

PHILOSOPHY & PUBLIC POLICY

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Convention and Competence: Disability Rights in Sports and Education

In the last six months, federal district courts have issued decisions in two highly publicized cases alleging discrimination on the basis of disability. In one, the Professional Golfers Association (PGA) was ordered to allow Casey Martin, a talented contender with a serious leg impairment, to use a golf cart in its championship tournaments, in contravention of its existing rules. In the other, Boston University (BU) was permitted to maintain its foreign language requirement without exceptions for learning-disabled students after a court-mandated faculty committee determined that the requirement was "fundamental to the nature of a liberal arts degree" at that university.

Both cases were brought under Title III of the Americans with Disabilities Act (ADA), which prohibits discrimination in "public accommodations," a term which covers a wide range of facilities, institutions, and organized activities. Both addressed the same issue under Title III: Was the proposed exception a "reasonable modification," or would it "fundamentally alter the nature" of the good, service, or activity in question?

The drafters of the ADA expected the meaning of "reasonable modification" to be fleshed out in the courts, and the two rulings were made in the context of the distinct bodies of case law governing organized sports and higher education. Still, the cases *look* similar, at least from the distance of a newspaper report, and so it may seem puzzling that they were resolved differently. Why should the PGA not be allowed to decide that walking is fundamental to tournament play, if BU is

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allowed to decide that a foreign language requirement is fundamental to its liberal arts program?

Several explanations suggest themselves. The courts may be more deferential to the judgment of faculty committees, given the greater prestige of academics and the long tradition of university self-government, than to professional athletic associations. The nature of Casey Martin's disability was clear and undisputed, while the diagnosis of "learning disability" on which the BU students' ADA claim rested remains deeply controversial. Finally, the opportunities available to the plaintiffs in the two cases were strikingly different. While there is only one PGA Tour (the most prestigious of the four tours offered by the PGA, and arguably the most prestigious in golf), there are lots of places to obtain a liberal arts degree—some more prestigious than BU, and many not requiring two years of a foreign language. For these reasons, the courts may have been more inclined to require inclusiveness and accommodation on the part of the PGA, while holding BU to a less demanding standard.

Ultimately, however, we cannot explain the appearance of inconsistency, or assess the merits of these decisions, without some understanding of how the ADA defines discrimination and what it requires for its redress.

What the ADA Demands

In enacting the ADA, Congress found that people with disabilities had been systematically denied "the opportunity to compete on an equal basis" by pervasive discrimination, involving not only "outright intentional exclusion" but also "architectural, transportation, and communication barriers," "exclusionary qualification standards and criteria," and the "failure to make modifications to existing facilities and practices." The ADA thus treats discrimination against people with disabilities as, in part, a sin of commission—the imposition of exclusionary practices and standards—and, in part, a sin of omission—the failure to remove barriers and to make reasonable modifications. This understanding of discrimination reflects a recognition that our society has deliberately or negligently excluded its disabled members from a wide range of activities by structuring those activities in a way that makes them needlessly inaccessible.

Eliminating such structural discrimination often requires significant changes in the physical and social environment. The most visible accommodations required by the ADA are the design features that ensure access for people in wheelchairs or people who are blind: curb-cuts, ramps, accessible entrances and bathrooms, braille signs, and computers that read their

own screens aloud. But the ADA also requires less tangible accommodation, in the "design" of jobs, tasks, and activities. As one recent law review article observes, "By contrast to earlier prohibitions against discrimination, the ADA incorporates a more explicit understanding of the contingency of existing job configurations: that they need not be structured the way that they are. Rather than taking job descriptions as a given, reasonable accommodation doctrine asks how the job might be modified to enable more individuals to perform it."

The demand for restructuring may make the ADA look more "affirmative" than other civil rights laws; the measures required to accommodate people with disabilities appear more extensive, and less directly linked to the redress of prior intentional discrimination, than those required to protect the rights of women and minorities. But in fact, the changes mandated by the ADA are more circumscribed than those mandated by other civil rights legislation. For example, the ADA requires job restructuring only for those disabled individuals "otherwise qualified" to perform the job's "essential functions." Moreover, it requires modifications only if they are "reasonable," if they do not impose an "undue burden," and, to bring us back to the present cases, if they do not "fundamentally alter the nature" of the activity, good, or service being offered.

These exceptions make the antidiscrimination mandate of the ADA a good deal more conservative than it initially appears, but they still demand a bracing exercise in institutional self-examination. They require employers, public and private service providers, and, ultimately, the courts to decide what constitutes the essential functions of a job or the fundamental nature of an activity, good, or service. Because the functions of a job, the requirements for a degree, the rules of a game or social practice depend to a large extent on convention, habit, and the practical imperatives of bygone eras, it will often be difficult to say whether they are essential, or why. And because the ADA places the burden of proof on those who seek to maintain exclusionary practices, the difficulty of establishing that such practices are essential will often work to the benefit of those demanding accommodation.

Demonstrating Competence

If the implementation of the ADA has been complicated by uncertainty about the essential nature of various activities, goods, or services, it has also been complicated by uncertainty over what constitutes competence or qualification in those persons who are excluded from them. Formally, the second concern might not appear independent of the first: the competence or qualification of a person with a disability

would seem to depend on the essential requirements of the job or the fundamental nature of the activity. But competence is not always assessed with reference to the requirements of a particular task or job. We will sometimes be more certain about a person's talent for achieving the outcomes associated with an activity than about the activity's fundamental nature; even those who claimed that walking was fundamental to the PGA Tour conceded that Casey Martin had already shown himself to be a formidable golfer. It may also be that our understanding of an activity's fundamental nature will be decisively *shaped* by our convictions about an individual's achievement. If we are more certain of the consummate skill that Casey Martin displays in playing golf than we are about the specific skills which golf requires, we may deny that the highest-level professional golf could possibly require any skill that Martin lacks. Along with his defenders, we may conclude that the PGA Tour is essentially a shotmaking competition.

There is a second reason why the assessment of competence is so uncertain: competence is more likely to

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have been attained and exhibited in some domains than in others. This may be the most striking contrast between the PGA and BU cases. Golfers who seek to compete in the PGA Tour will have had abundant opportunity to demonstrate their talent in other tournaments, while students at a liberal arts college most likely have promise rather than actual accomplishments to show. Admittedly, some college students can boast a Westinghouse Science Prize or a poem published in the *New Yorker*. But they are the exception. A liberal arts education offers few venues for precocious achievement, and talent in its specific domains may simply take longer to cultivate and display. The PGA case thus appears closer than the BU case to the ADA's paradigm injustice of a talented person with a disability denied an opportunity to "participate in, and contribute to, society."

