

Original Investigation

Evidence and the Politics
of Deimplementation: The Rise and Decline
of the “Counseling and Testing” Paradigm
for HIV Prevention at the US Centers
for Disease Control and Prevention

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Policy Points:

- In situations of scientific uncertainty, public health interventions, such as counseling for HIV infection, sometimes must be implemented before obtaining evidence of efficacy.
- The history of HIV counseling and testing, which served as the cornerstone of HIV prevention efforts at the US Centers for Disease Control and Prevention (CDC) for a quarter of a century, illustrates the influence of institutional resistance on public health decision making and the challenge of de-implementing well-established programs.

Context: In 1985, amid uncertainty about the accuracy of the new test for HIV, public health officials at the Centers for Disease Control and Prevention (CDC) and AIDS activists agreed that counseling should always be provided both before and after testing to ensure that patients were tested voluntarily and understood the meaning of their results. As the “exceptionalist” perspective that framed HIV in the early years began to recede, the purpose of HIV test counseling shifted over the next 30 years from emphasizing consent, to providing information, to encouraging behavioral change. With this increasing emphasis on prevention, HIV test counseling faced mounting doubts about whether it

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“worked.” The CDC finally discontinued its preferred test counseling approach in October 2014.

Methods: Drawing on key informant interviews with current and former CDC officials, behavioral scientists, AIDS activists, and others, along with archival material, news reports, and scientific and governmental publications, we examined the origins, development, and decline of the CDC’s “counseling and testing” paradigm for HIV prevention.

Findings: Disagreements within the CDC emerged by the 1990s over whether test counseling could be justified on the basis of efficacy and cost. Resistance to the prospect of policy change by supporters of test counseling in the CDC, gay activists for whom counseling carried important ethical and symbolic meanings, and community organizations dependent on federal funding made it difficult for the CDC to de-implement the practice.

Conclusions: Analyses of changes in public health policy that emphasize the impact of research evidence produced in experimental or epidemiological inquiries may overlook key social and political factors involving resistance to deimplementation that powerfully shape the relationship between science and policy.

Keywords: HIV test, HIV infections, counseling, Centers for Disease Control and Prevention.

ON OCTOBER 9, 2014, THE CENTERS FOR DISEASE CONTROL and Prevention (CDC) announced in a letter to health departments and community organizations that the agency was ending its decades-long support for an approach to HIV prevention that paired brief risk-reduction counseling with HIV testing. Acknowledging that the provision of prevention counseling in combination with HIV testing had been a long-standing intervention for people at high risk of HIV infection, the letter underscored that the decision to discontinue support was “not taken lightly” and had been reached only after an extensive review of the available scientific evidence and consultations with experts inside and outside the CDC.¹

This death knell for the venerable practice of “counseling and testing” for HIV—a prevention paradigm that had been a defining feature of the “exceptionalist” public health encounter with AIDS for a quarter of a century²—underscores the complex circumstances under which the CDC sought to base its policies on what it considered hard evidence, as well as the challenge of changing course in the face of long-standing

institutional commitments. HIV counseling has had many lives.³ It has served as a means for providing emotional support and information amid an unfolding public health crisis; a strategy for ensuring that the vulnerable were warned of the social risks of HIV testing and were not tested without their consent; an approach to providing education on sexual risk reduction; and a system for promoting behavioral change among those at risk of HIV infection. This history of the counseling and testing approach to HIV prevention illustrates the influence of institutional resistance on the development of public health policy and examines the unique challenge of deimplementation.

The CDC's most recent deliberations over the fate of HIV test counseling were sparked by the October 2013 publication of the results of a randomized controlled trial, Project AWARE, which concluded that the provision of brief prevention counseling at the time of HIV testing did not reduce the subsequent acquisition of sexually transmitted infections.⁴ An accompanying editorial, published in the *Journal of the American Medical Association (JAMA)*, asserted that the trial's results suggested that eliminating HIV test counseling would be "crucial to a broader uptake of HIV screening" and that the very perception that counseling was an indispensable part of the testing process had itself become a barrier to reducing the burden of HIV.^{5(p1680)} The CDC echoed this view in its October 2014 letter, emphasizing that test counseling "should not be a barrier to HIV testing" and that the AWARE study, along with other evidence, had "clearly" indicated that prevailing HIV test-counseling practices "should no longer be implemented."¹

The debate over the future of HIV test counseling has involved more than the impact of one well-designed trial, however. For 3 decades, controversy has haunted the peculiar marriage of serological testing with behavioral counseling, two very different interventions that at one time seemed inseparable but that came to compete for funding and attention. From the beginning, the HIV counseling and testing paradigm faced a range of questions of great significance for public health practice in the era of AIDS: Did the provision of HIV counseling and testing change behavior? What did offering "counseling" in the context of HIV testing entail? What could explain the persistence of HIV test counseling despite numerous questions about its effectiveness in altering the sexual behavior of persons testing negative?

This history underscores that from the beginning, in the mid-1980s, the HIV counseling and testing approach possessed many characteristics

of a compromise. Only with the arrival of unambiguous advances in HIV treatment a decade later and a dramatically altered social and political context for those at greatest risk of HIV infection could the counseling and testing arrangement begin to slowly unravel.

This analysis raises questions about what it means to practice “evidence-based” public health. It also addresses recent calls for analyses of the social and political factors involved in deimplementation⁶ and illustrates the extraordinary difficulty with which established practices are abandoned, even when the empirical evidence for their continuation is sparse and other effective interventions are available.⁷ In March 2015, the National Cancer Institute (NCI) identified deimplementation (or “de-adoption”) as a new priority research area, calling for inquiries into approaches that could “induce physicians and health systems to abandon ineffective interventions.”⁸ The NCI’s announcement noted that although a long line of research had examined how new discoveries are disseminated into practice, knowledge of the factors involved in de-adoption was “limited.”⁹ Indeed, a decade earlier, a systematic review of the literature on the diffusion of health service innovations found little research on the subject of how and why people and organizations discontinue practices after having adopted them.¹⁰

It is not our intention in this article to assess the merits of the available systematic research on HIV test counseling. Nor is this an exercise in deploring the obstruction of “optimal” policy paths by the deadweight of the status quo. Rather, we aim to richly describe and analyze how actors inside the CDC and within its network of partner organizations interpreted the science on test counseling and shaped the evolution of HIV prevention policy.

Methods

This article is based on an analysis of archival and published material in addition to data gathered from 2 dozen interviews completed between 2012 and 2015. The analysis was supplemented by materials gathered at the National Archives in Atlanta, Georgia, and College Park, Maryland, the New York City Municipal Archives, and the private collections of several key informants.

