

parents from one enrichment activity to another: two sports, two musical instruments, Scouts, Odyssey of the Mind, after-school language programs, science discovery programs, theater workshops. Parents who have a different vision of what childhood might be are reluctant to pursue it, for fear that their children will be left too far behind. One parenting magazine recently published an article about a family that actually chose not to participate in any after-school activities, where this was considered sufficiently unusual to merit a feature article in a national magazine.

The irony in all this is that Ritalin is prescribed for attention deficit disorder. Yet as we struggle to enhance our children faster than our neighbors manage to enhance theirs, we fill our lives with an even greater level of distractions. Diller speculates that if Huck Finn and Tom Sawyer walked out of Twain's pages and into a suburban American school today, they might well find themselves on Ritalin. He worries about our inability to tolerate and appreciate a range of temperaments and personality styles. I worry about this, too, but more about whether we are losing the ability to let children be children—or at least to let them be average

children, not gifted, very gifted, or extremely gifted, savoring childhood as it slips by all too quickly.

If we want our kids to pay attention, maybe we have to begin paying attention to what it is that's worth paying attention to.

—Claudia Mills

Claudia Mills is assistant professor of philosophy at the University of Colorado at Boulder, the founding editor of the *Report from the Institute for Philosophy and Public Policy*, and the author of many children's books. Sources: Lawrence H. Diller, *Running on Ritalin: A Physician Reflects on Children, Society, and Performance in a Pill* (Bantam Books, 1998), and "The Run on Ritalin: Attention Deficit Disorder and Stimulant Treatment in the 1990s," *Hastings Center Report*, vol. 26, no. 2 (1996); Erik Parens, "Is Better Always Good? The Enhancement Project," *Hastings Center Report*, vol. 28, no. 1 (1998) (Parens quotes Dan Brock and David B. Allen and Norman Fost); Peter J. Whitehouse, Eric Juengst, Maxwell Mehlman, and Thomas H. Murray, "Enhancing Cognition in the Intellectually Intact," *Hastings Center Report*, vol. 27, no. 3 (1997) (this article cites Gerald Klerman on "pharmacological calvinism").

Public Deliberation and Scientific Expertise

The relationship between experts and the public seems to have changed in the past few decades, especially in the area of science. It is not easy, however, to generalize about the nature and direction of this change. On the one hand, as scientific knowledge becomes increasingly sophisticated and specialized, the public's reliance on experts appears to grow, since most individuals are unable to assess scientific claims for themselves. On the other hand, there are many contexts in which the public seems *less* inclined than formerly to defer to expert judgments.

This essay is concerned primarily with the role of expertise in public deliberation about health and biomedical research issues—and, conversely, with the public's role in deliberations that at one time might have been restricted to experts alone. At the same time, I am interested in the character of various voluntary associations that mediate between experts and the public. A great many associations of this kind have been formed in this century—from professional orga-

nizations, such as the American Association for the Advancement of Science, to health charities, such as the American Lung Association or the March of Dimes, to various self-help and activist groups that have only emerged within the last ten or twenty years. In any effort to understand the relation between experts and the public, it is important to examine the social function of these associations and their attitudes towards expertise.

I will begin, however, by speaking more generally about how the contribution of experts to public deliberation about medical or scientific issues has typically been understood.

Outsiders and Insiders

In the literature on expertise and deliberation, two conceptions of the experts' role are dominant. The first conception describes experts acting in what we might call a "technocratic" or "outsider" mode. Here, science

(expertise) is not really part of the public sphere—the space within which public deliberation can take place—but helps to determine its boundaries. For example, whether tuberculosis is a hereditary disease is not an issue for public deliberation. The experts pronounce on the matter, and thus place it outside the public sphere. A failure to accept the authority of expertise presumably reflects ignorance, confusion, or irrationality.

The technocratic mode easily allies itself with the supposedly sharp and simple contrast between “hard” facts and “soft” values. On this view, public deliberation over values—including how and when to bring them into play—is entirely appropriate. Public deliberation over facts is not only absurd but invites disaster. To be sure, there can be disagreements over whether the core issue in a policy debate is factual or normative. But there is no disagreement, according to the technocratic mode, over the scope of the experts’ authority. It is up to them to determine the facts; the public deliberation and any resulting decisions should be framed entirely within that determination.