In saying this, we do not mean to suggest that the ADA requires plaintiffs to display competence as clearly as Casey Martin did. Indeed, most people who claim discrimination based on disability will probably fall somewhere between Martin and the BU students, with achievements more concrete than the students' but less compelling than Martin's. Our suggestion is simply that in close or disputed cases—particularly cases where the fundamental nature of the activity is at

all uncertain—plaintiffs are more likely to prevail if they can clearly display competence or qualification in the activities from which they have been excluded.

The “Fundamental Nature” Test

However unfair Casey Martin’s exclusion from the PGA Tour might have appeared, it might not have been illegal if walking were indeed fundamental to the highest-level professional play. On this point, there was conflicting and ambiguous evidence. The PGA rules clearly stated that contestants were to walk the course, and some players regarded that as a formidable challenge in hot, humid weather and difficult terrain. But walking was not (otherwise) part of the

There is often disagreement about whether a particular function is incidental or essential to a job or activity.

competition: players did not get lower scores for faster walking, and no minimum pace or time was specified. Moreover, many players felt that walking was actually advantageous, giving them a feel for the course they would lack if they rode in a cart. Finally, the fact that other tournaments permit carts did not settle the issue of how to regard the walking requirement in the PGA Tour. That requirement may be seen as gratuitous, since walking is deemed essential in no other tournament, or, no less plausibly, as a defining requirement of the PGA Tour, distinguishing it from other tournaments.

Behind this specific clash of interpretations lies the more general question of how the courts could ascertain the fundamental nature of a conventional activity like PGA Tour golfing. This question invites comparison with the inquiry mandated under Title I of the ADA as to whether a given requirement is an “essential function” of a job. Title I prohibits employers from refusing to hire or retain “otherwise qualified” individuals on the basis of their disabilities; an individual is otherwise qualified if she can perform the “essential functions” of the job with reasonable accommodation. If the person with a disability cannot perform an essential function even with accommodation (such as the provision of assistive technology), the individual is not qualified.

Though many of the functions that people with disabilities cannot perform are clearly incidental to the jobs they seek to do, such as walking up a flight of stairs to work as a computer programmer, there is often disagreement about whether a particular function is incidental or essential (e.g., is the ability to

quickly analyze a fact pattern and apply complex rules essential to lawyering, or is speed incidental, and extra time on bar examinations therefore a reasonable accommodation for applicants with learning disabilities?). Such questions—which were rarely asked before civil rights laws forced employers to address them—will sometimes be difficult to answer. But generally they can be resolved by examining a company’s past practice, its productive and financial goals and constraints, and the practice of similar organizations: Does the employer really need this employee to perform this function in order to maintain its productivity or market share, comply with OSHA or EPA standards, or increase its dividends?

The inquiry may be less straightforward when a person with a disability seeks access to an activity, good, or service rather than a job. Formally, the language of Title I (regarding employment) and Title III (regarding public accommodations) is quite similar. Where the former requires “reasonable accommodation,” the latter requires “reasonable modification”; both make an exception for undue burdens. And much as an employer is not required to accommodate a person with a disability who cannot perform the essential functions of the job, an organization is not required to modify the activity, good, or service it offers if that change would “fundamentally alter [its] nature.” If walking indisputably had as incidental a role in golfing as it has in computer programming, the Casey Martin case would be an easy one under either section of the ADA.

The demand for reasonable modification suggests that the ADA recognizes the same contingency in the “existing configurations” of activities like sports and education as it does in employment. But the contingency in such activities is different from that found in jobs. Sports are conventional in a way that jobs are not (or are not generally thought to be). Their features are not dictated by the external objective of making a product or a profit, but are shaped by tacit consensus and informal practice of the participants themselves. Education falls somewhere in the middle: closer to employment if we see it in more instrumental terms as job training; closer to sports if we see it as a constituent of a good, cultured, or civilized life, e.g., “Part of being an informed and cultured member of our society is having learned (or at least having been exposed to) a foreign language or the Classics of Western Civilization.”

The more conventional character of sports, and arguably of education, may appear to make them more flexible, more amenable to modification, than the production- or profit-driven operations of a business. But their conventional nature is double-edged. The rules and practices that define a sport or a liberal arts education may be in some sense arbitrary, but they

Making Exceptions

One issue close to the surface but rarely discussed in cases like these is why we should have to choose between excluding people with disabilities from an activity, or altering its rules and conventions for everyone so that people with disabilities can be included. Why not simply make an exception to those rules or conventions for participants with disabilities? What does it matter if a few people are allowed to depart from the conventions that govern a sport or an academic program?

The most obvious concern is that exceptions would give some participants an unfair advantage, thereby imposing an undue burden on the others. Suppose that Casey Martin won a game on the PGA Tour by one stroke, pulling ahead on the final hole to beat a player exhausted by walking a long course on a hot, humid day. Or suppose that the two top seniors at BU had equal GPAs, but that one was a learning-disabled student who had gotten A's in foreign culture but would probably have gotten C's or D's in a foreign language, the other a non-LD student who had gotten B's in a foreign language but would probably have gotten A's in foreign culture. Would it be fair to award Casey Martin the trophy, and to make the learning-disabled student valedictorian?

A second concern is that exceptions would alter the fundamental nature of an activity. Clearly, this could happen if an "exception" were available to all—and if there were some advantage to non-disabled participants in the alternative way of engaging in the activity. But it could also happen even if the exception were limited to disabled participants, since our notion of what constitutes achievement in that activity would be affected by their success. BU, for instance, would be hard-pressed to claim that two years of a foreign language were integral to its conception of a liberal arts education if several of its recent valedictorians were learning-disabled students who lacked that coursework.

Operating in a legal framework somewhat different from the ADA, an Ontario court faced both of these concerns when it was asked to decide whether the province's Youth Bowling Council could exclude Tammy McLeod, a girl with cerebral palsy, from tournament play. Tammy aimed and released the ball down a ramp rather than holding it in her hand. The judge concluded that the girl was "not able, because of handicap, to perform the essential act of bowling—manual control and release of the ball." Under the ADA, such a finding would have settled

the matter: By analogy with Title I, the employment section, the bowling council would not be required to include Tammy if she was unable, even with accommodation, to perform the essential functions of the sport. But under the Ontario Human Rights Code, as the judge interpreted it, the bowling council *was* required to include her. A person with a disability is entitled to accommodation whether or not she can perform the essential functions of an activity, so long as the accommodation does not impose a hardship on the organizers or on other participants. In this case, the judge ruled that there was no hardship: Tammy's device gave her "no competitive advantage over others" (since it did not allow her to impart speed or spin to the ball), and her use of it did not require other bowlers to alter their manner of play in the slightest.