We identified sources for our interviews from our literature review and suggestions from experts. The participants included current and former

CDC officials, state health department officials, behavioral scientists, gay health advocates, and others involved in HIV prevention policy.

Doing Something About the AIDS Crisis: The Origins of HIV Counseling

To understand the sociopolitical context in which the CDC adopted its first policies on HIV testing and counseling, it is critical to look at the period before it assumed its role as the federal agency most responsible for addressing the American AIDS epidemic.

The notion that individuals who were sick with or at risk of AIDS would benefit from personalized counseling was an idea that emerged in the early days of the epidemic, well before an antibody test for HIV became available. "Counseling was born before testing," recalled Bernard Branson, a clinician who founded one of the earliest AIDS educational organizations in Baltimore, Maryland, and who later played a central role in shaping HIV counseling and testing standards at the CDC (written communication, September 5, 2014). Implemented first by gay community activists in response to governmental inaction in the face of a deadly epidemic, "crisis counseling" offered information, support, and palliative services to persons with AIDS or AIDS-related conditions and to the worried well. Histories of the AIDS epidemic indicate that gay health organizations started offering counseling services because they believed "no one was doing anything" about an emerging public health crisis wrought by a new and rapidly fatal disease.^{11(p4),12(p150)}

In New York City, the Gay Men's Health Crisis (GMHC), one of the first AIDS service organizations in the United States, established a telephone counseling hotline in the spring of 1982 that served as the "lifeblood" and defining activity of the organization, according to GMHC founder Larry Kramer.¹³ "I'd call every one of them back personally, explain everything. I started screaming for help from every social agency I could think of," recalled Rodger McFarlane, who launched the GMHC hotline on his home answering service.^{11(p4)} For the founders of GMHC, the "crisis" was not the spread of AIDS but the inability or unwillingness of existing social institutions to confront the outbreak.¹⁴ Indeed, a 1985 congressional review of the Public Health Service's response to AIDS concluded that public education, prevention, and the needs of AIDS patients had "not been considered funding priorities."¹⁵

These early community-based counseling efforts assumed important political and symbolic dimensions for AIDS activists. Health authorities began to acknowledge that community groups had developed valuable expertise in AIDS education: By May 1985, GMHC was counseling more than 40% of New Yorkers with AIDS, and the New York City Health Department had started referring callers who requested AIDS-related social services to the GMHC hotline.¹⁶ For volunteer counselors, bearing witness to the suffering wrought by the disease, educating the living about prevention, and “publicly owning AIDS” through intimate conversations provided a sense of purpose that challenged institutionalized homophobia.^{11(p29),17} Many counselors were motivated by their own fear of dying from AIDS.^{14(p535)} In the absence of a screening test that could identify those who were infected but not yet sick, there could be no bright line separating people with AIDS (PWA) from the counselors who assisted them. The PWA and the volunteer were “one and the same”: shipmates on a journey of collective suffering.^{11(p9)}

With the emergence of epidemiological evidence suggesting that AIDS was caused by a yet to be identified infectious agent that could be transmitted sexually,¹⁸ community-based counseling efforts increasingly emphasized risk reduction. In Baltimore, the Health Education Resource Organization (HERO) operated a hotline and distributed condoms and brochures in gay bars.^{19,20} By 1983, in California’s Bay Area, the San Francisco AIDS Foundation (SFAF) perceived a need to establish sessions led by therapists to “allow individuals to deal with lifestyle issues and risk reduction.”^{21(p51)} In the spring of 1984, CDC officials interpreted new surveillance data indicating that rates of gonorrhea were falling in a number of US urban centers as evidence that community-based AIDS education efforts were having an effect.²²

That year, the CDC commissioned a study of ongoing AIDS prevention efforts by AIDS service organizations and health departments in 9 US cities that would come to serve as a baseline assessment and the “philosophical foundation” for the agency’s approach to health education and risk reduction.^{23(p9)} These early community-based preventive efforts, grounded more in common sense than in behavioral science, gave the CDC a model to consider as the agency sought to develop a nationwide AIDS risk reduction strategy, of which the counseling and testing approach would come to form a central part.²⁴

Counseling as Consent: Protecting Autonomy in the HIV-Testing Process

By necessity, the CDC's work on AIDS in the epidemic's early years emphasized surveillance and epidemiologic investigations.²⁵ But in 1982, with the appearance of the first AIDS cases in recipients of blood transfusions, fears of a contaminated blood supply forced the question of how exactly the agency should seek to prevent transmission—even in the absence of a known causal agent, a test for its presence, or an effective treatment. James Curran, who led the CDC's early work on AIDS, recalled that with the advent of the antibody test came a sense that the agency “needed to do something” to inform people in the context of testing and that it was “better to have a process worked out while the science developed” (interview with James W. Curran, May 14, 2013). Curran expressed this view in an early draft memo on AIDS policy to CDC colleagues: “The public health importance of the problem requires that preventive action must not await the critical evaluation of approaches. The best theoretical prevention approaches should be encouraged and implemented now.”²⁶ [emphasis in original] It was in this spirit that testing and counseling were first linked. Testing would protect the nation's blood supply; counseling would assure that those who sought testing understood the social risks.

The development of the antibody test in 1984 provoked controversy from the start.²⁷ In the absence of an effective treatment for AIDS, which by the end of 1985 had killed more than 12,500 Americans,²⁸ some scientists began to argue forcefully that the best available approach to controlling transmission lay in testing all those at risk of infection, under the assumption that knowing one's status would lead to more selective sexual practices.²⁹ Indeed, the Public Health Service's January 1985 provisional recommendations on blood screening for AIDS had suggested that the test be offered to “persons who may have been infected as a result of their contact with seropositive individuals.”³⁰

In sharp contrast to this emerging view that the new test might be an important tool for prevention, gay health advocates saw in the release of the test “a runaway stagecoach.”³¹(p23) Unlike the hazy potential population health benefits of an unproven assay, the risks of stigma and discrimination were unambiguous and underscored in comments from conservative lawmakers who assailed homosexuality in the era of AIDS

as a “serious threat to the heterosexual world.”³² At a time when half of US states still regarded homosexual acts between consenting adults as criminal behavior,³³ promulgating the test as a preventive strategy appeared “more harmful to the patient than the disease we are trying to diagnose or treat.”^{31(p25)}

Technical uncertainties about the sensitivity and specificity of the test and about what a positive or negative test result really meant provoked real fears but also were leveraged by activists whose primary concern was discrimination.^{34,35} “If they test positive, they will panic. If they test negative, they may be falsely reassured,” warned a spokesperson with the National Gay Task Force.³⁶ Instead of taking a blood test of unknown prognostic value, at-risk individuals might as well “flip a coin,” asserted a draft brochure prepared by the president of the American Association of Physicians for Human Rights: “Flip a coin, the results will tell you just as much, but without the problems of confidentiality or potential loss of employment.”^{37(p25)}