The second conception of the experts’ role describes what could be called an “adversarial” or “insider” mode. On this view, the function of expertise is not to set the limits of the possible for public deliberation, but rather to furnish support for the positions of various parties engaged in that deliberation. Different groups acknowledge the cachet of scientific expertise and seek to appropriate it, or at least to counter the efforts of their opponents to invoke expertise in defense of *their*

*According to the technocratic conception,
a failure to accept the authority of
expertise reflects ignorance,
confusion, or irrationality.*

positions. Is there a greenhouse effect, and are we threatened by global warming? Is AIDS caused by HIV, or is it the result of drug overload? To participate effectively in the public debate, one must have experts on one’s side. And so, while the technocratic mode locates experts outside the realm of public deliberation, in the adversarial mode they take part *in* the debate—they are the “hired guns.”

This conception is plainly reminiscent of the role of expert witnesses in our adversarial legal system, where each side presents its own experts to refute the other side’s experts. In the formal procedure of a trial, however, there is, in the end, a judge or jury who is charged with making a determination as to which experts are credible. In the less structured arena of public deliberation, no such clear determination is made. Credibility can turn on the number of experts on a particular side, their prominence, or their alleged motives.

This conception needn’t reject the sharp contrast of facts and values, nor need it rest on a mistrust of science. It simply begins with the recognition that science is not a strictly cumulative enterprise. Scientific claims, laws, and theories have always been open to revision in the light of new observations, new experiments, and new theories, and we have every reason to expect this process to continue. Moreover, the practice of science often requires making judgment calls. Is a particular hypothesis worth testing, or has it been sufficiently tested already? Are the data points that don’t quite fit the curve a matter of insignificant random errors (noise) in the experimental setup, or do they indicate

*The character of scientific consensus
can change as new discoveries or
developments in theory arise.*

serious shortcomings in the underlying theory? Finally, the adversarial conception recognizes that science is an institution within society. Its members are subject to many of the same pressures and temptations as other people occupying other roles, and as a result their judgments may be biased or otherwise distorted. The presence of opposing experts goes some way toward diminishing the effects of bias.

Each of these conceptions has its place. In general, the technocratic conception presupposes a consensus among the experts on the relevant scientific issues. When there is none, the adversarial mode may be more appropriate. One ought not to apply the adversarial mode to the claim that the Earth rotates around the sun, nor the technocratic mode to the claim that the planet is suffering from a greenhouse effect. Since the character of scientific consensus can change as new discoveries or developments in theory arise, there is a dynamic between the technocratic and adversarial modes, so that over time, one mode might give way to the other as the appropriate one to govern deliberation.

It may well seem that once the experts have reached a consensus, the technocratic mode is the only rational option. There is, however, another possibility (and thus a third conception of expertise and deliberation)—experts and knowledgeable non-experts can engage each other in meaningful discussion regarding the scientific issues.

It must be remembered here that the term “expert” is a rough social classification, reflecting more a pedigree than the possession of any particular body of knowledge. Someone isn’t a scientist because of what she knows or believes, but because she possesses certain public credentials. (That is perhaps as it should be: expertise cannot require expertise for its identification;

otherwise the public would be unable to tell who is an expert.) This understanding leaves open the possibility that some people will know as much as or more than the experts do about a topic, even though these people are not "experts" themselves.

Such people—knowledgeable non-experts—would not be part of the deliberation that routinely goes on in the practice of science; they would not be accorded any voice. And once the deliberation characteristic of science has reached a consensus, it might seem, again, that non-experts are left with no reasonable option but to accept the results; the expert consensus would seem to be rationally uncontestable. Nevertheless, on this alternative to the technocratic mode—which we might call the "participatory" mode—when the issue is of public concern, experts and non-experts can

*Some people will know as much as
or more than the experts do about a topic,
even though these people are not
"experts" themselves.*

engage each other. The experts' claims may then be brought into the public sphere and contested. Once this occurs, the resolution of a scientific issue may no longer be determined by the experts alone; the experts may have something to learn from non-experts. Indeed, such deliberation may transform (the practice of) expertise, and thus the understanding of what constitutes good science.

Recent developments in some voluntary associations suggest that experts and non-experts may be more likely than before to adopt the participatory mode. Let me therefore shift from my initial level of abstraction to actual examples—one from the realm of voluntary health agencies, and one from the realm of support groups.

Fighting Tuberculosis

The American Lung Association, which today is concerned with all manner of respiratory disease, was originally devoted entirely to the problem of tuberculosis. Founded in 1904 as the National Association for the Study and Prevention of Tuberculosis, it is the oldest as well as one of the largest voluntary health agencies.