The judge went on to say, however, that if use of the ramp *had* given Tammy a competitive advantage, or if she were to adopt a more sophisticated device, the bowling council might well be allowed to exclude her. In effect, he ruled that Tammy could participate as long as she was not competitive. He gave her permission only to engage in a loosely parallel activity alongside real bowlers, in which she was unlikely to obtain a higher score than the real bowlers, and unlikely to be regarded as having won a bowling game even if she did. Though she could be a participant in some attenuated sense, she could never be a contender. This resolution is ironic in a case where the judge emphasized the inherently competitive nature of sports: "All sport at all levels involves competition; all participants strive to win." It may have been a fair resolution for a youth tournament, where winning is not the only thing, but if so, the decision was fair for reasons that belied its stated rationale.

It will, of course, be as difficult to say when an alternative way of performing an activity confers an unfair advantage as it is to say whether it departs from the fundamental nature of that activity. From the moment he began to dance around Sonny Liston in Las Vegas, to the moment he had the ropes loosened in the Kinshasa ring to defeat George Foreman with his rope-a-dope, Muhammed Ali was accused of gaining unfair advantage or threatening the fundamental nature of heavyweight boxing; he is now almost universally regarded as having improved it. A cart on a PGA Tour golf course is surely closer to looser ropes in a boxing ring than to ramps in a bowling alley. But closer cases and difficult judgment calls will inevitably attend the integration of people with disabilities.

may also acquire a non-instrumental value that few job descriptions possess. The ADA's exemption for modifications that fundamentally alter the nature of an activity, good, or service can be seen as protecting, perhaps too categorically, the attachments and expectations that develop around conventional activities.

In the BU case, the court deferred to the considered judgment of a faculty committee that the foreign language requirement was essential to a liberal arts education at Boston University. There was ample precedent for this deference in other cases addressing the fundamental nature of an academic or professional program, based in part on the tradition of academic autonomy. (Indeed, that deference might have been greater if the BU president had not provoked the controversy with a wholesale attack on his school's program for students with learning disabilities and on the very idea of accommodating such disabilities.) Such deference may look elitist if we see the nature of a liberal arts degree as no less conventional than a golf tournament—why should academics be allowed to judge which of their conventions are fundamental while sports organizers must yield to the court's judgment? It will look a little less elitist if we see the requirements for a liberal arts degree as instrumental—developing the skills needed to succeed in civic or commercial life outside the academy (or within it, as professors). But the university might be reluctant to justify its foreign language requirement in instrumental terms. If the question is whether students perform better at various life pursuits with the minimal proficiency that two years of a foreign language confer, the BU faculty has no more expertise than other educators in providing an answer. Rather, the university may see the foreign language requirement as an essential constituent of a liberal education *as BU defines it*. In that case, its authority to impose the requirement is a matter of prerogative, not expertise.

Protected Values

We would like to conclude with some reflections on the values that may be protected by the "fundamental nature" exception of Title III. If the law were simply concerned with equitably distributing the costs of reasonable accommodation and modification among people with disabilities, employers, public accommodations, and the larger society, it is not clear why it would need such an exception in addition to that for "undue burden," as well as the overall requirement of reasonableness. If a public accommodation can modify its activity, service, or good without undue burden, what does it matter that the modification alters its fundamental nature?

This impatience with convention is found in some feminist writing on sports, which challenges the need

for rules that limit the participation and success of women. Thus, Janice Moulton maintains:

As it is now, athletes are used to adjusting their play to rule changes, and systems of scoring now exist to allow players at different levels to compete together. Informal games of many kinds are played with whoever shows up, and every school athlete has played in such games. The rules are freely revised to take into account the number of players, the playing field . . . , the level of skill, and anything else that is considered important. People who object to making changes in the standard rules may not realize how very often such rules are altered in practice.

As anyone who has followed the protracted controversies about rule changes in many sports will appreciate, however, players and spectators are often fiercely attached to the status quo, and regard even minor changes as threats to the integrity of the sport. Changes far subtler than those needed for the inclusion of people with various disabilities might well alter the style of play and the character of the game. The point is not that such changes would make the sport intrinsically better or worse, or would impose any tangible burden on the players, spectators, or organizers, but that they would alter familiar and cherished conventions. Moulton recognizes how sports talk pervades our social lives and civilization, but fails to recognize how much of that talk concerns the very details she would so readily alter in the interest of greater inclusiveness. It is not the improvised pick-up games that are debated in the barbershops and the tabloids; it is organized sports with highly specific rules and other conventions, a knowledge and acceptance of which is presupposed in the spirited discourse Moulton observes. This hardly renders those conventions sacrosanct, but it does suggest that changes can be wrenching and disruptive.

Moreover, one does not have to be a fetishist about existing conventions to worry about the broad postwar trend, in work, school, and sports, toward specialization. American sports used to place a premium on endurance and versatility, just as American universities once imposed a comprehensive liberal arts curriculum. A football career required a full 60 minutes on the gridiron, on defense and offense; a B.A. once required not only proficiency in Latin and Greek, and a familiarity with the classics of Western Civilization, but also an ability to swim several laps in an Olympic-size pool. The specialization that has overtaken many domains may be a welcome trend for those with finely honed but narrow talents and capabilities. But in these domains, many well-intentioned people fight to preserve an emphasis on versatility or well-roundedness, lest the participants become technicians instead of scholars or athletes. And even those not disposed to rearguard actions may feel some sense of loss when excellence in golf is confined to shotmaking or when pitchers no longer have to come to the plate to face their opposite

numbers on the mound, leaving that task to designated hitters. Whether or not we believe that the law should attempt to take cognizance of such costs, it must recognize the danger of deforming a practice so extensively that it is no longer one in which previously excluded or included people wish to participate. At that point, the attempt to reshape the practice becomes self-defeating.