It was in this charged atmosphere that officials at the CDC began to rapidly prepare a curriculum on what should be communicated to those seeking testing. The task fell mainly to the Training and Education Branch of the agency’s Division of Sexually Transmitted Disease (STD) Prevention, which was then emerging from an internal struggle over the techniques that the agency’s disease intervention specialists should use when talking with gonorrhea or syphilis patients.^{38(pp131-147)} Traditional approaches to interacting with STD clients, refined during the syphilis eradication efforts of the 1960s and early 1970s, reflected the authoritarian and paternalistic bent of public health and could be forceful and even adversarial in tone in order to overcome “the negative attitude of the patient toward the positive approach of the interviewer.”^{39(p105)} Elicitation of sexual contacts was a major goal of the “interviewing” process⁴⁰ and required program representatives to get past clients’ concerns about privacy, stigma, and legal or marital ramifications.³⁹ In tracking the spread of infections, STD investigators interviewed both positive and negative clients in the belief that all persons participating in hazardous sexual networks should be advised to reduce their risks (interview with William Darrow, March 14, 2013).

By the late 1970s, however, the STD control community, chastened by public revelations of unethical infringements on patient autonomy and basic human rights in the Tuskegee syphilis experiment and informed by a sense that browbeating was less effective with an increasingly sophisticated clientele, began to embrace motivational approaches to

client interaction grounded in theories of behavioral change. This shift in theory and attitude was reflected terminologically as the word “interviewing” gave way to “counseling.” “Old-timers” in the CDC’s STD Division grumbled that calling it “counseling” was heretical, insisting the new, watered-down approach to STD control, which placed contact tracing at the margins, was a debasement and a dangerous capitulation that would be measured in morbidity and mortality.^{38(p146)}

In fact, the complex politics and fear surrounding AIDS and the depth of uncertainty about what could be said about the meaning of antibody test results would push CDC policy even further from the assertive STD control tactics common in the battle with syphilis. Those charged with devising the CDC’s first AIDS test-counseling protocols recalled the unsettling feeling of scripting training materials for health departments in the face of “absolutely zero answers” about what a positive or negative result really meant and no experience counseling AIDS test clients. “We were winging it. We were absolutely winging it,” recalled Russell Havlak, who spearheaded the CDC’s earliest work on test counseling (interview with Russell Havlak, January 6, 2015). Rooted in the practical expertise of CDC staff with experience in STD interviewing, the materials amounted to the agency’s “best guess” on how to counsel AIDS test clients.^{23(p5)} It was important to the CDC to do “something visible” to support the states,^{23(p9)} even as the speedy rollout left agency personnel in the position of “dodging” key questions about the test that they simply were not able to answer (interview with Russell Havlak, January 6, 2015).

Gay community advocates provided direct input on the process via consultations and consensus conferences,^{23(pp1-5)} and indirect input via fervent “No test is best” demonstration campaigns and emphatic letters to health officials.^{41(p41)} “It will be essential to provide counseling before and after testing,” wrote Virginia Apuzzo, head of the National Gay Task Force, to a CDC administrator on January 18, 1985. “Before testing, to dissuade the individual from taking the test, so he/she is aware of the potential risks and the fact that there is no clinical value to the test results; after [testing], to try to explain the meaning of the test results—both positive and negative.”^{42(p95)}

Starting in the spring of 1985, the CDC rolled out training seminars in dozens of US cities focused on what counselors should communicate to test seekers.⁴³ Pre-test counseling presented those requesting testing with a primer on the test’s limitations and its possible psychological and insurance consequences and sought to verify that they still wanted

to be tested.⁴⁴ In an indication of the paucity of confidence in the test's accuracy, the thrust of post-test counseling depended not on the results of the lab assay but on social criteria.⁴⁵ Guidelines promulgated by the Association of State and Territorial Health Officials in March 1985 noted that for high-risk test takers, such as gay men, a positive result should prompt post-test advice on sexual precautions and clinical follow-up; low-risk positives, in contrast, were to be reminded of the test's limitations and told that their result "may be of questionable significance" and that there was "insufficient evidence" to warrant broad restrictions on sexual relations.^{44(p12)}

Although high-risk negatives were to be advised of the benefits of fewer sexual partners, stemming the conversion of negatives into positives was not yet a major focus of the embryonic national testing and counseling program. Indeed, the initial *Federal Register* notice announcing the alternative test site program, issued on March 12, 1985, noted that the sites were intended "to protect the nation's blood supply" and made no mention of prevention, risk reduction, behavioral change, or "safer sex."⁴⁶ In New York City, the program as implemented involved nothing short of urging at-risk persons to avoid the test and its potential to create "worries that need not exist."⁴⁷ Callers to the city's AIDS hotline were all but told that getting tested was a mistake.^{48,49}

For those who nevertheless did want to be tested, an ethical consensus was forming around the idea that the protection of patient autonomy and dignity required "sensitive and supportive counseling programs" to be available "before and after screening to interpret the results, whether they are positive or negative."^{50(p1770)} This approach reflected but one facet of the exceptionalist perspective that framed the early response to AIDS and repudiated coercive approaches to disease control that were well established in the public health tradition.² "Really the issue was, Do you really want to be tested?" recalled Fred Martich, one of 4 specialists who oversaw the CDC's early "train the trainer" seminars on testing and counseling. "The emphasis was not very much on behavioral change" (interview with Fred A. Martich, January 6, 2015).

Counseling as Education: Building the Test-Counseling Infrastructure

Less than 5 months after the antibody test was introduced, officials from the NIH, the US Food and Drug Administration (FDA), and

the CDC announced that early evaluations showed it was doing “an extremely good job” of identifying infected blood for disposal.⁵¹ Based on this evidence, CDC officials, satisfied that the worst fears of false negatives and false positives could be put to rest, acted quickly to endorse increased testing as a strategy for prevention. Operating on the premise that knowledge of infection status would foster “improved adherence” to safer sex and sterile needle guidelines, the agency’s September 1985 STD Treatment Guidelines asserted that voluntary screening of high-risk groups “should be encouraged.”^{52(p76S)} This strategy was given greater emphasis and dissemination 6 months later when the CDC issued its March 1986 *Morbidity and Mortality Weekly Report (MMWR)*, which noted that voluntary testing and counseling could provide an occasion for high-risk negatives to learn about AIDS and the need to “monitor their infection status.”⁵³

