Disputed Dimensions of Risk: A Public School Controversy over AIDS

DOROTHY NELKIN and STEPHEN HILGARTNER

Program on Science, Technology and Society,
Cornell University

IN THE ABSENCE OF A VACCINE OR CURE FOR AIDS there is general agreement about the need for public policies and programs to limit the transmission of AIDS-spectrum disorders. Some measures, such as educational programs, are widely accepted. But many other proposals are the subject of heated debate. The most bitter disputes center around efforts to isolate persons with AIDS. Despite strong scientific consensus that the disease is not transmitted through casual contact (Curran et al. 1985; Friedland et al. 1986), a wide range of controversial proposals have been based on this assumption. These have included enforced quarantine of infected persons, mandatory screening for the AIDS antibody, closing of gay bars and bath houses, constraints on marriage and child-bearing, and exclusion of infected persons from work, restaurants, and schools. AIDS victims have also faced discriminatory practices in the workplace, restaurants, and apartment buildings. Restaurants have screened food service employees. Hospitals have refused to admit AIDS patients, and undertakers have refused to handle their cadavers. Some churches have even changed their communion practices.

School board debates are a case in point as groups of parents throughout the country are attempting to bar children with AIDS from public schools. This article examines a lawsuit that took place in Queens, New York, where two local school boards sued the city

The Milbank Quarterly, Vol. 64, Suppl. 1, 1986

of New York in an attempt to prevent a seven-year-old AIDS patient from attending school.[1] Analysis of the proceedings sheds light on the complex constellation of social, political, and symbolic issues involved in disputes over policies to control AIDS.

Because it is one of the first AIDS disputes that has actually reached the courts, the Queens lawsuit served to crystallize the issues and provided an array of arguments that are likely to be developed in other cases. This is especially important because decisions about quarantines or other control measures rest with state and local authorities. At the national level, the Centers for Disease Control (CDC) offers guidelines, but has no enforcement power. Thus, the Queens case is a precedent for other communities considering similar policy questions; according to the city's counsel, many communities facing similar decisions have requested copies of the transcript.

As is characteristic of risk disputes (e.g., the controversies over nuclear power, drug safety, additives and residues in foods, and occupational health), heated debate over AIDS has been attributed to diverse factors. Does the controversy result from irrational fear or from justified concerns? From public mistrust of expertise or from overconfident experts? From public overreaction or from callous bureaucrats? From technical uncertainty or from conflicting values? Participants in the Queens hearings debated such questions, covering not only the scientific and medical evidence about AIDS, but also issues of political authority and the decision-making process. The judge, stating his intention that the hearing would serve to educate the public, relaxed the normal rules of evidence to facilitate discussion of the scientific aspects of AIDS. This article explores the many dimensions of the Queens dispute as they were revealed in the legal proceedings, suggesting the complexity of the public response to AIDS and the limits of technocratic perspectives in developing social policies for its control.

Examining legal proceedings is a useful way to study risk disputes. In effect, a hearing is a public performance, a drama, a ritualized

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[1] District 27 Community School Board, District 29 Community School Board, and Samuel Granirer vs. The Board of Education of the City of New York, The Department of Health of the City of New York, the Commissioner of Health and the City of New York; Supreme Court of the State of New York, County of Queens, September–October 1985. Honorable Harold Hyman presided. The Board of Education is a branch of the city government which operates through the local community school boards.

verbal combat involving multiple actors, all seeking to reify their version of reality, to control the definition and interpretation of evidence, and to convince the court of the validity of their position (Edelman 1977; Gusfield 1981; Campbell 1985; Molotch and Boden 1985). Embodied in the discourse on such adversarial rituals are people's beliefs, their values, and the assumptions that filter their perceptions of risk. In the courtroom, science becomes a political resource, employed by competing interests as a tool of persuasion.

Analysis of the hearings reveals a wide range of issues. The hearings brought out, first of all, different images of the risk itself. How is the risk of AIDS defined? What, in the minds of the protagonists in the hearing, are the scenarios of risk?

Second, a central issue in the debate was the adequacy of current scientific knowledge: How much scientific uncertainty surrounds the subject of AIDS transmission? What constitutes adequate evidence? How should policy makers respond to incomplete scientific knowledge?

Third, the testimony revealed tensions about the credibility of expertise: Whose judgment is to be considered in evaluating the acceptability of risk? Who can be trusted to provide responsible information?

Fourth, much of the debate centered on the legitimacy of the procedure through which the decision was made: Who should be involved in decisions about controlling risk? What are the appropriate roles of scientific and medical expertise? What are the proper roles of the city government and the local school board in decisions about school policies?

Finally, the discourse during the hearings brought out different arguments about the balance of rights and responsibilities in the effort to control the risk of infection.

The Queens AIDS Controversy

On September 7, 1985, Ed Koch, the mayor of New York City, announced that an ad hoc committee of experts had decided to allow a seven-year-old child diagnosed as having AIDS to attend public school. The identity of the child and the location of the school were kept confidential. At that time there were about 78 children under the age of 12 in New York City known to have had the disease, and

52 of these had died. Four of the remaining children wanted to attend school.