At the turn of the century, tuberculosis was a leading cause of death in the United States. As many as 10 to 15 percent of all deaths were attributable to tuberculosis, far exceeding deaths attributable to heart disease or cancer. Moreover, there was a social stigma attached to tuberculosis; victims were frequently poor, urban dwellers—often immigrants—living in grim circum-

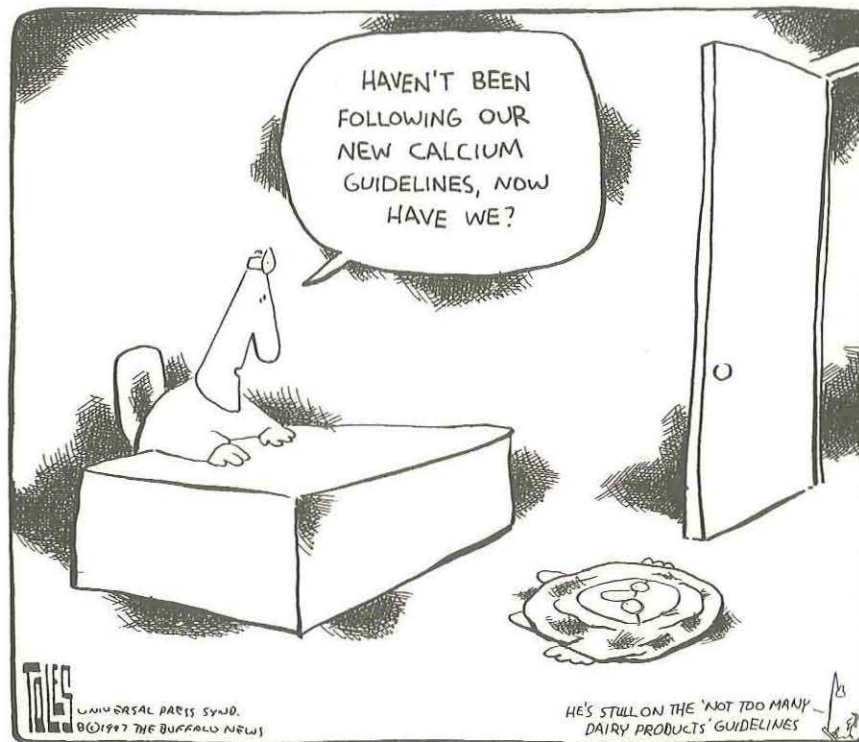
stances. No one knew how the disease arose or how to treat it. Public health actions, such as the sanitation movement, which were so effective against infectious diseases like cholera, had no apparent impact on tuberculosis. Special "lung hospitals" were established, but these served more to isolate victims than to offer any effective treatment. Sanatoriums appeared, catering mostly to the afflicted in the middle and upper classes, but these were based on a cumulative lore regarding the general benefits of marine or mountain air, exercise, and rest—nothing specific to tuberculosis.

As scientists came to learn about effective ways to prevent and treat the disease, they were faced with the challenge of translating that information into action. The National Association for the Study and Prevention of Tuberculosis was the creation of some of the leading physicians of the time. Its mission was to shape the public agenda regarding tuberculosis by educating the public and advising the government and other institutions on how to respond to the disease. No such voluntary effort against a specific disease had ever been undertaken before.

The organizers quickly realized that to make the Association effective, they would have to expand its membership to non-scientists, and so its rolls were soon opened to "lay people." To be sure, "lay people" didn't mean everyone; rather, it referred to professionals who were not physicians—i.e., health officers and social workers. Still, the recruitment of non-scientists had an immense influence on the anti-tuberculosis movement. As historian Richard Shyrock has noted,

Social reforms, led entirely by laymen, had acquired an evangelical quality during the 1800's; while in contrast those led by scientists, such as the sanitary campaign, had usually remained coldly objective. The tuberculosis movement combined these two qualities to mutual advantage. Because of medical direction, the tuberculosis societies rarely viewed their objective as a moral issue or indulged in the emotional enthusiasm which this might have involved. At the same time, thousands of laymen came to support the movement with increasing fervor. They provided aid which scientists could not have given, yet such aid was tempered at all times by scientific guidance. This blend of qualities was something new under the social sun.