If the ADA does give weight to convention in exempting public accommodations from changes that would fundamentally alter the nature of their activities, goods, and services, this is consistent with the generally conservative and incremental character of that statute. The ADA is committed to opening up existing employment, facilities, activities, goods, and services to people with disabilities, but it was not designed to equalize opportunities in more radical ways. While the interests of people with specific disabilities might be well served by the creation of new sports emphasizing skills in which they were likely to have developed compensatory superiority—the rough analogue of a proposal made by Jane English for reducing sex inequality in sports—or of more universities like Gallaudet, the ADA requires nothing of the sort. Rather, it calls for the maximum feasible integration, and leaves it to the courts to decide whether what is of distinctive value in an enterprise can be preserved by changes that permit people with a given disability to participate, and even to compete and win. Will the singular virtues of the highest-level professional golf be compromised if players use carts to go from hole to hole? Would a BU liberal arts degree lose its special character if it were conferred without two years of a foreign language? Such questions will often be difficult ones, both for disabled individuals who seek inclusion and for institutions which are pressed to change. Nevertheless, they provoke a valuable exercise in institutional appraisal.

—Anita Silvers and David Wasserman

Sources: Pamela S. Karlan and George Rutherglen, "Disabilities, Discrimination, and Reasonable Accommodation," *Duke Law Journal*, vol. 46, no. 1 (October 1996); Ruth Shalit, "Defining Disability Down," *New Republic* (August 25, 1997); Michael Grunwald, "U.S. Launches Drive for Disabled Golfer: Justice Dept. Invokes ADA in Martin Case," *Washington Post* (August 24, 1998); Janice Moulton, "Why Everyone Deserves a Sporting Chance: Education, Justice, and College Sport," in *Rethinking College Athletics*, edited by Judith Andre and David N. James (Temple University Press, 1991); Jane English, "Sex Equality in Sports," *Philosophy and Public Affairs*, vol. 7 (Spring 1978); *Youth Bowling Council of Ontario v. McLeod*, 75 Ontario Reports (2d).

Disability, Difference, Discrimination: Perspectives on Justice in Bioethics and Public Policy

Anita Silvers, David Wasserman, and
Mary B. Mahowald,

with an afterword by Lawrence C. Becker

How should our society respond to individuals with disabilities? What does it mean to be disabled, and is a disabled person necessarily less independent and less competent than a person who is not disabled? Is a life with a disability any less worth living than a life without one? In this compelling book, three experts on disability issues, ethics, and the law address pressing issues in public policy and bioethics, including the prospect of genetic discrimination, heroic treatment of seriously impaired neonates, and how to assess the benefits and burdens of ending the segregation of people with disabilities. The authors bring leading theories of justice to bear on matters of concern to a wide variety of disciplines dealing with disability, including feminist, minority, and cultural studies, and they do so in the context of the groundbreaking Americans with Disabilities Act. *Disability, Difference, Discrimination* will be of great interest to the legal, philosophical, and medical communities engaged in ongoing debates about disability.

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"The authors offer novel and enlightening perspectives on disability and justice. I learned a lot from their different ways of approaching this difficult tangle of issues. All three essays in this volume challenge commonly accepted patterns of thought and will repay careful study."

— Richard Arneson, University of California, San Diego

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December 1998
176 pages
\$54.00 (cloth)
\$18.95 (paper)

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

Do Means Matter? Evaluating Technologies of Human Enhancement

New technology often gives us new ways to do something we have always done, or at least always wished we could do. And new technology is often accepted as good or moral because it helps us achieve established ends more easily or efficiently. In medicine, for instance, new techniques such as noninvasive surgery are quickly accepted because they achieve the same ends as the older techniques, and in fact do so with certain advantages. And in ethics, one sometimes hears an argument of this form: The new technique is acceptable because, after all, we have always achieved the same end through another means.

But what if the end in view is something like improved classroom performance by grade-school children? This end can be achieved through reduced class size (using traditional or established means) or through prescriptions for Ritalin for some of the students (a new means). If the traditional ends and means are good, is the new means also good? Does using Ritalin instead of reducing class size to achieve this end make a moral difference?

Or what if the end is heightened cognitive performance, which can be achieved through classic educational strategies but which some day in the future

might be achievable by genetic techniques, possibly even by human germ-line genetic enhancement? Again we might wonder: If the traditional ends and means are good, is the futuristic means? Would using genetics instead of education to achieve this end make a morally significant difference in the meaning of the end?

ment, or that our philosophical or religious traditions warn us against it, while technology seems to offer a new temptation. It is rather that we in Western culture are enhancement enthusiasts. In Christianity, for example, personal enhancement is the central organizing motif: Human beings are redeemed (some would say "born again") into a new mode of existence. And virtually everyone in the West agrees on the importance of education or on other forms of human effort in pursuit of one's goals. Life for us is one long project of self-improvement.

So it is hardly the case that technology offers enhancement while Western religion or philosophy defends the human status quo. On the contrary, technology is worrisome precisely because it offers a new means to achieve the old ends. For when we ask about the ethics of a new technology of human enhancement, we can readily imagine this argument being made: We have, after all, always sought to achieve these goals through traditional means; the new means seek the same goals, but they achieve them more quickly or efficiently; therefore, the new means are good, perhaps even better than the old means.

The prospect of hearing this argument, especially when applied to psychopharmacology or to human genetic manipulation, immediately gives rise to a worry, at least for some, that we are missing something important—that we are sliding too easily from old means to new, without looking carefully for the moral difference between them. "We have always done this by other means" may be comforting, but is it sound moral reasoning? Or so the worry asks.

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The question of means, though it can arise in relation to therapy or treatment, becomes especially difficult when we turn to the prospect of medical or scientific means of human enhancement. The reason is not that we in Western culture are against enhance-

Two Arguments and Their Limits

What lies behind this worry? Does it point to an important intuition about new means and their relationship to old means and old ends, or is it merely a form of nostalgia or technophobia? In order to unfold this concern more fully, two arguments have been suggested. First, it is sometimes thought that old means are in some sense natural, while new means are artificial. The objection here is not the naive claim that

nature is always good and artifice bad, or that by "nature" we mean "traditional," which is good, while by "artificial" we really mean "nontraditional," which is bad. The objection may be more forcefully stated in this way: It is natural to human beings to nourish and indeed to enhance themselves and their children by means of good diet, education, moral example, or religious activity. Parents who do these things for their children are to be praised for doing what human parents naturally should do. Furthermore (and more important), these activities are not so much means to an end—such as enhancing our children or equipping them to get ahead in a competitive world—as they are the natural expression of parental affection. As such, they are never simply replaceable by other means, which might include anything such as vitamin pills, music lessons, special sports instruction, or psychopharmacology. It is not that any of these other means are necessarily bad or inappropriate in the right situations; they are just not the sorts of things that human parents are naturally expected to do for their children, or that human beings are naturally expected to do for themselves.