New York City's policy, consistent with the guidelines provided by the Centers for Disease Control (CDC) and the recommendations of the National Education Association, is to make decisions about the education of AIDS children on a case-by-case basis, and to maintain strict confidentiality about the identity of the children involved. The health department had appointed a panel of four persons (Suzanne Michaels, a social worker employed by the health department as liaison to the Board of Education; Dr. Pauline Thomas, a pediatrician from the department; Rosalyn Oratz, a Board of Education administrator who was a former teacher, and Agnes Green, president of the United Parents Association) to consider the cases and make recommendations. After consulting with physicians, they recommended that one of the four children, the seven-year-old, be allowed to go to school. The final decision rested with New York City's Commissioner of Health, Dr. David Sencer. Following the current scientific knowledge about transmission mechanisms, Dr. Sencer, in consultation with the chancellor of the city school system, Nathan Quinones, allowed the child to attend class in one of the 622 elementary schools in the New York City system. To maintain confidentiality, no one in the school system knew which school the child would be attending.

The city's decision, announced two days before the opening of the school year, met with extraordinary alarm. A boycott was organized. On September 9, the first day of classes, the parents of about 10,000 of the 960,000 children in the New York City school system kept them at home. Anxious parents marched in the streets with posters: "Our children want grades, not AIDS"; "Stop the lies: We want facts"; "Better safe than sorry." They resented the "fancy talk" of scientists, "the percentages and probabilities." Before sending their kids to school they wanted to be certain they would be safe.

In statements to the press, local school board officials revealed their concern about the disease ("The most serious epidemic in recorded medical history") and about technical uncertainty ("There is no medical authority who can say with authority AIDS cannot be transmitted in school"). They voiced their mistrust of expertise: "We should not experiment with our children"; "I don't want all the medical experts telling me 'Don't worry.' I'm worrying" (*Time* 1985, 24). And they

made it clear that they believed the decision violated the autonomy of the local school boards.

Following the school boycott, two community school boards (districts 27 and 29) in Queens brought suit against the city of New York, the city Board of Education and its chancellor and president, and the city Department of Health and its commissioner of health. The plaintiffs sought to remove the child and to prohibit other AIDS children from attending school. Later, 28 additional boards from all five New York City boroughs joined the lawsuit. The dispute moved from the streets to the New York State Supreme Court, with Justice Harold Hyman presiding. Below we analyze the text of the Queens hearings, examining conflict over the definition of risks, the adequacy of evidence, the credibility of experts, the legitimacy of the decision-making process, and the balance of rights. The 3,000 pages of transcript include examination and cross-examination of 5 witnesses for the community and 9 for the city (see Appendix). In this article we have quoted extensively from this transcript; some quotes are slightly edited to avoid the redundancy of speech.

The Definition of the Risks

Body fluids—saliva, tears, sweat, vomit, stools—were a major preoccupation throughout the six weeks of the Queens school board hearings. Again and again, the lawyers and witnesses for the school board drew up "what if" scenarios, speculating about possible (and impossible) routes of transmission among children in school. What happens if an AIDS child has a nosebleed or cuts himself? What if children prick themselves and exchange blood through blood brother rituals, or if they chew common pencils, share common food, share toothbrushes, draw blood in a fight, get bitten by the same mosquito, bite each other, stumble over a stanchion in a schoolyard, or drink from the same water fountain? What if a child has lesions on his body or passes bodily secretions which come in contact with another child or adult? What about vomit? Drooling? Spitting?

The scenarios, expressing understandable parental anxiety, were often described in detail. A child with AIDS gets a nosebleed; the blood spurts partially on the floor and partially on another child's

desk. A second child has an open wound and touches the blood. Or a young boy with AIDS goes into the bathroom and urinates, but he doesn't lift the seat. His aim is not that good; when he leaves, someone else sits down on the wet toilet seat.

The city and the school board approached these scenarios differently. The school board lawyers, focusing on the uncertainties, accused the city health department of neglecting such possibilities in their decision to send the child to school. They believed that body fluids containing the virus must be considered "potentially infectious," and they sought definitive assurance that the scenarios brought up as possibilities would pose no real risks. Witnesses for the health department did not claim to have completely analyzed every possibility, but they dismissed the scenarios as irrelevant—so unlikely to spread the disease that they did not merit consideration. Commissioner of Health David Sencer argued: "We have assigned a level of risk to transmission by saliva to be so minimal that it does not have a practical implication." Similarly, Pauline Thomas, the pediatrician from the Department of Health, defended the decision to send the child to school even though all possibilities had not been considered: "The panel felt that there wasn't any need to have a complete guarantee about all future interactions."

The president of community school board 27, Samuel Granirer, on the other hand, expressed the view of his constituents. He argued that exchange of body fluids among children is not simply a matter of casual contact: "In terms of my feelings, . . . I don't feel casual contact is really what happens in a second-grade room. I feel very strongly that bodily fluids is an issue." To school board witnesses the risk from casual contact was especially great for children. They conveyed an image of children wallowing in their secretions, unsocialized in sanitary behavior, and basically out of control. They also portrayed children as highly vulnerable, fragile, and unpredictable, so that special sanitary measures are needed to protect their health.

While the school board brought up worst-case scenarios, the city tried to convey the notion of relative risk. Children sometimes get hurt by participating in athletic activities or by riding the school bus. No school board has proposed abolishing student athletics or the school bus program. As the child's attorney observed, "There is a theoretical risk that the ceiling will collapse, and indeed, ceilings in rooms have collapsed, but such far-fetched possibilities are not a proper basis for making policy." The response from the community was

simple: they wanted guarantees, not odds. Robert G. Sullivan, the attorney for the school board, voiced the sentiments of his clients: "The odds aren't that great but I'm a parent, and a parent is a funny kind of human being, and a parent isn't much interested in odds." The disease was a death sentence: "One cannot be too careful."