It should be clear from its structure and membership that the Association was deferential to the expertise of the medical establishment. Informing the public about controversies regarding the etiology or treatment of tuberculosis was not deemed part of the Association's educational mission. George Palmer, president of the Illinois State Association for the Prevention of Tuberculosis, stated in 1915: "We will have to adopt [sic] our creed and doctrines and present them to the laity as though they were unanimously adopted and almost spontaneously created. Our controversies of orthodoxy and faith should be reserved for the inner chambers of our scientific and professional conferences."



8/10/97

TOLES © 1997 The Buffalo News. Reprinted with permission of Universal Press Syndicate. All rights reserved.

These sorts of misrepresentations are unlikely to be endorsed now. Nevertheless, for the most part this deference to medical expertise has continued in the Association's modern incarnation, as well as in other major health charities. This should not be at all surprising. Many health professionals serve as volunteers and sit on the boards of such associations, which consider themselves partners with clinicians and researchers. Challenging medical expertise or voicing skepticism would be seen as irresponsible.

The AIDS Movement

One of the striking developments in the area of voluntary associations in recent years has been the growth of support groups for people with a particular disease, behavioral problem, or emotional condition. There appears to be at least one group for every known disease. These groups vary in size, from small groups that meet occasionally in someone's kitchen, to large organizations that have a national presence. Their structures and agendas can be formal and specific, or they can proceed in a much more haphazard fashion. Some groups are chiefly therapeutic in nature: people hope that by participating in the group's activities, they can resolve their problem (or cope more effectively with its

consequences). Others are chiefly concerned with mediating between patients and the community, the government, and the health professions by serving as a clearinghouse for information and a coordinator of action. But since these two functions can be combined in various ways, it is best to think of the two types as marking off the ends of a spectrum.

Mediating support groups have been especially prominent with respect to the AIDS epidemic. Almost from the time the disease was first noticed—when it was still being characterized as a "gay disease"—support groups were formed to provide information and to alert certain populations of risk. These groups did not simply pass on the latest expert findings. From the start, they reported on, and took sides in, controversies among the experts over the nature of the disease and the identifiable risk factors. Later, as the etiology of AIDS became better understood and a rough consensus regarding the causal importance of HIV was formed, attention turned to treatment and the testing of various drugs. While developments were duly reported in the various medical journals as well as the CDC's *Morbidity and Mortality Weekly Report*, alternative support-group and community publications, such as *Gay Men's Health Crisis' Treatment Issues* and *AIDS Treatment News*, began to

appear as well. These newsletters drew upon a broad range of treatment reports, anecdotes, and unofficial testings. According to some commentators, many clinicians and researchers consulted these newsletters to obtain information they could not find in the standard medical journals.

The new, perhaps trendsetting, feature of several AIDS support groups was their decision to challenge expert judgments about the conduct and interpretation of research. The debate over the demand for "clean data" in clinical trials provides a good example.

Because researchers seldom know what kind of interaction or interference may occur if a subject is taking other medication along with the investigational drug, they typically require that subjects in a clinical trial take no other medications. The problem with this demand, with respect to AIDS clinical trials, was that many HIV-infected people could not meet it. They were seeking out and trying all sorts of drugs in an effort to combat the disease. Under the circumstances, they believed that they had nothing to lose. Since many also wanted to participate in clinical trials—the typical motive being to have access to the latest experimental drugs—some potential research subjects would lie about their medication history, while others would forgo even taking aspirin in order to qualify as research subjects.

Several AIDS activists challenged the demand for clean data. They argued that by imposing this requirement on research subjects, scientists ran the risk of producing results that would not be clearly applicable to real-world conditions. In other words, "clean data" would be of doubtful clinical use. Many researchers responded by pointing to the uncertain applicability of data that *aren't* clean. Since the data would be unclean in different ways, reflecting different possible drug interactions, how could any generalizable results be obtained?

It might seem that questions about experimental design ought to be debated strictly among experts themselves. In this case, however, experimental design became a public issue, in which certain support groups of non-experts engaged the experts. This larger debate took place on newspaper op-ed pages, in letters to the editor in professional journals, in comments at professional meetings, and in discussions by institutional review boards. Eventually, the experts conceded the point, including one who wrote an article in the *New England Journal of Medicine* entitled, "You Can Teach an Old Dog New Tricks: How AIDS Trials Are Pioneering New Strategies." The scientific consensus (the "biomedical norms governing the acquisition of knowledge through AIDS clinical trials") shifted as a result of public deliberation.

Failed Deliberation and the Zero Mode

We should note that the participatory mode will not always come into play as it did in the debate over clinical trials. Consider the public controversy over certain cancer therapies.