While this argument has serious limitations if seen as an argument against unnatural or artificial means, it does point to an important insight, namely, that not everything we do is a means to an end. Some things are done simply out of self-respect, or out of love for another, or out of a sense of what is appropriate in a relationship, such as that between parent and child. A

Some activities are not so much means to an end as they are the natural expression of parental affection.

mother does not hug her newborn in order to enhance its future emotional and cognitive state, although we now know that this will occur as a result of her action. She hugs her infant for the sake of love and joy, not as a means to an end. So to suggest that some future pill might accomplish the same end is to commit a category mistake. A pill is not therefore bad; it simply occupies a different moral space, and its legitimacy needs to be argued on other grounds than by saying that it achieves the same thing as a mother's hug.

For people of religious conviction and practice, the observance of the rituals of a tradition is not so much a means as an end. Observing one's faith may make one feel "closer to God," or it might even improve one's health by helping relieve stress or by providing systems of social support. But religious people do not follow the practices of their faith *in order to* achieve these ends; rather, they do them because they believe that

they live in such a universe, or in the presence of such a God, that worship is the natural or fitting response. People worship, not because it gets much accomplished, but because if there is a God, it is the right thing to do. Once again, some future pill might accomplish the same effects as religious practice; but to suggest that it achieves the same ends as religion is to

Technology, precisely because of its power and efficiency, seems to cheat us of the experience of accomplishment.

misunderstand religion, for the practice of religion is not about achieving ends but about a right relationship with that which is ultimate.

Now of course, as culture and technology change, "what parents naturally do for their children" or "what people naturally do for themselves" also changes. We today regard it as a fairly natural thing for parents to read books to their children by incandescent light, something which could not be done before light bulbs, or, for most people, by any light, before the printing press. So again, the argument's value is not in helping us decide whether new means are right or wrong but in confronting us with the instrumentalism that characterizes so much of our thinking.

The second argument is this: Assume that new means are effective in achieving traditional ends, such as athletic or intellectual accomplishment. The new means, such as psychopharmacology and genetic alteration, are perhaps more efficient or easier than the traditional means. But for that reason, they should be opposed, because there is a value in the traditional means themselves, quite independent of the ends they achieve. There is, after all, a glory and a dignity in human accomplishment attained the "old-fashioned way," through sweat and struggle, sometimes against great odds. It is something like the mountain climber who struggles to the top of a great peak, but then on flying home ascends quickly by jet over the top of the mountain and, looking down at the summit, feels cheated of the value of the original climb. Technology, precisely because of its power and efficiency, seems to cheat us of the experience of accomplishment, which is something valued in distinction from the achievement of the end.

The significance of this argument lies in its calling attention to the value that inheres in certain means, over and above the value found in the end considered by itself. The value in climbing the mountain peak—the physical and mental discipline, the experience of the gradually opening vistas, the sense of personal accomplishment—is entirely distinct from the value of

being at the summit. Attaining the summit by a new, technological means might be a good thing under some circumstances, but if the new technical possibility generally discouraged people from attempting the old means, the extra value that lay distinctly in the old means would be lost. Indeed, there may be some areas of human activity in which the value that is distinctive

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our human struggle,
they do not eliminate it.*

to the means far exceeds the value found in achieving the end. Mountain climbers are likely to claim this argument for their sport. If it is correct, then a new means will be a poor trade-off. It is not so much that people would be cheated by technology but that they would be tempted to cheat themselves through technology. This argument, by calling attention to what we might lose, warns us of the cost of cheating.

The argument should not, however, be taken as a categorical objection to the use of new means, for the simple reason that while new means may relocate our human struggle, they do not eliminate it. The fact that I write at a computer makes writing easier by eliminating retyping and other frustrations, but writing itself is an intense struggle, and it will remain so under any technological condition. The technological advance does not eliminate the struggle so much as relocate it; indeed, it makes it possible to eliminate secondary aggravations and focus attention on the core struggle at hand, namely, expressing new insight in just the right words. Even if technology increased our cognitive ability itself—giving us not just faster computers but faster brains, so that we could calculate or write or think more clearly—these activities would still be a struggle in the face of even greater intellectual challenges which we human beings would inevitably set ourselves. Therefore, any concern that new, technological means eliminate human struggle altogether seems ill-founded. At the same time, the argument offers an important warning, namely, that we should consider carefully the value that is distinctive to the old means, value that could be lost if we simply replace old means with new.

Ends and Other Effects

It is worth exploring how our anthropology (or conception of the human) becomes a factor in this discussion. A strong anthropological dualism would permit us to say that there are physical and technological means that affect the body and even the brain, but that

there are also social, psychological, and spiritual means that affect the self or the soul, and that these two categories do not compete or overlap with each other. Any amount of future technological alteration of the brain would leave human beings in roughly the same social and spiritual predicament in which we currently find ourselves.

If we reject such dualism, we will recognize that already with psychopharmacology and in the future with genetics, it is possible to alter the brain in ways that alter the self or soul. If so, then these questions quickly arise: Is the alteration of the self by technical means the same as its alteration by traditional means? Is there a morally significant difference between different means and their effects? If so, can an analysis of this difference offer us any guidance in making decisions about the proper use of new technologies?

I want to consider each of these questions. First, is the alteration of the self by technical means the same as its

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contains a built-in prejudice
for technology.*

alteration by traditional means? I will argue that it is not. Now if we define what we mean by "alteration" narrowly, as a specific, measurable end, it may be possible to achieve the same end through technology as through traditional means. But if we agree to such a narrow definition, we will have already made an important decision about the relationship between a specific end to be achieved and the full range of effects that result from our use of one means as opposed to another. That decision, to focus on a narrow definition of an end, is consistent with a broad tendency of modern thought toward that which is specific, measurable, abstracted from its full context of meaning, and therefore "thin." This tendency of thought contains a built-in prejudice for technology, for by defining ends narrowly, it allows us to think that technology achieves them.

The alternative to such "thin" description is not dualism but the recognition of the essential "thickness" of human experience, even when it is described strictly at the genetic/neurological level. For instance, in saying that a pill achieves the same effect as prayer, we might mean that the pill makes us feel the same way, or that it raises the level of serotonin or other key neurotransmitters to the same extent as does prayer. We can certainly criticize this claim at its psychological level: Prayer and the pill do not really make us feel the same way, for even if the effects are experienced as the same in some respects (relaxation, confidence, self-assurance), in other respects (an awareness of the



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obligations imposed by God, for example), they are hardly the same. But we can also criticize this claim at the molecular and cellular level: Prayer and the pill do not really achieve the same neurological effects, for even if the serotonin level looks the same, prayer is a robust mental activity with countless other neurological correlates, all occurring in a sequence of neural events markedly different from the effects of a pill. Once we reject a narrow or "thin" account of change, and consider the full array of effects of any human activity, we see that significantly different means can (and often do) have significantly different effects.