Thus, careful as the public health establishment had been from the inception to publicly emphasize that the new blood screening tool was “not a test for AIDS,”⁵⁴ it nevertheless quickly embraced the antibody-testing process as a potentially powerful device for modifying AIDS-related risk behaviors and reducing transmission. In fact, those intimately involved in the rollout of the CDC’s HIV testing efforts later acknowledged that within the agency, “it was conceded from the very beginning, it was never argued, that this testing would become a diagnostic tool [for HIV infection]. It was taken as an article of faith.”^{23(p4)}

It was in this context that counseling assumed a starring role, a shift reflected in the May 1986 reauthorization of the alternative test sites, which renamed them “Counseling and Testing Sites.”⁵⁵ Promoting “safer sex” via counseling in association with testing would now be a priority function of the program. The new combination strategy—behavioral counseling linked with biomedical testing—represented a rejection of the impassioned views of both those who insisted that the threat of AIDS demanded no-nonsense public health policies, including mandatory screening, and those who warned that HIV testing, if too broadly applied, threatened to “create a caste system in which there will be a large group of ‘untouchables.’”⁵⁶

At a February 1987 conference on the uses of the antibody test in AIDS prevention, CDC officials affirmed their position that voluntary testing would function as an “adjunct” to counseling because “most of the good that is done . . . is mediated through the counseling. The testing without the counseling accomplishes very much less good.”^{57(p2)} Updated

guidelines on HIV prevention in the context of antibody testing, published in August 1987, invoked the new mantra “counseling and testing” 18 times.⁵⁸ Although some health officials noted privately their suspicions that the new counseling emphasis represented a “monkey wrench” designed by gay activists to obstruct routine testing (interview with Mark Barnes, March 27, 2013), the counseling and testing paradigm quickly became the “cornerstone” of HIV prevention efforts.⁵⁹ For AIDS doctors, providing counseling helped build rapport with patients and addressed a deeply felt professional need to offer something concrete that might arrest both the mounting toll of AIDS-related suffering and their own grim experience of clinical impotence that one pioneering San Francisco clinician likened to serving as a “travel agent for death.”^{60(p171)}

For gay activists, however, the public health establishment’s embrace of counseling was regarded with some suspicion. For some of them, the CDC’s subtle shift from “testing and counseling” to “counseling and testing” smacked of manipulation (interview with David G. Ostrow, December 10, 2014). By foregrounding an intervention closely associated with the affected community and refining it with a scientific orientation to be paired with increased testing, the CDC seemed to be inching toward the medical-model approach that some activists suspected it had always wanted. Other critics argued that the nation’s limited prevention resources would be better spent on community-level education or questioned whether the sorts of brief counseling that could be delivered in the hectic testing context would actually have a measurable impact on the epidemic.⁶¹ Indeed, existing test-counseling practices could be perfunctory and “focused on the test results” much more than on prevention, recalled one veteran counselor of his work at the San Francisco AIDS Health Project starting in 1986.^{62(p97)}

By the late 1980s and early 1990s, the CDC’s counseling and testing program was undergoing rapid growth and institutionalization.^{62(p97)} Education campaigns under the banner “America Responds to AIDS,” media coverage of the risks of heterosexual transmission, and publicity surrounding the efficacy of the drug zidovudine (AZT) in slowing the onset of the disease boosted demand for testing.⁶³ After basketball star Earvin “Magic” Johnson’s disclosure in November 1991 that he was HIV positive, a deluge of anxious clients flooded the nation’s testing centers.⁶⁴ Accompanying this rapid growth in the program was a steep decline in the percentage of clients testing positive. In May 1986, at the end of the first year of test site activity, the CDC reported that of 79,100

persons tested, 17.3% had tested positive.⁶⁵ By 1990 this figure had dropped to 3.8% (of 1.5 million tested), and by 1992 it reached 2.0% (of 2.7 million).^{66(p68)}

In the face of this declining yield, the CDC's counseling and testing program—the largest of all US HIV prevention efforts in terms of resource support—began to fall under heavy scrutiny from critics in the federal government.⁶⁷ “If we are providing a significant proportion of counseling and testing services to relatively low-risk individuals, then a potentially serious misallocation of limited resources may exist,” testified Michael Zimmerman of the General Accounting Office (GAO) in June 1988 before the Senate Committee on Governmental Affairs.^{68(p315)} A drumbeat of critical GAO reports followed, concluding that the CDC's counseling and testing services were not reaching key high-risk groups, did not follow up on the 40% of clients who did not return for their test results, and displayed wide variation in the extent of counseling offered.^{69,70} Of particular concern were deficient evaluation practices: “Little detailed information is available on the function and effectiveness of HIV counseling and testing services, particularly as they relate to changing high-risk behaviors,” stated a GAO report in June 1991.⁷¹

Scholarly reviews concurred that the data on the effectiveness of counseling and testing in changing risk behaviors were “mixed.”^{61(p1533)} Existing studies indicated that those testing positive seemed to exhibit more risk reduction than did seronegatives.⁷² Particularly troubling were scattered anecdotal reports of a “disinhibition syndrome” in some of those testing negative, in which the favorable test result—or perhaps even exposure to didactic test-counseling sessions—served to inadvertently prompt or license continued risk taking.⁷³ Feedback provided to the CDC by counselors working in the early years of the program suggested that “people who were seropositive or high risk seronegative in post-test counseling, for reason of shock or absolute elation, were not listening to what you were saying about risk reduction.”^{23(p12)} It was noted within the agency as early as 1989 that if an effective biomedical treatment did not rapidly emerge, agency planners would have to “wake up” and acknowledge that they had “no confidence” that the counseling and testing program had diminished transmission.^{23(p18)}

In response to this unsettled situation, in 1990 a group of scientists in the CDC's Division of STD/HIV Prevention began reviewing the literature for evidence that the counseling and testing approach was achieving its desired effect. Noting that the question most frequently posed by

policymakers was, What impact has C&T had on HIV risk behavior?, the review lamented that although behavioral science research in general had indicated that few people made lasting changes following a single counseling session, “this is the standard to which C&T is most often held.”^{74(p2419)} After analyzing the data from 50 studies, the authors found little clear evidence that the paired interventions were achieving risk reduction in such high-risk populations as gay men and intravenous drug users. In an acknowledgment that the review’s dispiriting findings were not unexpected, the CDC scientists concluded that “it is not surprising that the combination of HIV testing with a single pretest and a single post-test counseling session does not effect sustained behavioral changes in all individuals.”^{74(p2427)}

The publication of this review, in November 1991, prompted a House subcommittee to pointedly challenge the CDC’s approach to AIDS prevention. “Do you agree that the vast majority of the studies in this article report that there is no significant short-term or long-term behavior change resulting from counseling and testing?” asked the subcommittee in a written query.^{75(pp176-177)} In reply, the CDC stated that it believed “counseling and testing is often the first step in making a permanent, positive change in behavior.”^{75(p177)} Noting that an expert panel of the National Research Council had concluded that it would be “unethical” to withhold test counseling from one arm of a study in order to assess whether it was effective in changing risk behaviors,^{76(p332,n13)} the agency underscored that it was in the process of developing a large-scale randomized trial that would test a new form of “enhanced” HIV counseling and testing against its existing regimen.⁷⁷

Counseling for Change: Grounding Test Counseling in Behavioral Theory

By the 1990s, the heated discussions about HIV counseling and testing had begun to produce divisions within the CDC itself. In parts of the agency, those who were most enthusiastic about counseling continued to assert that the heightened anxiety of the testing context presented a unique “teachable moment” during which prevention messages could have an impact. Those who were skeptical of the benefits of HIV test counseling, in contrast, contended that CDC dollars should be devoted to a medical prevention model centered on increased testing.