These different images of the risk set the stage for a lengthy technical dispute over the adequacy of the evidence about the transmissibility of AIDS.

The Adequacy of Evidence

Much of the hearing revolved around technical evidence concerning the probability of transmitting the virus which could lead to AIDS. For days the lawyers and the judge probed the arguments of the witnesses, all but one of whom was a scientific or medical expert (see Appendix). But while each side focused its case on a range of technical evidence—from laboratory, epidemiological, clinical, and behavioral studies—the city and the school board interpreted this evidence in very different ways. While the city cited current scientific knowledge to demonstrate that there was virtually no risk in sending the child to school, the school board emphasized the gaps in scientific understanding to argue that current knowledge was unable to support the city's decision. Battle lines were drawn over the extent of scientific uncertainty, the interpretation of existing evidence, and the policy implications of what is presently known.

Following the consensus of the scientific community, the witnesses for the city explained the epidemiological, clinical, and laboratory evidence that consistently indicated that casual contact posed minimal risk. Noting the absence of cases outside the high-risk groups, epidemiologists argued that the disease would have spread further by now if it were easily transmissible. They described studies of people who were in prolonged and close contact with AIDS patients. Family members (who were not sex partners) and health care workers did not contract the disease, nor did children sharing the same bed, food, toothbrushes, or eating utensils. Moreover, witnesses for the city argued that the virus occurred in such small quantities in saliva and tears that these fluids were unlikely routes of transmission. Finally, they described laboratory studies showing that the virus was very

fragile, hence all but incapable of surviving outside the body. Taken together, this corpus of evidence formed a coherent pattern, suggesting to city officials that the risks of sending the child to school were extremely small.

The local school board was not convinced. In an attempt to undermine the technical basis for the city's case, its lawyers and witnesses pursued two main lines of attack. First, they tried to find cases of AIDS victims who were not in the high-risk groups. Second, they argued that scientific and statistical evidence about the *probability* of transmission through casual exposure to the body fluids of an infected person did not rule out the *possibility* of such transmission.

This position came forth in response to a recurring question posed by the city lawyers: "Isn't it a fact, Doctor, that there is not a single reported case in the medical literature in which AIDS has been demonstrated to have been transmitted other than A) by sexual intercourse with an infected person; B) by injection of contaminated blood or blood products; or C) by an infected mother to her child before or during birth?"

All of the witnesses—for both sides—had to admit this was true. But the partisans of the school board denied that the evidence adequately demonstrated that these were the *only* ways the disease could be transmitted. For example, Dr. Lionel Resnick, a dermatologist, admitted that no cases had been *demonstrated* to have been transmitted by other means; but he maintained that "it hasn't been looked at as to whether saliva or tears can cause an infection, so if it hasn't been looked at, how can you say that it may not occur?" Dr. Resnick, who had been involved in laboratory studies of the virus on a project with Dr. Robert Gallo at the National Institutes of Health, in effect challenged the conclusion of the epidemiological studies by shifting the burden of proof.

On a related line of attack the school board argued that the city could not rule out the possibility that contact with blood, tears, or saliva could transmit AIDS. As Dr. José Giron, chief of infectious diseases, Flushing Medical Center, put it, "We know that the AIDS virus . . . is in those body fluids [so] one has to consider each of these body fluids as potentially infectious." And later, "When all is said and done, we are dealing with a situation that doesn't have all the data."

Others raised doubts about the certainty of the studies of transmission among family members. Dr. Arye Rubinstein, pediatrician and immunologist at Albert Einstein Medical College, recognized that children who shared the same bed or toothbrush with AIDS patients "so far" had not acquired the disease. "It doesn't mean that if we have a longer follow-up, that we are not going to find exceptions. . . ." He admitted that such cases would "probably be an unusual occurrence," but nevertheless questioned the wisdom of the city's decisions.

The lawyers for the school board, and the judge as well, probed for examples of AIDS cases that fell outside the risk groups. They repeatedly cited the case of an English nurse who had acquired the disease by accidentally sticking herself with a needle contaminated with the blood of an AIDS patient. The petitioners also claimed to have found a doctor who knew of a health care worker with AIDS acquired through casual contact, though he provided little documentation. The school board and the judge proceeded as if a single counterexample to the usual transmission patterns would destroy the city's case. In contrast, the city rested its conclusions on the corpus of evidence as a whole.

The recurring discussion of the "what if" transmission scenarios forced the city's witnesses to confront the difficulties of extrapolating from a body of data to make inferences about situations that have never been observed. Unable to make definitive statements, they framed their judgments in probabilistic terms. They could state with "a reasonable degree of medical certainty" that a particular scenario would not spread the disease, but they could not prove that transmission would never occur.

For example, when pushed for answers with 100 percent certainty, Dr. Donald Armstrong, chief of infectious disease at Memorial Sloan-Kettering Medical Center, a witness for the city, could only argue "with a reasonable degree of medical judgment" that the virus could not be transmitted by a bite: "I didn't say a hundred percent it would not be transmitted by a bite."

Scientists are socialized to avoid definitive statements and to use a language of probability. Thus, their testimony was peppered with qualifications: "extremely unlikely," "reasonable certainty," "infinitesimally small," "would not be expected." The school board and the judge interpreted such qualifications as lack of knowledge: "They

don't know the answers." Confusion reigned between evidence and proof, between facts and theories, between findings and explanations, between probable judgments and unassailable conclusions.