So then we ask: Is there a *morally significant* difference between different means and their effects? To which, of course, I would answer yes. The weight of the significance will depend on the person making the decision between alternative means. For example, if we want to be less anxious and more self-confident and we believe this state can be attained either through prayer or through a pill, our choice will depend on whether there are other effects, contingent upon either one of these means, that are either to be desired or avoided. If we simply want to be relieved of anxiety quickly, the pill is the obvious choice. If we believe there are manifold effects of prayer, and we value

them, we might choose prayer. My point here is not that one choice is right and the other wrong; that depends on the broader matrix of values to which a person adheres. My point is simply that different means bring about different effects that may be morally significant.

The Pursuit of Advantage

As a society, we should hope that we will learn from each other how new means mix with old, whether they conflict or complement each other, and where the general warnings or dangers might lie. I will close by describing two areas of potential concern.

The first has to do with the relation between treatment and enhancement. Technologies such as robotics and computers are now being used, with widespread approval, to surmount handicapping conditions. As new developments occur in this area, the approval will likely extend from computers to pharmacology and genetics. But once we agree that any new technological means may be used to surmount some aspects of handicapping conditions, we may find it very hard to know how to define a handicap or to limit the use of technology to those cases. Unless we learn to reflect

**Enhancing Human Traits:
Ethical and Social Implications**

Erik Parens, editor

New biotechnologies—ranging from genetic manipulation to psychopharmacology and new surgical techniques—are rapidly making it possible to enhance an individual's appearance, mood, mental and physical abilities, and even personality in ways previously only imagined. In this volume, scholars from philosophy, sociology, history, theology, women's studies, and law explore the looming ethical and social implications of these new biotechnologies.

To clarify the issues, the contributors grapple with the central concept of "enhancement" and probe the uses and abuses of the term. They identify the critical difficulty in distinguishing between treatment and enhancement—a distinction crucial to future policy-making as well as to moral debate. Focusing in particular on the moral issues pertaining to cosmetic surgery and cosmetic psychopharmacology (a category which includes Prozac), they also examine notions of identity, authenticity, normality, and complicity.

Other essays in this collection address the social ramifications of the new technologies, including the problems of access and fairness; the threat of imposing dominant conceptions of normality; and the temptation to ignore the complex causes of some forms of suffering.

An important and timely contribution to current discussions about medical technology and bioethics, *Enhancing Human Traits* elucidates what is at stake for society in using the new medical technologies.

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more openly than we now do on human differences (and to distinguish this topic from racism and other pathologies), we might find ourselves backed into approving a technology for everyone because we want

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unjustly, we need to be particularly wary
that new means will not fall under
the familiar patterns of injustice.*

to approve it for some. And if we pick up the use of these technologies without a healthy regard for the differences among human beings, we are likely to make serious mistakes in judgment.

The second concern has to do with social justice. There is a growing sense that psychopharmacology is being used, not for therapy or even for enhancement in the sense of self-development, but as a booster to equip us for an increasingly competitive society. One can imagine the temptation to use genetics in the same way, to give our offspring an advantage against their enhanced competitors. When we think honestly about this, we may begin to wonder if we have not already used education for just this purpose, to give a privileged advantage to some of our offspring so that they may outperform those not so advantaged. If in fact we have used traditional means unjustly, we need to be particularly wary that new means will not fall under the familiar patterns of injustice, perhaps augmenting their magnitude. Otherwise, our tendency toward a "thin" description of effects, conjoined with our tendency to ignore differences, could bring about a relentless technological pursuit of advantage.

—Ronald Cole-Turner

Ronald Cole-Turner is the H. Parker Sharp Associate Professor of Theology and Ethics at Pittsburgh Theological Seminary. This essay is an abridgment of a chapter from *Enhancing Human Traits: Ethical and Social Implications*, edited by Erik Parens (Georgetown University Press, 1998). Printed with the permission of Georgetown University Press.

One Pill Makes You Smarter: An Ethical Appraisal of the Rise of Ritalin

The statistics at least *seem* alarming. The production of Ritalin, an amphetamine derivative used for the treatment of attention deficit disorder in children (and, lately, in adults as well), has risen a whopping 700 percent since 1990. According to figures given by Lawrence Diller in *Running on Ritalin*, over the decade, the number of Americans using Ritalin has soared from 900,000 to almost 5 million—the vast majority children from the ages of 5 to 12, though there is a significant rise in Ritalin use among teens and adults as well. No comparable rise is reported in other countries, though a much smaller surge has taken place in Canada and Australia. In Virginia Beach, Va. (perhaps the most egregious example), 17 percent of fifth-grade boys were taking Ritalin in 1996 to control behavior problems and improve school performance. (Boys on Ritalin outnumber girls in a ratio of 3.5 to 1; when I was recently complaining to another mother about my own son's academic difficulties, she said simply, "Welcome to the world of boys.")

Stimulants have been used to treat behavior problems in children since 1937; Ritalin itself appeared on the market in the 1960s to treat what was then called "hyperactivity"—impulsive, disruptive behavior by children who just "couldn't sit still." In recent years, however, the root problem has been identified as "attention deficit disorder" (ADD), either with or without attendant hyperactivity.

Symptoms of ADD, according to the standard survey used in its diagnosis, include: "often fails to give close attention to details or makes careless mistakes in schoolwork," "often has difficulty organizing tasks and activities," and "often avoids, dislikes, or is reluctant to engage in tasks that require mental effort (such as schoolwork or homework)." Symptoms of ADD-H (the variant with hyperactivity) include: "often fidgets with hands or feet or squirms in seat" and "often has difficulty playing or engaging in leisure activities quietly." Ritalin, by most accounts, is remarkably effective in getting such children to settle down and pay attention, with resultant (at least short-term) gains in parental sanity and academic achievement.

The fear, stated quite baldly, is that as a society we are drugging our children in ever-larger numbers to get them to conform to adult expectations. Dislikes

homework? Makes careless mistakes? Squirms in seat? To many it seems that we are drugging our children to get them to stop being *children*. I myself feel profoundly troubled by the rise of Ritalin—and by my own temptation to use it for my child, who, yes, makes careless mistakes and has been known to fidget. But, I will argue, it is surprisingly difficult to pinpoint any justifiable sources of discomfort here—both harder than one might think, and more illuminating. The effort to do so will lead us into an exploration of a range of issues about how we view our children and ourselves.