Several associations, including the International Association of Cancer Victims and Friends, which publishes the *Cancer News Journal*, and the Cancer Control Society, which publishes *Cancer Control Journal*, believe, contrary to the expert consensus, that cancer is not a tumor disease but rather a metabolic disease in which the tumor is merely an obvious symptom. Cancer treatment should not consist in destroying tumors so much as changing diet and administering various enzymes, most notably the apricot-pit extract known as laetrile. Other associations, such as the American Cancer Society and the AMA, have denounced these groups as promoting quackery.

Despite the expert consensus against laetrile, various experts who were part of this consensus tried to initiate deliberation with the proponents of laetrile by performing animal experiments, clinical trials, and retrospective case reviews, even though the initial negative data on laetrile would not normally have led to further investigation. For the most part, these efforts had little impact on the dissident groups. In some cases, instead of seeking deliberation about the expert consensus, these groups adopted the adversarial mode, identifying experts who were sympathetic to their cause. In other cases, however, what we might call the "zero mode" prevailed.

In the zero mode, experts are deemed to have no status whatsoever, on the grounds that the issue is not one about which there can be expertise. In the case of cancer therapies, some of the associations promoting laetrile seem animated chiefly by the principle that

The scientific consensus regarding the design of clinical trials shifted as a result of public deliberation.

people should have the freedom to choose their therapy, regardless of expert opinion, and not by scientific questions, such as whether the standard tests are adequate in assessing the efficacy of laetrile. For some, interest in laetrile is part of a broader interest in holistic medicine, natural therapies, and alternative medicine—an interest that is often based more on New Age and other forms of modern spiritualism than on specific scientific issues. Invoking any of the other conceptions of the experts' role—technocratic, adversarial, or participatory—in debating therapies misses the point.

**Ethics of Consumption:
The Good Life, Justice, and Global
Stewardship**

**David A. Crocker and Toby Linden,
editors**

Scholars in diverse fields now agree on the importance of investigating the impact of consumption practices on the global environment, quality of life, and international justice. In this comprehensive collection of essays, respected scholars from many disciplines—philosophy, economics, sociology, political science, demography, theology, history, and social psychology—examine the causes, nature, and consequences of present-day consumption patterns in the United States and throughout the world. Individual essays evaluate the impact of consumption practices on our own lives, our institutions, other people, and the environment. They also give explicit attention to the principles relevant to a consumption ethic, as well as to the policies and practices that such an ethic permits or requires.

"This excellent collection explores the theoretical and practical dimensions of consumption as an ethical and environmental issue. The contributors are a good mixture of philosophers, social scientists, and activists. This volume offers analysis and thought rather than slogans, and illustrates how 'practical ethics' ought to be done."

—James W. Nickel, University of Colorado

"Conscientious consumption is good for the consumer, fair to other people, and environmentally sustainable. It is benign in its impact on people and on the environment, and equitable. David Crocker and the eminent authors he has gathered in this provocative book examine the ethics of consumption in a novel and passionately dispassionate way. It is the best book on an important but neglected topic."

—Paul Streeten, Chairman of the Editorial Board,
World Development

564 pages
\$80.00 (cloth)
\$25.95 (paper)

Rowman and Littlefield Publishers, Inc.
4720 Boston Way
Lanham, Maryland 20706
1-800-462-6420
Credit cards accepted

I do not wish to suggest that the zero mode is necessarily anti-science or is invoked only by small minorities or groups considerably out of the mainstream. Especially if we look at expertise in areas other than biology and medicine, there are several public controversies in which analysis by experts might seem useful or appropriate but in which the zero mode reflects the prevailing sentiment. While some people claim scientific expertise on such issues as drug legalization, crime prevention and punishment, and race relations—e.g., in economics, criminology, or sociology—for the most part such experts play little if any role in these debates. The prevailing judgment is that the (important) issues in these debates are not a matter of expertise.

A Trend?

In assessing the nature of contemporary voluntary associations that do attempt to mediate between experts and the public, it would be rash to generalize solely from the contrasts between the tuberculosis movement at the turn of the century and the AIDS movement of the past two decades. In order to make a strong claim—e.g., that changes in the character of voluntary associations formed around specific diseases have altered the relationship between experts and non-experts—we would plainly need first to establish some generalities about the variety of associations that identify themselves as voluntary health agencies or support groups. Until further research is done, suggestive cases are the best we have.