Establishing the level of risk was one issue; deciding about the acceptability of risk was yet another. Thus, different interpretations of the scientific knowledge were paralleled by conflicting views of its policy implications. The city officials and their expert witnesses believed that the uncertainties were so small that the child should be allowed to attend school. But the school board argued that where there are any scientific uncertainties about such a catastrophic disease, schools must avoid the risk at all costs. The community wanted "something definitive to protect the children."

Even when they agreed on the evidence, the two parties frequently reached opposite policy conclusions. Dr. Pauline Thomas estimated that there are somewhere between 200 and 2,000 carriers of the HTLV-III virus among children in the city schools: "It makes little sense to keep one child out where so many others are probably carrying the virus." Attorney Sullivan, however, reached the opposite conclusion: "The fact that you don't know about all the others doesn't mean you shouldn't do something about the one you do know about."

The Credibility of Experts

Closely related to the conflict over the adequacy of knowledge was a struggle over the credibility of technical experts. The city maintained that its decision reflected the consensus of the scientific community. Its lawyers and witnesses emphasized the solidity of this expert consensus, asserting that the decision was a rational one based on the best available technical advice. They stressed that the city had carefully considered the guidelines from the Centers for Disease Control (CDC), the latest scientific research, and the opinion of the child's physician. "We make our decisions on the basis of knowledge, we weigh risks and benefits . . . and we take appropriate action," said Commissioner Sencer. Thus, the city called forth expert witnesses to provide the scientific backing for a decision they viewed as a technical choice.

The school board's lawyers and witnesses attacked these claims, charging that the city's experts were overstepping the limits of established

knowledge to present their biased view. Emphasizing the disagreements among experts, they defined AIDS policy as a matter of political, not technical choice. As such, they claimed, decisions about controlling AIDS should be made in the political arena.

The city's witnesses repeatedly expressed their confidence in the credibility of scientific expertise as they discussed the CDC guidelines, the technical evidence, the state of scientific knowledge, and the extent of expert agreement. In his summation, Frederick Schwarz, the city's attorney, argued: "With the exception of the first witness and possibly the second witness, Drs. Rosenblatt and Resnick, every single other witness agreed with the administrative decision made by Dr. Sencer; that is, every witness on either side, . . . including Dr. Rubinstein and Dr. Giron, agreed that there should not be [a policy of] automatic exclusion of children with AIDS [from school]."

The extent of confidence among scientists about the limited possibilities of transmission was dramatically captured in an exchange between Attorney Sullivan and Dr. Pauline Thomas. The attorney asked Thomas, as mother as well as physician, what she would do if her own child were bitten by an AIDS patient. "Would you want to have your child receive the blood test . . . as a precaution; yes or no?" Maintaining her previous position, she replied "I would not." Later, in a conversation with reporters, she added: "I have all these irrational fears. I know what it's like to be a mother. But I am also a pediatrician and epidemiologist" (*New York Times* 1985).

Just as the school board charged the city with overstating the certainty of current scientific knowledge, so it questioned the degree of technical consensus. Lawyers and experts for the school board argued that the scientific consensus was incomplete and fragile, noting areas of expert disagreement and stressing the limits of current knowledge in a rapidly changing field.

To reinforce his argument about the fragility of the expert consensus, Attorney Sullivan drew out the disciplinary tensions between epidemiologists and virologists. During the cross-examination of epidemiologist Rand Stoneburner he cited the study by virologist Robert Gallo on transmission of AIDS through prostitutes. In response Stoneburner observed that Gallo moved beyond his area of expertise by writing on this topic. "Dr. Gallo is not an epidemologist; he's a virologist and a laboratory scientist. . . . I don't think Dr. Gallo did any of the contagion or transmission studies. That's epidemiology."

Testifying for the school board, Dr. Lionel Resnick focused attention on conflicts among scientists: "When you get many leading experts together you have a lot of controversy. . . . A lot of experts disagree on a lot of issues." Attorney Sullivan attributed such differences in expert opinion mainly to political or philosophical biases: "There are doctors who differ, AIDS experts who differ." He argued that when the experts disagree "the differences are not with respect to scientific matters but are . . . philosophical."

The school board also attacked the credibility of the city's experts by emphasizing the constantly changing state of medical knowledge. Stressing the fallibility of experts in this context, Attorney Sullivan called attention to Dr. Sencer's earlier role in the swine flu vaccine controversy. Dr. Sencer had been the director of the Centers for Disease Control during the swine flu affair. On the basis of considered scientific opinion he had recommended that the public be vaccinated, but four months later the vaccine was withdrawn when some people developed Guillain-Barré syndrome. "What happens," Attorney Sullivan queried, "if four months from now you are as wrong as you were in 1976?" Attorney Sullivan emphasized the possibilities and the consequences of error: "Can anyone say that we are not going to learn new things about AIDS three months from now, six months from now, or a year from now?" And at another point, "You're making these kids go to school. What if we find out you are wrong and the kid who sat next to this kid with AIDS and wrestled with him or did whatever, gets AIDS? What do we say to him?"

Attorney Sullivan drove the point home: "I don't want to watch on [CBS Television's] '60 Minutes' two years from now when Mike Wallace grills David Sencer about the fact that he was wrong this time. . . . They force some seven-year-old child to go to that classroom. The child doesn't even know it. They force him to sit in front of a child who has AIDS. They force him to do that not knowing. . . . But when the child is dying from AIDS, and comes into the courtroom looking for redress, they'll say you can't sue. You have no right to sue. You go away. Your only consolation is you get to watch Mike Wallace grill Doctor Sencer on TV and get some satisfaction out of that."