Here, then, are some possible responses to our concerns about the rise of Ritalin, followed by some speculations about the deeper—and legitimate—fears that fuel these concerns.

Rationales for Treatment

On some accounts, the rise in Ritalin simply reflects our commendably growing willingness to treat a serious and common disorder that has too long been left untreated. That there is soaring use of any drug is not itself a problem, if the drug is treating a genuine medical condition that responds favorably to treatment. If there is some real disorder in the area of children's brains that controls their ability to pay attention (current research is focusing on the prefrontal cortex), and this disorder is causing problems in school and home, and it can be easily treated, *shouldn't* it be treated? Why should children have to struggle with their schoolwork, and parents struggle with discipline, if the root cause of disappointing academic performance and poor behavior is a medical one that can be easily treated? On one expert's estimate, attention deficient disorder is even now underdiagnosed, and so we should expect—and welcome—a further doubling of Ritalin use in response.

However, it is unclear that there really is any one, clearly identified "thing" that "is" attention deficit disorder. Diller argues persuasively that when parents or doctors speak of a child as "having" ADD, this tends to mean only that the child in fact scored positively on a certain number of questions on the kind of survey described earlier. Certainly diagnosis of ADD

is inexact, to say the least—often based largely on reported frustration by parents and teachers, sometimes made (as admitted by some teachers I've spoken to in my own local schools) by prescribing Ritalin on a trial basis and seeing if it works.

The trouble with the latter approach is that Ritalin almost always "works," in that it almost always enhances performance, at least in the short term (Diller reports that there is no evidence of long-term improvement in children taking Ritalin). According to one study cited by Diller, "stimulants had essentially the same effects on normal children as on children with attention or behavior problems." Diller notes an increasing amount of what has been called "diagnostic bracket creep," as the criteria for diagnosis become ever more loose and generous, allowing more borderline ADD children to benefit from drug treatment.

Now, it can be argued that it shouldn't matter whether children receiving Ritalin have some underlying "brain disorder" that causes inattention, or whether they are inattentive for other, less physiologically based reasons. Why is the *cause* of a condition relevant to whether or not we have reason to try to treat it? For example, if parents are debating whether or not to treat an abnormally short child with growth hormone, David B. Allen and Norman Fost have argued that it shouldn't matter whether the child's height is caused by a hormone deficiency or by his genetic endowment: What should matter is whether this is causing a problem for him, and whether it can be successfully treated.

With the diagnosis of attention deficit disorder so elastic, however, one begins to wonder whether the

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to treat it?*

"disorder" in question is simply that the child places at the lower end of the spectrum for behavior or achievement—that is, that parents, clinging stubbornly to Lake Wobegon fantasies, insist that all children generally and their own children in particular should be "above average," or certainly not below average. (I have discovered from my own experience that teachers are also quick to suggest an ADD evaluation for a child with any academic difficulties.) If attention or behavior problems interfere with a child's achieving his or her "full potential," parents and teachers may be increasingly tempted to turn to medication, even where this can mean not just allowing their children to perform "normally," but raising them significantly above the norm. Diller mentions one student whose use of

Ritalin allowed him to become his high school's valedictorian: Off the drug, he still performed well, but his grades slipped, from straight A's, to A's intermingled with B's.

Some of us will be troubled by using Ritalin in such cases. But why shouldn't every child be able to use whatever means are available to improve his or her performance, whatever his starting point? If we were to raise poor performers to the mean, but refuse to raise average performers above the mean, this could seem unfair to the superior performers. Why shouldn't they have a chance at enhancement, too?

Ritalin as a Means of Enhancement

As Ronald Cole-Turner points out, in his article in this issue, most of us are already "enhancement enthusiasts." We not only strive to improve our children all the time, but would criticize parents who neglected to do so. If we give children Ritalin to enhance their academic performance—well, don't we send them to school in the first place for the same reason? It doesn't seem all that problematic to want our children to be more attentive, more responsive, better behaved, better able to learn: Isn't better, by definition, *better*? Cole-Turner argues, however, that while the goal of enhancement may be a legitimate one (I will raise doubts about this below), we need also to look at the means. Means *do* matter.

First, some means may be problematic in themselves, including the use of drugs. A friend with whom I was discussing the rise in Ritalin use voiced the reactions of many in saying, "Putting kids on drugs? Uh-uh." Now, drugs of any kind are often attended with a myriad of negative (and perhaps not yet discovered) side effects. But stimulants like Ritalin have been used to treat behavior problems in children for six decades with few observed ill effects. Ritalin causes insomnia, which can be avoided by not taking it in the evening; some children experience suppressed appetite. But the vast majority experience no distressing side effects at all.

The term "drugs" generally carries with it a stigma: When we think of "children on drugs," we think first of illegal drug use; when we talk about "drugging our children," we visualize children wandering through the day in a dopey, feel-good haze. It is important to free Ritalin from such unwarranted associations. Its use is legal, although controlled, and, far from inducing a fuzzy "drugged" state, it works to increase the ability to pay attention. With Ritalin, children don't "tune out," but "tune in." Or so we might claim.

Second, as Cole-Turner argues, some means to an end may be valued for their own sake and in their own right—either because they also represent ends that we value, or because we value reaching the end only after an experience of striving and struggle. If we choose a



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"quick fix" to solve our problems and achieve our goals, we may end up achieving different goals altogether, or, at the least, give up the long and ultimately more rewarding journey to our destination. In the case of Ritalin, the fear is that we will be content to give "problem children" a couple of little pills every day, rather than put in the extra effort as parents and teachers to reach them and teach them, to help them learn and grow in a more messy and non-medicalized way. Specifically, the fear is that we will see Ritalin as a means of bypassing tough and loving parental discipline or real (and expensive) commitments to shouldering the rising costs of effective public education.

Now, clearly we value parental love and discipline and the long journey of education as ends in themselves, not just as means to producing more successful children. Focusing for the moment on education, we don't send children to school simply to get them to acquire a certain body of knowledge and master a certain body of skills, but because the process of learning is itself valuable. I still remember the thrill the first time I really "got" long division. Or the shock of joy with which I first learned, from my high school American history teacher, that there really are two sides to every question. We may worry that Ritalin provides an easy way out of facing the challenge—and reward—of truly educating our children. For teachers

who can teach and classroom environments in which children can learn cost vastly more than daily doses of Ritalin.

To this concern about Ritalin, I have two responses. First, Ritalin could be defended as a means, not of bypassing the journey of education, but of permitting certain children to engage in the journey more fully, to

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pay attention to the journey in all its richness. Ritalin doesn't substitute for learning; it at best assists in providing one of the preconditions for learning—the ability to pay attention to what is being taught. Ritalin or no Ritalin, we will still need to teach our children, both how to behave and how to learn, in the most creative ways possible.