Meanwhile, leading prevention specialists working outside the agency began to insist that federal HIV prevention resources should be devoted to broad condom-promotion campaigns in light of the CDC's own exacting review demonstrating "the limited effectiveness of counseling and testing as a centerpiece strategy for AIDS prevention."^{78(p112)} Mary Jane Rotheram-Borus, director of UCLA's Center for HIV Identification, Prevention, and Treatment Services, started in 1995 and funded by the National Institute of Mental Health, recalled that by the early 1990s, "it was clear that counseling was ineffective. No one followed the guidelines—ever—and the quality was poor" (interview with Mary Jane Rotheram-Borus, March 18, 2013). Because clinics were reimbursed on the basis of the number of tests provided, there was no incentive to maintain high-quality, time-consuming test counseling. In some settings, it was routine to prompt patients to pursue repeated testing.^{62(p98)}

Such challenges were reflected in the scathing conclusions of an external review of the CDC's HIV prevention strategies commissioned by the CDC Advisory Committee on the Prevention of HIV Infection. The 1994 report observed that the counseling and testing program was not being implemented as designed, was not working effectively, and needed "major changes."^{66(p67)} Visits to federally funded test sites and STD clinics had revealed "little effort to assist people in reducing high risk behaviors." Referral services typically were nonexistent. Counselors expressed frustration that many clients seemed not to heed risk-reduction messages, opting instead to seek testing every 3 to 6 months in an act of ritual purification, and noted with alarm that many who tested positive said they had interpreted earlier negative results as "an indication that their previous high-risk behaviors were safe." The review proposed that many of these problems arose because "counseling" was "a generic term with many different meanings."^{66(p65)} In the context of HIV testing, "counseling" could mean offering informed consent; it could mean intervening to encourage behavioral change; it could mean providing psychosocial support.

It was this concern that drove the CDC to overhaul its test-counseling procedures to ground them securely in psychological theory. New technical guidance on HIV test counseling, based on expert opinion, was distributed to health departments in February 1992.⁷⁹ The new guidance underscored that HIV counseling "must do more than provide factual information in a didactic manner" and endorsed personalized, empathic techniques in which the client would be guided to "take

‘ownership’ of his/her risk for HIV infection” and develop and enact a plan for behavior change.⁷⁹ Additional HIV counseling standards and guidelines for high-risk test clients, issued in 1994, emphasized the importance of using the pre-test counseling session to “negotiate” an attainable risk reduction plan. In the post-test session, counselors were instructed to “renegotiate or reinforce” the existing plan, although it was acknowledged that “the client will most often focus on the actual result itself rather than behavioral and prevention messages.”^{80(p2)}

This overhaul was undertaken alongside an effort to design a randomized trial that could rigorously test the new protocol’s efficacy. Designed in the early 1990s but not published until 1998, more than a decade after the CDC had launched its national counseling and testing program, the results of the multisite trial, Project RESPECT, appeared to provide high-caliber evidence in support of the CDC’s “client-centered” combination of pre- and post-test HIV counseling. For many at the agency, the study put to rest the CDC’s own acknowledgment that until that point, “the efficacy of such counseling in reducing HIV or other STDs had not been shown.”^{81(p1166)} A press release noted that the “now-proven” approach was implemented with existing clinic staff and cost only 8 additional dollars per client. “With this program the ideal can be real, with few additional resources,” noted the release, quoting the lead investigator, Mary Kamb.⁸²

The new evidence did not resolve the controversy, however, but merely served to energize the opposing forces within the CDC. Those who remained broadly skeptical that the sorts of brief counseling sessions that could be delivered in the HIV-testing context could reliably alter risk behaviors found the RESPECT trial hardly definitive. They noted that the study had not included gay men and offered cash incentives to participants. Appearing to buttress this perspective were the results of a new meta-analysis of the effects of HIV counseling and testing on sexual risk behavior—published in the *American Journal of Public Health* (*AJPH*) in 1999—which concluded that “HIV-CT, at least as it was implemented in the studies reviewed, does not appear to be an effective intervention for the primary prevention of HIV infection.”^{83(p1403)} The study found that HIV-negative individuals did not reduce their risk behavior any more than untested participants did.

The conclusions of this meta-analysis were sharply challenged by the CDC’s RESPECT investigators in a letter to the *AJPH*. The authors had “inappropriately used their findings to evaluate CDC’s client-centered

HIV prevention counseling method,” asserted the CDC investigators, adding that the agency’s new approach was “categorically different” from older techniques used in the majority of the studies in the meta-analysis.^{84(p1152)} David Holtgrave, who served as director of the CDC’s Division of HIV/AIDS Prevention–Intervention Research and Support from 1997 to 2001, recalled that the authors of the meta-analysis had taken “a whole bunch of things and called them counseling but that were really comparing different things.” If the authors had looked at counseling approaches that were “more engaging of clients,” he noted, the results would have been more positive (interview with David Holtgrave, March 31, 2013).