The school board also portrayed Dr. Sencer as biased, attacking his professional standards and suggesting that he suppressed dissent. At one point, Attorney Sullivan refused to release the name of a physician

who claimed to have evidence about a health care worker who had contracted AIDS through casual contact. He feared that the physician would be punished for contradicting the conventional scientific wisdom. The judge defended Attorney Sullivan's effort to protect the physician: "You know very well that Dr. Sencer or his department has a great deal . . . I wouldn't say control . . . I'm not looking for this doctor to be punished because he's open and above board." The city's lawyers defended the commissioner's integrity arguing that it was inconceivable that the health department would suppress dissenting evidence: "We are interested in scientific inquiry. . . ."

In his summation Attorney Sullivan made the following claim: "Every doctor [who testified]—every single doctor—was concerned in one form or another, be it with bites, bleeding or saliva, except for all the doctors employed by the city of New York. That's an amazing coincidence. . . . What kind of influence does this man Sencer have over his people?" (We are convinced, from our reading of the transcript, that not all of the witnesses would agree with this characterization of their testimony.) Attorney Sullivan went on to charge the city experts and officials with not being candid: "We just don't trust Chancellor Quinones anymore and we don't trust Doctor Sencer anymore. . . . We say the following on the subject of AIDS: We say that we don't know the answers. But the only thing we implore you to consider is that they don't know the answers either. And when they say they do, they don't."

The Legitimacy of the Decision-making Process

In this atmosphere of mistrust, the political legitimacy of the city's decision-making process became a major issue. The city maintained that the decision was based on careful deliberation by the relevant experts on its advisory panel; that is, it was the outcome of a reasoned, rational approach to the issue. Made on the basis of facts, it was "certainly not arbitrary or capricious." To the school board, however, the decision was made by administrative fiat.

The city maintained that it had carefully considered the risks, including such "theoretical risks" as biting and blood spills. Attorney Schwarz noted that while some experts believe these risks are "essentially nonexistent," others see them as "theoretical" but nonetheless worrisome.

Thus, the city had adopted "the more conservative approach." Despite evidence indicating that bites and blood spills were unlikely to transmit the virus, these were treated as potential risks. "The panel, . . . if anything, erred on the side of caution. . . . They looked at the question of biting and found the child had no propensity to bite. They looked at the question of nose-bleeds and they found there was no history of nose-bleeds. And they looked at this child's capacity to function in the school system and they concluded that the child was normal or above normal in every relevant respect. . . ."

The school board countered that the decision was the work of an arrogant and unresponsive bureaucracy. Days were spent dissecting the role of the health department's panel, and attacking Health Commissioner David Sencer as an "authoritarian" individual, a "commanding figure" who made the decision "without anybody else having an opportunity to overrule him or even to discuss it with him." Dr. Sencer, who admitted that the advisory panel was, in fact, selected in order to build public confidence, was accused of using it simply as a public relations device. "They lied to me," Attorney Sullivan charged. "They led us to believe that a panel was making that decision. They knew all along that the decision had been made."

Attorney Sullivan further questioned the choice of people on the panel. Why was the school board association not consulted? Was the president of the United Parents Association really representative of the community? Why were there only four people? It became clear that the school board believed that panelists should have been chosen to represent constituencies in the community, while, in fact, they had been chosen because they had the background or expertise that the health department judged to be most relevant to the issue.

The general dissatisfaction with the decision-making process within the school system emerged in the cross-examination of Nathan Quinones, chancellor of the New York City Board of Education. Attorney Sullivan attacked Chancellor Quinones for failing to gain the confidence of teachers; that is, for neglecting to build political backing for his decision. Grilling him about his contact with the schools and their teachers, Attorney Sullivan implied that Chancellor Quinones just sat in that "terrible monument called 110 Livingston Street" (headquarters of the Board of Education) in isolation from the "real world of schools."

As the cross-examination of Chancellor Quinones continued, it became clear that the community viewed the AIDS issue as an adversarial

one, requiring a political approach to mediate the tensions in the relations between the central school administration and the local community school boards. However, Chancellor Quinones strongly insisted that "we have a common responsibility." "There is certainly no adversarial relationship, either between the Central Board and District 27 or 29, or any other. I don't believe that there is any . . . question as to our respective and our common responsibility in providing a safe and appropriate educational process for our students, and we are going to have to live together. . . ."

Despite the efforts to establish a consensus, the central city school administration viewed the problem in a very different decision-making context than did the community. Chancellor Quinones and Dr. Sencer both saw the need of a uniform approach to AIDS, carefully orchestrated and centrally controlled. In his summation the city attorney argued that the state legislature had recognized the need for city-wide decision-making about handicapped children and special education. "The legislative judgment to keep these somewhat emotional, potentially enormously divisive issues—of what to do with someone who is different . . .—to keep those out of the local authorities' hands is, I believe, a wise policy." Attorney Sullivan, in contrast, argued for local control: "In New York City we are bypassing the individual districts because we don't trust them to keep confidences, and in effect big government is taking over and doing the jobs that are normally left to the individual districts." This argument, however, begged an important issue, namely the need of coordinated national policy in a public health emergency.

During the hearings the judge also criticized the "bureaucratic incompetence" of the city—for failing to give public notice of a Board of Education session in which AIDS was discussed, for waiting until just before the school year to make a decision, and for failing to come up with a comprehensive plan. The judge questioned Chancellor Quinones: "Had the bureaucracy really done everything possible to protect the city's children? No one can expect you to do everything, but it is expected that you have competent help."