This suggests, second, that when it comes to parents and to teaching, we do not need to fear that we will take the easy way out, because, quite simply, there is no easy way out. Cole-Turner points out correctly that while new means "may relocate our human struggle,

they do not eliminate it." Even if we are what Gerald Klerman has called "pharmacological calvinists," who reject drug-based solutions as too easy, who value the hard way just because it's hard, this gives us no reason to resist Ritalin. Anyone who is a parent or teacher knows that there will be no shortage of hard work in raising and educating children. If hard is what we want, we're home free: However hard we want parenting and teaching to be, it will be hard enough.

Equality and Competitiveness

As I approach what I take to be the most serious worry about Ritalin, let me mention one other objection that is sometimes raised to it and other programs of medical enhancement. This objection concedes that Ritalin can provide genuine and legitimate advantages for those who use it, but charges that these advantages are not distributed fairly. Responsible diagnoses of attention deficit disorder are expensive and beyond the budget of many families, who are already poorly served by an inadequate health care system. With the

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than our own imperfect selves;
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somebody else.*

rise of Ritalin, whose use is concentrated among white, upper-middle-class families, the children of the rich get cognitively richer, and the children of the poor fall ever further behind.

This objection, if it stands on its merits, could be met by efforts to equalize provision of Ritalin (as well as access to medical care generally). If racial or class disparities in Ritalin use were our chief concern, the solution would be obvious. But in my view, the biggest problem with Ritalin lies not with the kids who don't get it, but with (at least some of) those who do.

The real reason that I remain uncomfortable with the rise of Ritalin concerns not the means of enhancement, but the goal itself—what our motives are for seeking enhancement so diligently and desperately, and, even more, what we as a society are currently counting as enhancement. What, in the end, are we trying to gain?

Now, there are clear advantages to being able to pay attention, clear advantages to being able to learn. Dan Brock notes that often our efforts at enhancement are meant to provide us with "intrinsic goods" that we value for their own sake. If these are what we are seeking in putting our children on Ritalin, this doesn't seem particularly troubling. But it seems to me, chiefly as an observer of my own life in one white, upper-middle-class American neighborhood, that many of us

want more than this. We don't want to be better than our own imperfect selves; we want to be better than somebody else. We don't want Garrison Keillor's vision of a world where all the children are above average—we want a world where our own children are more above average than anybody else's. A friend of mine who is a principal in an affluent suburban elementary school says that in his school there are only

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are themselves beyond reproach.*

three kinds of children: gifted, very gifted, and extremely gifted. We have grade inflation because so many students and parents insist on getting top grades that now teachers give top grades to almost everybody. And we give our children Ritalin in part because we cannot bear that they be below average; indeed, we cannot bear that they not be above average. This goal itself is troubling to me, independent of any questions about the means to achieve it.

Of course, as Brock observes, such a goal is ultimately self-defeating: Once everyone achieves the same relative enhancement, the competitive benefit of the enhancement disappears. But it may be a long time before we figure this out. And in the meantime we have to live in the world that we have been creating.

The concerns that I am raising now are targeted not only against Ritalin use, but against other, more familiar and widely accepted means of enhancement as well. For I don't think that our non-pharmaceutical strategies to produce better, brighter children are themselves beyond reproach. When I compare my own childhood experiences with those of my children, I feel a sorrow that I think runs deeper than mere nostalgia for a sentimentalized version of one's own past.

When I was a child, competitive sports didn't begin until fairly late in elementary school; now they begin for some children in kindergarten or even preschool. Children who wait until third or fourth grade to join a soccer or basketball team find themselves at an insuperable competitive disadvantage. In fact, in my neighborhood, a number of the children have already burned out on a sport and decided to drop it by the age at which children a generation ago were just beginning. I began piano lessons in third grade; my own children began in kindergarten. How else can they keep up with everyone else's children who have also been studying music from the cradle—indeed, with children who listened to tapes of Mozart in utero?

And so middle-class children have childhoods in which they are chauffeured by their ever-more-frantic

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*

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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

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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

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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-

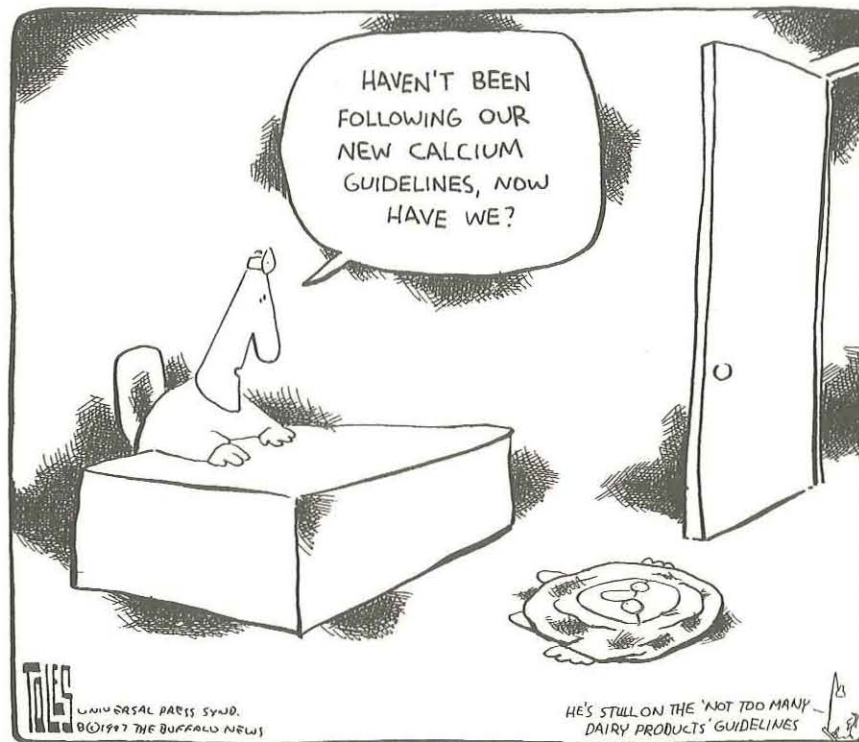
stances. No one knew how the disease arose or how to treat it. Public health actions, such as the sanitation movement, which were so effective against infectious diseases like cholera, had no apparent impact on tuberculosis. Special "lung hospitals" were established, but these served more to isolate 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

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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

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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.

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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

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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).



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