Meanwhile, it was clear that a gap remained between the hopes that federal health planners placed in their network of test sites and the stark realities facing test counselors working in the states. Speaking at a meeting of test site coordinators in May 1997, the director of California’s HIV counseling and testing division noted that while many health officials up the “food chain” of government thought of the counseling and testing approach as “the cure,” counselors working on the front lines of HIV prevention understood the program’s limitations.^{62(p103)} The director emphasized the importance of spending time on referrals, both because it was clear that the test-counseling encounter was not doing enough to reduce risk behaviors and because providing referrals allowed test sites to bill the federal government an extra \$5 per client.^{62(p105)}

Counseling in Decline: The Slow Unraveling of the Counseling and Testing Paradigm

At the same moment that the CDC was beginning to impress upon its small army of HIV test counselors the importance of employing its new theory-based approach to counseling, researchers seeking biomedical interventions that might arrest the progression of HIV infection were making advances that culminated in a watershed moment in the treatment of AIDS.⁸⁵ At the end of 1998, an editorial in the *New England Journal of Medicine* announced that “good news” had arrived in the battle with AIDS: the number of deaths from the disease had finally declined, thanks to the availability of potent new combinations of antiretroviral drugs.⁸⁶

The impact of the advent of highly active antiretroviral therapy (HAART) reverberated across the full spectrum of CDC approaches to HIV prevention, including the counseling and testing program, by then a decade old.⁸⁷ No longer did it seem beyond question that the HIV test had to be ensconced in protective layers of personalized counseling. The epidemic remained vast, and new cases were not in decline.⁸⁸ To identify the large numbers of infected individuals who were unaware of their status and get them into treatment, some barriers to routine testing would have to be removed. In 1998, Kevin De Cock, a British clinician who directed the CDC's Division of HIV/AIDS Prevention–Surveillance and Epidemiology from 1997 to 2000 and later led the World Health Organization's (WHO) AIDS activities, began to argue that the advances in HIV treatment, and the failures of counseling and testing, required that the testing process be “normalized” in recognition of the fact that “what once was protection of individual rights may now represent negligent practice and missed opportunities for prevention.”⁸⁹(p292)

Changing norms in the health sciences also began to exert new pressures on the CDC to ask searching questions about the epistemic basis for its HIV prevention efforts, including the counseling and testing approach. In the late 1990s, members of Congress began to perceive a difference between the prevention science activities supported by the NIH and those being carried out in community settings and funded by the CDC.⁹⁰ Such scrutiny prompted the CDC to collaborate with the Institute of Medicine to compile a new authoritative document, the *Compendium*, first issued in November 1999 and consisting of a select set of effective behavioral interventions (EBIs) that could be justified scientifically under the exacting precepts of “evidence-based” medicine.⁹¹ RESPECT-style HIV test counseling, supported by the CDC's own 1998 trial, which had won the agency's Charles C. Shepard Science Award for excellence in original research, was deemed to meet the CDC's new criteria for rigor and impact—in heterosexual adult populations—and was included in the first edition of the *Compendium*.⁹¹(pp1-11)

It was remarkable, then, that just as the CDC appeared to have finally certified its test-counseling strategy as an evidence-based intervention that the foundations of the counseling and testing paradigm began to crack. The imperatives of clinical pragmatism, not simply debates over the empirical evidence, forced the issue. In 1999, an analysis by the Institute of Medicine found that HIV transmission from mother to child persisted despite the existence of effective antiretroviral chemoprophylaxis

in part because some providers, finding counseling to be a burden, did not offer testing to all pregnant women.⁹² Confronted with this challenge, the CDC undertook a review of its guidelines. Whereas previous agency guidelines had emerged from the deliberations of a conclave of experts and had been almost “Delphic” in nature, recalled Mary Kamb, lead investigator of the RESPECT trial, this new review was driven by a fundamentally different posture on what should count as evidence. Using systematic methods adopted from the US Preventive Services Task Force, the reviewers assembled complex tables of quantitative research results to determine whether the available empirical evidence was “good or not good” (interview with Mary Kamb, December 3, 2013).

The CDC’s review of the literature on test counseling, spearheaded by Kamb, who had so enthusiastically announced the results of the RESPECT trial, found little empirical evidence that counseling interventions had been beneficial, especially for key high-risk groups such as gay men. The review did, however, conclude that for certain populations, like adolescents, there was a body of evidence—foremost the data from the RESPECT trial—indicating that test counseling could offer benefits. “But for most people who were being tested—the worried well—what was the benefit? There was no benefit,” recalled Kamb of the agency’s turn-of-the-century evidence review (interview with Mary Kamb, December 3, 2013).

After an extensive series of consultations with stakeholders, the CDC’s new guidelines for HIV counseling, testing, and referral, published in 2001, officially decoupled counseling and testing. Underscoring that counseling remained a “high priority” in settings in which the HIV prevalence was high because of the “proven efficacy” of prevention-counseling models, the guidelines nevertheless acknowledged that “providing it [counseling] to everyone receiving HIV testing might not be feasible” and that practitioners needed flexibility: “Certain providers might be able to offer prevention counseling but not an HIV test, whereas others might be able to offer an HIV test but not prevention counseling.”⁹³ Noting that the terms “pre-test” and “post-test” had been abandoned, the guidelines suggested that single-session counseling sometimes could be used.

The CDC’s embrace of flexibility was in part a response to new, rapid HIV-testing technologies that allowed clients to receive their results on the same day, an advance that promised to address the problem of test seekers who did not return for their results.⁹⁴ Recognizing that the

adoption of rapid testing threatened its 2-session RESPECT counseling model, the CDC undertook a new trial, RESPECT-2, to compare the efficacy of counseling with rapid testing with counseling with standard testing.⁹⁵ For those at the CDC who viewed HIV test counseling as an expensive practice of dubious efficacy, the results of the new trial, published in 2005, provided a new basis for concern. Hints in the data—although not statistically significant—that the RESPECT intervention might be prompting “disinhibition” among men who had sex with men (MSM) following a negative result raised the possibility that the agency’s counseling and testing approach was not simply burdensome but also potentially dangerous. Inside the CDC, the question of whether “RESPECT hurts MSM” became a source of debate, with those who persisted in their skepticism of counseling asserting that even a hint of such unintended consequences should prompt a rethinking of agency policy.

The next year, it became clear that the ethics of counseling and testing had shifted dramatically for those influencing HIV prevention policy at the CDC: New agency recommendations for routine HIV testing in clinical settings announced that a special consent process and test-linked prevention counseling would no longer be required.⁹⁶ In so doing, the CDC made clear that among the oldest functions of test counseling—assuring informed consent—was no longer central to HIV testing in the HAART era. Consent could be presumed in the context of the opportunity to opt out of testing. And whereas for 2 decades, test counseling had stood as an effort to protect those at risk of HIV infection from their own risky behaviors, the emergence of an effective treatment had made it necessary to protect the public from the possibility that the CDC’s counseling requirement was itself doing harm by impeding the uptake of HIV testing (interview with Bernard Branson, November 17, 2012). More than 250,000 Americans were believed to be infected but unidentified, and agency personnel had come to believe that those who were unaware of their status were a threat to public health.⁹⁷ Taking note of the success of universal HIV-screening strategies and the fact that the prevention benefits of test counseling were “less clear,” the 2006 recommendations noted that busy providers often did not have the time to offer counseling and might perceive it as a barrier to testing.⁹⁸

Reflecting the nature of the behind-the-scenes debate in the CDC over RESPECT, as well as the reality of the agency’s long-standing commitment to the importance of test counseling, these new guidelines did

not extend to nonclinical settings, such as community centers or mobile vans. For agency decision makers, the continuation of test-counseling services in such settings could be justified both because the clients involved were believed to be at high risk and because of “the political consideration at the time that expanding testing was creating a lot of resistance among advocate communities if it was done without counseling,” recalled one agency informant, who by then had concluded that the time to abandon test counseling had arrived (interview with CDC informant, not for attribution). Indeed, at the time, some frontline public health workers in AIDS service organizations still felt that “if we don’t do the counseling, then people are going to jump off bridges” (interview with HIV policy expert, not for attribution).