But the school board argued that more than incompetence was at work. In his summation Attorney Sullivan said that at first the school board had believed that the officials in the city health department were "nice people who just couldn't run anything." But, he charged,

toward the end of the trial they were forced to conclude that "it wasn't incompetence." "We discovered . . . on almost the last day of the trial, that we were dealing with people in power with such a high opinion of themselves that one man [Dr. Sencer] made this decision a long time ago." Attorney Sullivan accused city officials of lying to the community. Chancellor Quinones "didn't tell us that he led us down the garden path." David Sencer made the decision and "they waited until 36 hours before school opened to force that decision down everybody's throat. . . ."

The city maintained that such accusations were wrong. Attorney Schwarz defended the city's process and officials. "We . . . have not been stubborn or bureaucratic or arrogant. I think we have been flexible, and to the extent possible . . . without violating a principle, we have . . . accommodated points of the other side." For example, the city agreed to provide gloves for cleaning blood spills to teachers who wanted them. Similarly, "we have taken the more conservative view and said why not have . . . alcohol swabs available." Moreover, the city took the "extraordinary step" of asking two school board expert witnesses "to serve on a special advisory panel which would give us any new ideas that are useful."

The school board found such arguments unconvincing. As accusations of callousness, carelessness, and cavalier attitudes appeared and reappeared, the hearing revealed the deep mistrust of city authorities pervading the dispute. A witness for the city, Louis Cooper, M.D., director of pediatrics at St. Lukes-Roosevelt Hospital and a professor at Columbia College of Physicians and Surgeons, succinctly summarized the result of the bureaucracy's efforts to develop a reasonable decision-making procedure: "If one of the expected outcomes of any public process is public trust and comfort and security about outcome, then, in hindsight, that process didn't achieve that goal."

The Balance of Rights

Public agencies have the responsibility to balance the rights of individuals against the needs of public health. In the Queens case the rights of several parties were at stake: the sick child, the other children in the class, the teachers, the parents, and the larger community of AIDS

patients. Often these rights conflict. Excluding a child from public school or any individual from normal social activities infringes on his or her rights; but conversely, at least in clear-cut cases of contagion, allowing somebody with an infectious disease into a school can violate the rights of others. How these rights should be balanced became the subject of heated debate as conflicting concepts of justice, concerns about discrimination, and conclusions about the risk fueled a dispute over whose rights should prevail (see Hastings Center 1985).

The Queens community defined the stakes in parochial terms as a tradeoff between educating one child at home and protecting the other students in the class. Even if the risks were minimal, isolating one child seemed like a reasonable precaution. The need to protect children outweighed any question of discrimination. As Attorney Sullivan put it, "One year of home education isn't such a bad thing."

For the city the case had broader policy implications. If the child were excluded from school this would legitimate public fear. Widespread panic could lead to discriminatory practices, interfere with scientific research, and confound efforts to control the spread of the disease. Thus, in addition to safety, the city worried about what message the decision would convey to the public about the risk of AIDS.

The community's perspective on rights emerged mainly in debates about confidentiality. According to the school board, it was necessary to inform the teacher about the child, for the teacher alone has the day-to-day contact to monitor the situation and to take necessary precautions. It was also argued that teachers have the right to be informed of the identity of the child so they can take precautions to protect themselves. "Don't you think that the teacher deserves the same protection in dealing with AIDS patients that health care workers deserve?" asked Attorney Sullivan. Finally, the school board lawyer claimed that parents also have the right to be informed. After all, they might choose to send their child to another school where there are no AIDS patients. What if a student gets bitten by a child with AIDS? "Don't I as a parent have the right to be informed that my child got bitten?"

The city, in contrast, insisted on the right of the child to confidentiality, the right, that is, not to be branded as a pariah. Convinced of the minimal risks, the city's witnesses believed that the social costs of disclosing the identity of the AIDS patient—the possibilities of stigmatization, the effects of isolation—outweighed other considerations.

Chancellor Quinones pointed out that if confidentiality were violated, "Life for the child within the school, within the community setting, would be virtually impossible for that child and for all members of that child's family." Dr. Sencer concurred: The AIDS patient's right to privacy had to be primary because in the present climate of public opinion, disclosure would lead to ostracism. In light of what is known about risk, Dr. Sencer insisted that the precautions normally in place to maintain a sanitary schoolroom were quite adequate, so that there is no reason to collect and reveal potentially harmful information if it is unnecessary or cannot be effectively used. Finally, disclosing the identity of this child was logical only if other children were given the antibody test, for it is likely that others are carrying the virus as well.

According to Dr. Sencer, the right to confidentiality is essential if scientists are to gather the information necessary to develop appropriate public health measures. Breaching confidentiality would discourage people from being treated and thereby hinder research on the epidemiology of the disease. Dr. Margaret Hilgartner, a pediatric hematologist, testified that some of the hemophiliacs she treats had refused to take the HTLV-III antibody test, which indicates exposure to the virus. They were worried that a positive test result would turn them into social outcasts. Discrimination, she argued, is "going to have a great effect on what we learn about the natural history of the disease. . . . If more of our patients are ostracized, more of them will say to me, 'I don't want to know and I will not enter into your research.' "

Finally, city officials argued that the question of rights must be considered in the context of the citizen's entitlement to education. Children are entitled by law to attend school unless there is clear evidence that attendance is potentially harmful, as in the case of a disease that is highly contagious in the course of normal activity. Given this entitlement, the burden of proof must lie with those who would keep the child out of school. Unfounded fear is not sufficient; there must be clear and convincing evidence of risk before the rights of a child can be violated.

