the same kind of highly publicized fight as the Rays and for their pains were frozen out by their neighbors. Hoping to start over again, the Whites had moved a few

miles away, not knowing how they would be received. What they found was hospitality.

There is nothing out of the ordinary about the Indiana Arcadians either, no reason to suspect that their town is the Peaceable Kingdom incarnate. Yet their school superintendent and school board, as well as the community itself, had calculated the risks very differently. They had learned the depths of significance imbedded in the cliché that life means taking risks. And they comprehended risks that their counterparts in Florida never talked about—the risk that hardening their hearts against Ryan White would be wounding not only to him but to themselves as well, and the risk that building a wall to keep Ryan out would teach the wrong lesson to their children.

Across the country, when confronted with the news that a child with AIDS was in their midst, some towns behaved like Arcadia, Florida, turning themselves into communities of exclusion. Others, like Indiana's Arcadia, became communities of openness.

The reasons that people responded as they did—first as parents, then as citizens acting together—cannot be rendered as a tale of us versus them, liberals versus conservatives, bigots versus the enlightened, rich versus poor, or big city versus small town. AIDS strikes with an awful democracy. And everywhere people have wrestled with the same powerful feelings, the same conflicting impulses for self-preservation and communion, that AIDS brings up.

This book tells a series of closely-linked tales about AIDS, communities, and children, beginning with Kokomo in 1985 and ending two years later. They are charged stories: of a mother with the AIDS virus, forced to choose between living with her child and his being allowed to attend school; of an AIDS-infected black teenager accused of having sex with his classmates; of a junior high school selecting a boy with AIDS as its "first citizen." Together, they reveal something about how we regard our children, how we deal with sex and dread and death, how we are led in times of crisis by politicians and bureaucrats and judges, and how we govern ourselves.

Many of us have tried to distance ourselves from AIDS by

thinking of it as a disease that affects someone else, some outsider. But when that psychological stratagem fails, when this disease enters our households (as in the moment when the eight-year-old comes home with the fateful news), AIDS offers startling and compelling insights. It becomes something like a mirror that we have happened upon unexpectedly. And when we look into that mirror, comprehending the two Arcadias and making sense of the Arcadias lodged within ourselves, the unfamiliar faces revealed there are our own.

C H A P T E R O N E

Telling Tales

July 30, 1985, started out as a typically uneventful summer day in the boxy brick buildings of the Western School Corporation, headquarters of a crossroads school district in the Indiana heartland. Situated in the village of Russiaville, Western serves several farming hamlets as well as a slice of the nearby town of Kokomo. With students gone, summer is a quiet time for school anyplace, so teachers and administrators were scarce. Anyone who could get away had disappeared, as likely as not to go boating in Mississinewa Reservoir or to laze in a cabin in cooler country.

But the superintendent, James O. Smith, happened to be at work. Smith had taken the post just a year earlier and, though he had already been an Indiana superintendent for nearly a quarter of a century, was still very much the outsider in Western. Perhaps it was his newness on the job, or perhaps it was the newness of the issue, that led him to miss the significance of a call from an Indianapolis TV reporter. How was Western going to handle the request of Jeanne White that her thirteen-year-old son Ryan—diagnosed as having AIDS—be admitted to school, the reporter asked.

Smith didn't pause to ask how the reporter had gotten hold of the story. He himself had been over the White case, off and on, for months, and had made up his mind to take what seemed the only safe and sensible course: to keep Ryan home. But, as he told the reporter, he hadn't been able to reach Jeanne White. The reporter gave Smith the

number where White was located and Smith telephoned with the official word. "She didn't sound too surprised," Smith recalls. "She seemed to expect it."

What Smith did not expect—what no one expected—was that this seemingly routine decision would make headline news, that Ryan White would become the nation's AIDS poster child, while Kokomo, a town that until then had been best known for its mentions in Bob Hope monologues, would acquire a reputation for its stance on AIDS. Ryan White's protracted fight to return to school won him no friends in Kokomo, where people still shake their heads at a boy and a family whom they regard as unduly keen on self-advertisement. But the Whites' determination, their insistence that a boy with AIDS be treated no better and no worse than anyone else, made Ryan an exemplar for other families and other towns across the country.

The conflicts over schoolchildren with AIDS that unfolded in Kokomo and elsewhere seemed to come from nowhere, like a tornado that caught the nation off guard. During the early years of the AIDS epidemic, children were not regarded as being at risk. This was a gay disease, the conventional wisdom went.

That belief was reflected in the name that the Centers for Disease Control (CDC) in Atlanta, the nation's AIDS monitor, initially gave this mysterious killer. GRID, it was called: Gay-Related Immune Deficiency.