It might also be objected that the AIDS epidemic—and thus the organizations created in response to it—is too exceptional to indicate possible trends in health-related associations. In the first place, AIDS support groups are tied in various ways to the broader political concerns of many gays and lesbians, whose early activities and consciousness-raising efforts predate the AIDS epidemic. Members of these groups have long been skeptical of society's responsiveness to their protests regarding stigma and discrimination. Consequently, as AIDS was at least initially perceived to be a disease that affected only gays, many AIDS support groups were not inclined to trust the medical establishment's findings or efforts. The women's health movement, which also predates the AIDS epidemic, had already set the stage for questioning medical authority. Furthermore, the gay community affected by AIDS was, to a considerable extent, an affluent, well-educated part of the population. This combination of features helps explain why many AIDS groups would not wait upon expert findings but instead were inclined and able to deliberate with the experts on the subject matter of their expertise.

Nevertheless, these special features do not mean that some of the strategies of the AIDS movement will not be replicated by other groups. Indeed, to some extent the AIDS movement has come to be seen as a model for other disease organizations. For example, several commentators have noted the rise of breast cancer support groups whose success in getting research and treatment issues on the public agenda owes a good deal to techniques borrowed from the AIDS movement. Although most of the media attention has been focused on their successful efforts at fund-raising and lobbying, the breast cancer groups have also engaged the experts on such issues as the advisability of mammograms for women in their 40s.

Assuming that there is a trend in favor of the participatory mode in addressing scientific and medical controversies that become public issues, is this a change

*If the experts deserve their name,
only in rare cases will the
expert consensus need to be
challenged or corrected.*

for the better? In one sense, it surely is. The public's choices are not limited to the technocratic, the adversarial, or the zero mode; non-experts are not required to be deferential, skeptical, or dismissive with regard to expertise. Even when faced with an expert consensus, members of the public needn't believe they must always either defer to the experts or question the legitimacy of expertise in the matter altogether. Adoption of the participatory mode can lead to alteration of an existing consensus or help clarify to a broader audience the compelling reasons for that consensus.

Sometimes, however, the participatory mode is not an option. If there are no knowledgeable non-experts, there can be no participatory mode governing public deliberation; if there is no expert consensus for the knowledgeable non-experts to challenge, then the participatory mode, as I have described it, cannot be invoked. Moreover, while the knowledgeable non-expert's challenge may begin by alleging that the experts' entrenched perspective blinds them to certain considerations, it cannot rest there. The challenge must ultimately rest on arguments that the experts can

acknowledge and assess and then reply to or accept. If the non-expert has no such arguments, or if the experts' replies are not seriously offered or seriously considered, there is no deliberation and it would be pointless to act as if there were. The participatory mode has its place, but it doesn't belong everywhere. Indeed, one might argue that if the experts deserve their name, only in rare cases will the expert consensus need to be challenged or corrected.

Still, I wish to conclude by pointing to one likely and tangible benefit that may follow from the availability of the participatory mode—its effect on levels of trust, both on the part of the public towards experts and on the part of experts towards the public. In the technocratic mode, the public's trust in the experts is mainly *assumed*. In the participatory mode, appropriately applied, trust is *built* in both directions. Voluntary groups in our own day are less likely to obey Palmer's call to present the experts' claims as "almost spontaneously created." His suggestion that the public should be led to believe that there is no deliberation in science, that the facts somehow speak for themselves, that subsequent deliberation with non-experts is irrational, is no longer tenable. That is quite likely a good thing for the public and the experts alike.

—Robert Wachbroit

A longer version of this essay will appear in *Civil Society, Democracy, and Civic Renewal*, edited by Robert K. Fullinwider (Rowman and Littlefield, forthcoming). The volume is a project of the Institute and the National Commission on Civic Renewal; the Commission and its associated research activities have been funded by a grant from the Public Policy Program of the Pew Charitable Trusts. Sources: Richard Shyrock, *National Tuberculosis Association 1904-1954: A Study of the Voluntary Health Movement in the United States* (National Tuberculosis Association, 1957); Michael Teller, *The Tuberculosis Movement: A Public Health Campaign in the Progressive Era* (Greenwood Press, 1988); George Palmer, "The Need for Uniformity in Anti-Tuberculosis Education," *Journal of the Outdoor Life*, vol. 12 (1915); Steven Epstein, *Impure Science: AIDS, Activism, and the Politics of Knowledge* (University of California Press, 1996); T. Merigan, "You Can Teach an Old Dog New Tricks—How AIDS Trials Are Pioneering New Strategies," *New England Journal of Medicine*, vol. 323 (1990).