Attorney Sullivan, however, turned the concept of entitlement around to focus on the mandatory nature of education, and he thereby shifted the burden of proof. Because education is required by law, students must be protected or else be provided the information about risks that would allow them to make a choice about which school to attend.

Attorney Sullivan argued that the risk of AIDS is everywhere—in subways, at work, at the movies, at restaurants—but these are all voluntary activities. "I have the right to choose whether or not I want to get on the subway, to go to a movie or to a restaurant . . . but we mandate that our children go to school five days a week. We force them to school. They have no choice." The burden of proof, he concluded, must lie with those who place children at risk by sending an AIDS child to school.

The Symbolic Politics of AIDS

The summations for the Queens hearings concentrated mainly on two points. The city's counsel, Frederick Schwarz, argued the rule of law: Given the existing statutes, the city's policy must be upheld. Attorney Sullivan attacked the rule-of-law argument by defining the situation as novel, and focused his summation on the city's inept process of decision-making.

The judge's decision, announced on February 11, 1986, incorporated both of these arguments. On the basis of existing law he upheld the city's policy of determining on a case-by-case basis whether AIDS-infected children should attend school. But the judge also reprimanded the city for inept decision-making procedures. His support of the city's decision, counter to the inclinations he had expressed so strongly during the trial, reflected several factors. He noted in the decision that a second medical panel, convened by Dr. Sencer, had reported that the child was infected with the HTLV-III virus and showed evidence of immune suppression, but in fact did not meet the CDC definition of having AIDS. Thus, he or she was probably no more contagious than other children who were seropositive but had not come to the attention of the school authorities. In addition, the medical and epidemiological data about the transmission of AIDS were increasing and seemed to support the city's case.

His ruling, however, mainly rested on the legal obligations of the city authorities vis-à-vis the provisions of the New York City Public Health Code and the state education law concerning automatic exclusion from school. These, he found, concerned "communicable diseases." "At best the regulations of the city treat AIDS as reportable but not communicable . . . since AIDS is nowhere defined or classified as a

communicable disease, the health regulations . . . relied upon by the petitioners are all inapplicable." In this legal context, the city's policy could not be overturned. Further, on the basis of legal precedent, the judge supported the policy of confidentiality of medical records.

In defending his decision, the judge differentiated between "the court of public opinion" and "the law." "Although the court certainly empathizes with the fears and concerns of parents, . . . it is duty bound to objectively evaluate the issue of automatic exclusion according to the evidence gathered and not be influenced by unsubstantiated fears of catastrophe."

The judge did, however, forcefully reprimand the chancellor and the city Board of Education for making decisions in executive session, for failing to seek broader community input, and for leaving too much discretion in the hands of the commissioner of health. While their behavior did not legally violate statutory authority, it "bespeaks the hostile attitude historically displayed toward community participation." The judge observed that city officials operated with "a notion that they knew what was best and would make all the decisions for everyone's good. Believing this, they acted in imperious fashion . . . behind a cloak of secrecy." While their decision-making procedures did not violate the law, they "missed the spirit of the law"; that is, they forgot that officials must govern "with the consent of the people." Thus, he claimed, instead of inspiring confidence and trust they created frustration and hostility: "It is these public officials themselves who predictably, although unwittingly, let loose the forces of anxiety and fear." He recommended that all future policy be developed more openly.

While the city's procedures may have reinforced anxiety and fear, the community attitudes expressed in this case were quite consistent with the general climate of fear about AIDS. A Harris poll in September 1985, for example, found that 53 percent of the American people believed that AIDS is highly infectious and can be spread through such exposure as sitting in a classroom with an AIDS patient. In a CBS News poll 47 percent believed it could be contracted via a drinking glass; 28 percent believed they could catch it from a toilet seat. A TV station in Memphis, Tennessee, polled its listeners about whether they would send their child to school with an AIDS child; 493 said yes, 741 said no. And in New York City a *Daily News* poll

in October 1985 reported that four out of ten New York City residents thought that people with AIDS should be quarantined.

Given the strong scientific evidence that AIDS cannot be transmitted through casual contact, it is tempting to dismiss widespread public fear of this risk as "irrational." We believe, however, that this temptation should be resisted. While such pejorative terms may have political uses, they contribute little to an understanding of the reasons for public concern. Indeed, if such labels are mistaken for explanations, they can further confound the development of reasonable policies.

The literature on risk perception and experience with other risk disputes help to illuminate the processes that have generated public fear of AIDS. Psychological research on risk perception has shown that people tend to be most fearful in situations where the consequences can be devastating, uncontrollable, involuntary, and irreversible—even if the chances of an incident are very small. Risks which are unfamiliar and unknown are also especially frightening; thus, public concern often focuses on risks that are new, technically uncertain, or have delayed effects (Fischoff, Lichtenstein, and Slovic 1981). That AIDS is this kind of risk has been emphasized in the news coverage of the disease (Schwartz 1984; Check 1985). The press has conveyed images of imminent doom about "the lethal scourge," compared AIDS to highly infectious diseases such as hepatitis, typhoid, and the plague and, above all, has emphasized the technical uncertainties about transmission of this "mysterious disease." "Not enough is known to draw conclusions." It is "clouded with uncertainties." "We have no idea when or how it is going to end."