The CDC suspected that some toxic agent linked to gay sex—tainted poppers, perhaps, or a batch of bad lubricant—might be the cause. Even when those leads proved dead ends, even when it became plain that AIDS could be passed through blood as well as sperm, by heterosexuals as well as homosexuals, the scientific community still resisted the idea that AIDS might reach children.

In 1981, Dr. Arye Rubinstein, chief of pediatrics at Albert Einstein College of Medicine in New York City, prepared a paper describing five infants, children of drug addicts, whose immune deficiencies mirrored those displayed by gay men. But the editors of the *Journal of the American Medical Association* (JAMA) and the *New England Journal of Medicine*, gatekeepers to

scientific respectability, refused to publish Rubenstein's findings: GRID was a gay disease, they insisted, not a disease of children.¹

While the experts were fixated on homosexuals and, later, drug abusers, hemophiliacs, and Haitians, these infants and many hundreds of others like them were being infected with AIDS *in utero*. One-third of these doomed youngsters were abandoned by their AIDS-afflicted mothers at birth, left to live out lives of undetermined length in the impersonal wards of public hospitals.

And while the scientific establishment was assuring the public, quite without justification, that the chances of contracting AIDS through blood were less than one in a million, many of the nation's 20,000 hemophiliacs under medical treatment, including 8,000 youngsters of school age, were being infected by AIDS-tainted batches of the blood-clotting product they depend on to lead normal lives. Although no one suspected it during those early days of the epidemic, the proportion of young hemophiliacs carrying the virus was far higher—estimates range between 60 and 90 percent—than of gay men living in the sexual fast lane.

In May 1983, the prestigious *JAMA* reported—erroneously, as it turned out—that routine household contact might spread AIDS, and the first signs appeared of what was to become an epidemic of panic. But despite the fact that the *JAMA* story concerned immune deficiencies detected in children living with an adult who had AIDS, the fear it aroused had nothing to do with the young. Instead, it was the apparent ease, the casualness, of transmission that seemed so ominous. Police officers and firefighters balked at touching the clothing of anyone who might conceivably have AIDS unless armored in face masks and rubber gloves. Prisoners at New York's Attica Penitentiary launched a hunger strike because the cafeteria's eating utensils had been used by an inmate who later died of AIDS. Many morticians declared their unwillingness to embalm the bodies of those felled by the disease.

When Ryan White was turned away by the Kokomo public schools in the fall of 1985, public attention finally focused on

children—and furiously so. Across the entire country, the CDC asserted, no more than fifty children with AIDS were well enough to attend school, but the attention they commanded was far out of proportion to their number.

Ryan White's story developed into a staple of the nightly news, along with the theatrics of thousands of protesters in New York City, who carried a coffin bearing a sign reading "Is This Next?" through the streets of Queens to protest the enrollment in school of a child with AIDS. Two years later came the infamous burning house in Arcadia, Florida. Although these were headline-grabbing stories, they were not the only stories to be told. In dozens of cities and towns across the country—as diverse as Granby, Connecticut, and Sun Valley, Idaho; Asheville, North Carolina, and Chicago—youngsters with AIDS have been accepted in school.

These dramas of acceptance and exclusion, and the moral backdrop against which they were played out, depended on shared understandings of what AIDS meant, understandings that had taken shape before children with AIDS ever enrolled in school. While AIDS and children were not linked in people's awareness, AIDS itself evoked a wide range of deeply disturbing meanings. What happened in Kokomo and Arcadia, and everything that came between, makes sense only within the larger framework of what AIDS conjures in the popular mind.

Not in the beginning, not even as the 1980s drew to a close and the epidemic spread across America, was AIDS understood simply as a disease. At first it was ignored, indeed almost unspeakable; later it was the subject of countless headlines. But so much of what was whispered or shouted, though ostensibly about AIDS, really was about other things. People claimed to be talking about an epidemic, and no doubt believed they were doing so. But what they actually discussed often was somewhat different: their attitudes toward homosexuality, perhaps, or their doubts about science. "Nothing could be more punitive than to give a disease a meaning," writes Susan Sontag, but AIDS has been loaded down with many meanings. Most fundamentally, it has become impossible to talk about AIDS without talking about death, sexuality and deviance.

The nature of AIDS would have made it a source of panic no matter whom it struck first. As an inevitably fatal disease, it evokes a special sort of dread. Some fears draw people together—the assault of an enemy on one's country, for instance. But death too starkly and directly glimpsed can confirm individuals in their essential isolation, and so set one against another.² That is why most cultures take such care to ritualize death, to cover it up. AIDS offers an unwelcome reminder of the reality behind the mask of ritual.