Community-based constituency pressure during the prepublication period had, in fact, persuaded the CDC to soften the language of its recommendations, from stating that test counseling was “not recommended” in health care settings to recommending that such counseling be “not required,” an alteration that underscored the central role of politics in evidence-based policymaking.⁹⁹ Such modifications did not blunt the emergence of pointed criticism. After the guidelines were published, two bioethicists questioned why the CDC had failed to heed the evidence produced in the RESPECT trial and wondered whether cost-efficiency was the “true motivation” behind the new counseling recommendations.¹⁰⁰ Longtime counseling supporters also denounced the test-counseling rollback, asserting that the CDC’s policy shift could be construed as a “negligent and harmful act.”¹⁰¹

Despite these objections, it was apparent that those who were convinced that test counseling was an essential and effective preventive intervention had interpreted the CDC’s “bizarre” decision to eliminate the counseling requirement in clinical settings as a dark tocsin marking “The Death of Client-Centered Counseling.”^{102(p51)} The shift was seen as a patent indication of “how the highest levels of CDC policy makers view[ed] behavioral interventions.”^{102(p51)} To proponents of test counseling, it was beginning to appear as if the gold-standard evidence generated in the RESPECT trial was functioning as an “inconvenient truth” for CDC leaders who, they believed, wished to eliminate the practice of test counseling altogether (interview with David Holtgrave, March 31, 2013). Indeed, momentum did appear to be shifting away from counseling and toward expanded testing as state after state began

to modify the HIV testing policies they had adopted in the late 1980s and early 1990s.¹⁰³

But HIV test counseling was not yet at an end. Remarkably, a veritable boom in RESPECT-style counseling was only just beginning, thanks to concurrent, and seemingly countervailing, policy commitments within the CDC. Prompted by a 2001 report from the Institute of Medicine urging the agency to accelerate the translation of its findings from prevention research into action,¹⁰⁴ in 2002 the CDC had developed the Diffusion of Effective Behavioral Interventions (DEBI) project, in which a subset of its EBIs were to be distilled into easy-to-use intervention kits to be disseminated to health departments and community organizations. RESPECT-style counseling had passed muster, with access to federal dollars linked to its adoption, and diffusion began in 2006.¹⁰⁵ Thus, at the very same moment that test counseling was being eliminated from health care settings as a consequence of the CDC's 2006 guidelines, the agency was ramping up training in RESPECT-style counseling in community settings in concert with the agency's push for expanded rapid testing. Through 2006, when the CDC stopped recommending HIV test counseling in clinical settings, the agency had completed just 7 RESPECT trainings; by the end of December 2013, the tally had reached 128, with nearly 2,100 trainees attending (written communication, Charles Collins, October 30, 2015). A broad national network of trained HIV test counselors working in community organizations were thus coming to define their very purpose in terms of the provision of RESPECT-style counseling.

Meanwhile, scientists exploring the potential of pharmacologic therapies to reduce viral loads and render the infected less infectious were increasingly coming to believe that an aggressive "test and treat" program might dramatically outperform existing behavioral risk reduction approaches and "counter prevention pessimism."^{106(p9)} In 2011, the results of a clinical trial involving HIV-discordant couples indicated that immediate initiation of drug therapy after a positive test result reduced by 96% the rate of transmission to the uninfected partner.¹⁰⁷ The next year, a trial conducted in Kenya and Uganda found that the use of antiretroviral therapy, pre-exposure prophylaxis (PrEP), by *uninfected* individuals could protect them from becoming infected.¹⁰⁸ As drug treatment became plausible as a preventive strategy for both seropositives and those merely at risk of infection, was test counseling to become the handmaiden to pharmacologic intervention?¹⁰⁹ Would behavioral

change involve an emphasis not on safer sex and sterile needles but on adherence to drug-dosing schedules?

By 2012, the proliferation of effective prevention options, the persistence of 50,000 new HIV infections in the United States annually, and the fact that inflation-adjusted federal domestic spending on HIV prevention had not increased since 1991 led CDC leaders to announce that it was time for a sober new strategy. An article titled “The Future of HIV Prevention in the United States” by two senior agency officials observed that while it had been common in public health to use “combination prevention” approaches, “giving equal weight to all effective interventions is inherently flawed.”^{110(p347)} In order to achieve “High Impact Prevention,” the CDC would have to prioritize among interventions and consider not simply efficacy but also cost-effectiveness, feasibility, and scalability. This shift took place in an institutional context in which CDC leadership had already signaled its view on the status of counseling. A 2010 commentary by the CDC’s director, Thomas Frieden, described a 5-tier “health impact pyramid” that placed “counseling and education” on the least effective level. “Counseling, either within or outside the clinical context, is generally less effective than other interventions,” wrote Frieden. “Successfully inducing individual behavioral change is the exception rather than the rule.”^{111(p592)}

For those working on the front lines of HIV prevention, the CDC’s continuing support for community-based test counseling during this period, when it was clear that “change was in the water,” painted a very confusing picture. “It was hard to get clear direction from CDC about where they were going on counseling, and what the model was, and who counseling was best for, and what the efficacy of it was,” recalled one HIV policy expert involved in state-level activities (interview with HIV policy expert, not for attribution). Different CDC constituencies held different beliefs and priorities.

Indeed, those within the CDC who supported test counseling insisted there was sufficient empirical evidence of efficacy and emphasized its low cost, its ethical importance, and the fact that the agency’s commitments to its platoon of community-based test counselors would make attempts at changing the policy akin to turning an ocean liner at sea. In contrast, CDC planners who argued in favor of scaling back test counseling asserted that the CDC’s lingering support for test counseling in an era of increasing HIV medicalization made it appear as if some parts of the agency had just stepped out of a time machine, pressing forward

with an anachronistic intervention designed to address an untreatable disease that no longer existed. For Mary Jane Rotheram-Borus, a long-time student of the CDC's HIV prevention efforts, the persistence of test counseling in the HAART era was a product of the agency's sensitivity to constituencies that were resistant to change: "There's an HIV industry that's very well funded. There were entrenched systems with huge incentives. Eliminating counseling would have eliminated a critical funding stream" (interview with Mary Jane Rotheram-Borus, March 18, 2013).