The risk literature further shows how the perceptions of risk are influenced by a range of cultural, political, and institutional factors (e.g., Douglas and Wildavsky 1982; Douglas 1986; Nelkin 1985; Short 1984). Fear is selective, shaped by moral and social biases which may become more important than the characteristics of the risk itself. The Queens hearings revealed ways that beliefs about AIDS are embedded in social definitions and political perceptions.

Moral judgments about sexual behavior and drug use were less explicit in this context than in AIDS disputes involving adults, but they still contributed to the stigma of the disease. The victim was neither a homosexual nor a heroin addict, but a child; that is, an "innocent victim" probably infected by blood transfusions. Yet, the

notion of AIDS as a demeaning disease—a disease associated with social deviance and immoral conduct—still emerged in the hearings. Judge Hyman, for example, raised the following hypothetical scenario while questioning Dr. Stoneburner, director of the city's AIDS program: "[Let's say] you've got a homosexual, he is reported to you, he's on his last leg. Don't you have the right for the safety of the general public to keep that man off the street, even though he may not be contagious merely by speaking to him or looking at him. But he is shown as a homosexual to go out into that same field to commit the same homosexual act? He can infect 150 more people within 150 days. . . . Now you've got his name, you've got his address, and yet the Department does nothing about picking this person up and seeing to it that he's either quarantined or something."

In such statements, AIDS operates as "a symbol for physical and moral contamination," evoking images of impurity, sin, guilt, and punishment (Tancredi and Volkow 1986). The stigma of the disease is enhanced by its association with body fluids. The preoccupation with body fluids at the Queens hearings, expressed in endless "what if" scenarios, is in part attributable to medical logic, since the virus had been found in some body fluids. But we are convinced that a cultural logic is also at work. Blood, semen, saliva, vomit, urine, and stools are seen as fundamentally contaminating; they are symbols of impurity and pollution, of danger and defilement (Douglas 1966). Unclean body fluids, taboo sexual conduct, forbidden drugs, deviant individuals, and deadly disease become mutually reinforcing metaphors of physical, moral, and social danger. These threats demand strong action: cleanse the schools of impurities. Isolate the diseased.

There is by now ample evidence—from the Queens case and from many other risk disputes—that symbolic and political issues have an important bearing on the acceptability of risk. Nevertheless, many scientists and public officials still assume that providing the public with scientific evidence will lead to widespread acceptance of controversial policies. In this tradition, the city of New York assembled a panel of experts, made a decision on the basis of scientific judgments, and announced it as a fait accompli. Though the decision was soundly grounded in current medical and epidemiological evidence, the city's decision-making process convinced the community that their concerns were not taken seriously. The conflict became the subject of a moral

crusade, amplifying the political tensions between the community and public officials and propelling the issue into the courts.

In this contentious climate the Department of Health experienced a collapse of credibility. Focusing on questions of responsibility and accountability, the local school board attacked the knowledge, the experts, the process, and the values that led to the city's decision. The two sides developed markedly different interpretations of the scientific evidence, the level of scientific uncertainty, and the appropriate policy response. And they differed on such basic questions as: What are the facts? Who should be believed? Whose rights and interests should prevail? Who should decide?

Technical evidence alone cannot answer such questions. The Queens case suggests the importance of the process through which decisions are made and communicated. As new conflicts arise, a key challenge will be to find ways to consider the constellation of attitudes, interests, values, and concerns that enter perceptions of risk. Feelings of trust or mistrust toward political authority and scientific expertise; folk wisdom about disease and contagion; cultural conceptions about children, parents, and families; concerns about civil liberties and discrimination; taboos about body fluids, sexual conduct, and cleanliness; notions of justice, fairness, equity, and rationality; and attitudes toward homosexuals, drug users, and marginal groups—all these provide the raw materials from which people fashion their response to AIDS.

APPENDIX: THE WITNESSES

For the School Board (Petitioners)

Dr. José Giron, Chief of Infectious Diseases, Flushing Hospital and Medical Center

Samuel Granirer, President of Community School Board 27

Dr. Lionel Resnick, Department of Dermatology, Mount Sinai Medical Center, Miami Beach, Florida (formerly National Institutes of Health)

Dr. Ronald Rosenblatt, former Medical Inspector for the Board of Education

Dr. Arye Rubenstein, Pediatrician and Immunologist, Professor of Pediatrics, Albert Einstein Medical College

For the City Department of Health (Respondents)

Dr. Donald Armstrong, Director of Infectious Diseases, Memorial Sloan-Kettering Medical Center
Dr. Louis Cooper, Chief of Pediatrics, St. Luke's-Roosevelt Hospital Center
Dr. Richard Goldstein, State Commissioner of Health, New Jersey
Dr. Margaret Hilgartner, Pediatric Hematologist and Oncologist, Director of Hemophiliac Clinic, New York Hospital, Cornell Medical Center
Nathan Quinones, Chancellor of the New York City Board of Education
Dr. David Sencer, Commissioner of Health, New York City
Dr. Edward Sperling, Child Psychiatrist, Bronx Municipal Hospital Center and Albert Einstein School of Medicine
Dr. Rand Stoneburner, Director of the Health Department's AIDS Epidemiological Surveillance Unit
Dr. Pauline Thomas, Pediatrician, City Department of Health

The Major Attorneys

David Ellenhorn, for the child
Frederick A.O. Schwarz, for the respondents
Robert Sullivan, for the petitioners

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Address correspondence to: Professor Dorothy Nelkin, Program on Science, Technology and Society, Cornell University, 632 Clark Hall, Ithaca, NY 14853-2501.