And AIDS was—is—medically frightening. It devastates the immune system and leaves the body vulnerable to an onslaught of bizarre diseases normally held at bay, many previously unknown among Westerners, some previously unknown in humans. Plagues typically bring swift death to their victims, but the long incubation period of AIDS makes it hard to know who has been exposed and who has not—who, in the sensationalized imagery of the early news stories, were the “walking time bombs.”

AIDS is an epidemic attacking ever-greater numbers, and epidemics have historically incited finger pointing. Jews were blamed for the outbreak of bubonic plague in central Europe during the fourteenth century and were slaughtered and loaded onto wine casks, which were then floated down the Rhine.³ In turn-of-the-century California, the plague was described by doctors as an “Oriental disease, peculiar to rice-eaters.”⁴

In the late twentieth century, when medical heroics have become commonplace, and when “medical science epitomizes the postwar vision of progress without conflict,”⁵ epidemics have come to be regarded as a horror of the past. The day before yesterday, on the swiftly moving scientific clock, came the polio vaccine; yesterday, the eradication of smallpox; tomorrow, it is confidently supposed, will come a cure for cancer or the near-infinite prolongation of the life of the human heart.

It is easy to forget that epidemics have been historically ubiquitous and that the present thicket of interconnections among people from far-flung quarters of the globe makes diseases potentially much easier to spread. In a matter of months, years at most, viruses that emerge in the remote African bush can find

their way to New York harbor—and Kokomo, Indiana. But that knowledge was lost to a generation of Americans who had known no serious epidemics. If epidemics like AIDS should not be happening, the unconscious logic proceeds, then someone must have done something terribly wrong.

The condition of being ill usually exempts individuals from ordinary responsibilities without moral disapproval. But AIDS is widely seen as a “disease of passion”—a disease of sex and deviance—that seems to single out individuals for judgment and guilt.⁶

Rarely is sex regarded neutrally. Whether whispered or shouted about, it remains our great mystery, invested with enormous power for good or evil, treated variously as the ultimate revolutionary act and the great unspeakable. For all our supposed modernism, all our in-your-face bluntness about once-shocking intimacies, much about sex remains taboo; and a disease spread sexually, through “body fluids,” still appears sinister and suspect.⁷

Not so long ago, sexually transmitted diseases defined entire classes of people. At the turn of the century, American blacks were described by doctors as “an especially syphilis-soaked race,” and a few years earlier English prostitutes had been characterized as “mere masses of rottenness and vehicles of disease.”⁸ That judgmentalism seemed to have vanished during the decade or so before AIDS appeared, when America acted out its sexual revolution. Then, we were our own most wondrous toys, playing with each other with religious—almost childlike—intensity.

All this freewheeling sexuality scandalized the moralists. Indeed, what prompted the emergence of the fundamentalist Moral Majority as a political force was its ambition to tear down the signposts of the sexual bazaar, to end abortion (with the casual and nonconsequential view of sex it seemed to connote), pornography, and homosexuality.

These were ancient moralist themes with powerful appeal in an America that, for all the bra burning, gay-lib parades, and

X-rated videos retailed at local 7-11s, had never entirely abandoned its Puritanism. When the herpes epidemic emerged at the outset of the 1980s, commentators quickly extrapolated its moral implications. “[Herpes] may be a prime mover in helping to bring to a close an era of mindless promiscuity,” opined *Time* magazine, which emblazoned the story with a scarlet “H” on its cover. “For all the distress it has brought, the troublesome little bug may inadvertently be ushering in a period in which sex is linked more firmly to commitment and trust.” The evangelist Billy Graham was more plainspoken about the meaning of herpes in God’s plan. “We have the pill. We have conquered VD with penicillin. But then along comes Herpes Simplex II. Nature itself lashes back when we go against God.”

To those on the religious right, herpes was the prophesy of doom. AIDS was its confirmation.

Almost immediately, the epidemic was transformed into a debate about sexual irresponsibility—especially homosexual irresponsibility. A 1983 *Newsweek* cover story sounded this note: “For Gay America, a decade of carefree sexual adventure, a headlong gambol on the far side of the human libido, has all but come to a close. The flag of sexual liberation that had flown as the symbol of the gay movement has been lowered.”

AIDS meant gay in the American equation even though, from the outset, groups other than homosexuals were being devastated by the disease. In New York City, which has the largest number of AIDS cases in the nation, the majority—53 percent—of those who died from AIDS between 1982 and 1986 were intravenous-drug users; substantially fewer—38 percent—were gay men. But that fact became known only after a retrospective study of the causes of death of several thousand drug users was conducted in 1987. Until then, statistics had pointed to gay men as the primary AIDS victims in New York.

Here again, social baggage had shaped scientific expectation, and scientists’ findings shaped popular perceptions. Homosexuals had made themselves visible, in their dying as in other aspects of their lives, while drug users had often died unnoticed.