It was in this complex milieu that findings from Project AWARE, a randomized controlled trial conducted in 9 STD clinics, became public. The results, published in *JAMA* in October 2013, found no significant difference in cumulative sexually transmitted infections between those who received counseling and those who did not.⁴ Coverage in the *Washington Post* appeared under the headline "HIV counseling is often ineffective. So we should make HIV testing less cumbersome."¹¹²

Immediately, the question of what to do about test counseling became a "very hot issue" in the CDC (written communication, Charles Collins, December 5, 2013). In fact, the agency was already in the midst of assessing its portfolio of interventions for HIV to determine which of them remained compatible with the agency's commitment to high-impact prevention and a new mantra that "sunk costs" could not be a factor in determining policy (interviews with David Purcell, January 9, 2014, and Jonathan Mermin, January 13, 2014). At the behest of the agency's senior leadership, a working group was empaneled and charged with weighing the evidence to determine future policy directions regarding counseling paired with HIV testing. By April 2014, it was clear that the agency's internal review had failed to show that test counseling was adding value to the CDC's HIV prevention efforts. By July, agency administrators had begun notifying some health departments that the CDC was suspending all training in RESPECT (interview with Charles Collins, July 30, 2014). The formal notification went out in October 2014.¹

The new CDC policy, which marked an end to the counseling and testing paradigm in the United States, does not suggest that all counseling approaches have lost support. The US Preventive Services Task Force, an expert panel charged by the federal government with producing recommendations based on systematic reviews of the evidence, endorses intensive behavioral counseling to prevent sexually transmitted infections in sexually active adolescents and at-risk adults.¹¹³ Moreover,

some social scientists and clinicians who have been long committed to the study of HIV counseling continue to assert that the empirical evidence is strong, that it is the CDC's priorities that have changed. Guidelines for HIV prevention in clinical care settings from the International Antiviral Society–USA Panel (IAS–USA), released in 2014, note that although test counseling is “a complex topic” and that the evidence for its effectiveness is mixed, the integration of biomedical and behavioral approaches should continue to serve as the “cornerstone” of efforts to curb the spread of HIV infection.¹¹⁴ The IAS–USA guidelines state that the panel “intentionally avoided distinguishing between behavioral and biomedical interventions” in order to underscore that providing prevention in care “requires a combination of activities.”

But with the release, in May 2015, of the results of the START trial indicating that HIV-infected individuals have a much lower risk of developing AIDS or other serious illnesses if they are started on antiretroviral therapy immediately after testing, it is clear that the battle against AIDS will increasingly be medicalized.¹¹⁵ Early therapy is seen as providing a “double benefit,” protecting not only the health of infected patients, but also reducing viral loads and the risk that they will transmit HIV to others.¹¹⁶

Conclusion

The 30-year saga of HIV counseling and testing provides a unique opportunity to examine the question of what counts as evidence and how scientific research and its absence shape the making of public health policy. In the face of an epidemic that became the defining challenge to public health in the last decades of the 20th century, public health officials moved to adopt policies that they had common sense and experiential reasons to believe might have an impact, despite the absence of strong empirical evidence. In fact, as we have shown, not until 1998 did a CDC-sponsored investigation suggest that counseling linked to testing could reduce the incidence of HIV infection. By then, both within the CDC and across the nation, test counseling had become a pillar of the public health response to AIDS, supported by a huge investment of resources and a cadre of personnel who had come to define their efforts to contain AIDS and provide respect for those at risk in terms of the counseling they provided. When social scientific evidence later

began to raise questions about whether counseling could be defended in terms of cost effectiveness, it was in the context of the medicalization of the discourse surrounding AIDS, the role of antiretroviral therapy in reducing the viral load of those already infected, and the need to protect those at risk from acquiring HIV.

It is not surprising that those who viewed their institutional and professional investments in counseling as under threat resisted the prospect of change. At a personal level, those who had devoted their working lives to addressing AIDS had to confront the judgment that their efforts had produced less impact than they had believed they would. The clinician Frank Davidoff has described a number of factors that may make it difficult for practitioners to abandon well-established practices whose effectiveness is later challenged, including the preference for the familiar, shame at having used a discredited practice, regret over sunk costs, fear of a loss of revenue, and basic inertia.⁷ The NCI has outlined factors that may inhibit deimplementation, including patient demand, practitioner knowledge, system inertia, and economic pressures.⁹ Several lines of research suggest that specialist societies may be particularly resistant to scientific reversals and calls to scuttle well-worn practices,¹¹⁷ especially when the intervention in question is judged to be important by society members.¹¹⁸

For public health specialists working in agencies charged with taking action to address emerging disease crises for which there is often little or no relevant research, it can be difficult or impossible to devise policies that are “evidence-based” in the conventional sense.¹¹⁹ Evaluating whether new policy approaches are working can be challenging and time-consuming, and in the meantime these interventions may acquire status and importance by virtue of their promotion by recognized authorities. Whether efficacious or not, their administration assuages anxiety engendered by perceptions of a disease out of control and demonstrates that responsible experts are “doing something” to ameliorate the unfolding crisis.⁴⁵

From the start of the fight against AIDS, HIV test counseling fulfilled multiple linked functions—ethical, political, preventive—that invested it with unique importance. Research evidence was later developed to support a policy already selected. The field of public health may be especially prone to the generation of “policy-based evidence,” because of the pressure to make “science-based” decisions under profound and often inescapable time constraints and because policy formation often

occurs at the limits of existing knowledge.¹²⁰ The impulse to take action may influence decision makers' interpretations of the evidence,¹²¹ and perceptions of a need to protect credibility and deflect criticism may promote a tendency to find evidence that supports existing policies and to conceal conceptual doubts in the backstage.¹²²

Moreover, public health policies are frequently developed and disseminated through a broad organizational infrastructure into which they become deeply embedded. Implementation presses policy into networks of stakeholders who may guard their positions and develop a sense of ownership over the unfolding project.¹²³ This infrastructural inertia makes reversal particularly difficult, especially for practices that are venerated as "scientific" and have become widely accepted and routinized.¹²⁴ In this respect, public health policy paradigms may resemble scientific paradigms in their essential stickiness.¹²⁵ For HIV test counseling, even in the face of persistent questions about whether it "worked" and in the presence of effective prevention alternatives, it was difficult for decision makers to embrace deimplementation.

All of this suggests that analyses of public health policy change that focus narrowly on matters of experimental or epidemiological evidence will overlook fundamental but harder-to-quantify factors involving the politics of public health that powerfully affect—indeed, often drive—the relationship between science and policy.

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