

SOUNDING BOARD

Health Care Disparities — Science, Politics, and Race

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Do members of disadvantaged minority groups receive poorer health care than whites? Overwhelming evidence shows that they do.¹ Among national policymakers, there is bipartisan acknowledgment of this bitter truth. Department of Health and Human Services (DHHS) Secretary Tommy Thompson has said that health disparities are a national priority, and congressional Democrats and Republicans are advocating competing remedies.^{2,3}

So why did the DHHS issue a report last year, just days before Christmas, dismissing the “implication” that racial differences in care “result in adverse health outcomes” or “imply moral error . . . in any way”?⁴ And why did top officials tell DHHS researchers to drop their conclusion that racial disparities are “pervasive in our healthcare system” and to remove findings of disparity in care for cancer, cardiac disease, AIDS, asthma, and other illnesses?^{5,6} Secretary Thompson now says it was a “mistake.” “Some individuals,” Thompson told a congressional hearing in February, “wanted to be more positive.”⁷

But when word that DHHS officials had ordered a rewrite first surfaced in January, the department credited Thompson for the optimism. “That’s just the way Secretary Thompson wants to create change,” a spokesman told the *Washington Post*. “The idea is not to say, ‘We failed, we failed, we failed,’ but to say, ‘We improved, we improved, we improved.’”⁸ According to DHHS sources and internal correspondence, Thompson’s office twice refused to approve drafts by department researchers that emphasized detailed findings of racial disparity.⁵ In July and September, top officials within the offices of the assistant secretary for health and the assistant secretary for planning and evaluation asked for rewrites, resulting in the more upbeat version released before Christmas.

After unhappy DHHS staff members leaked drafts from June and July to congressional Democrats (and to me), Thompson released the July version. For all who are concerned about equity in American medicine, issuance of the July draft was

an important step forward. The researchers who prepared it showed that disparate treatment is pervasive, created benchmarks for monitoring gaps in care and outcomes, and thereby made it more difficult for those who deny disparities to resist action to remedy the problem. And therein lies the key to how the rewrite came about — and to why the episode is so troubling.

A coherent vision motivated the proponents of the rewrite. This vision stresses the centrality of personal responsibility, both for our health and for our circumstances more generally. To call the rewrite’s supporters racially insensitive oversimplifies matters. In their eyes, assertions of racial inequity in health and medical care are objectionable because they point away from patient responsibility, toward the need for health care providers and government to do things differently. And initiatives to reduce disparities undercut the message that citizens should care for themselves.

In an internal DHHS memo, Arthur J. Lawrence, principal deputy assistant secretary for health and one of those who pushed for the rewrite, argued that the report’s section on health care providers’ responsiveness to patients’ needs “should either be dropped or rewritten to reflect . . . the importance of the exercise of personal responsibility in outcomes.” To “focus . . . so strongly on the system, its practitioners, and flaws,” Lawrence wrote, “suggests that the onus is only on that side of the equation.”⁹

Seen through this lens, the truth that there are leaps of inference between raw data and findings of racial disparity looms large, leaving room for doubters to raise questions. But these leaps of inference are not leaps of faith. They reflect painstaking assessment of relative probabilities, assessment that considers confounding factors and weighs the cumulative implications of multiple studies. The Institute of Medicine Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care, on which I served, identified more than 100 studies that sought to control for confounding var-

ables, including income, insurance status, and education.¹ Nearly all these studies, in our judgment, contained flaws in design or data analysis. For many of us, it was possible to imagine confounding factors, such as geographic variation in care and subtle differences in insurance coverage, that the study designs did not address.

Inference on our part was thus necessary. In concluding that racial and ethnic disparities in care exist, are associated with worse outcomes, and occur apart from insurance status, income, and education, we relied on the fact that most of the studies we examined supported this finding. The July draft of the DHHS report, prepared by researchers at the Agency for Healthcare Research and Quality (AHRQ), treated our conclusion as “definitive.”¹⁰ The December rewrite downplayed this conclusion, recharacterizing our report as having only “provided some evidence that racial and ethnic differences in quality of health care exist.”

In playing down our conclusion, the rewrite broke with the great weight of scientific opinion. This set the stage for an even more audacious move: insistence (by Lawrence and others who pushed for the rewrite) that the AHRQ researchers either perform multivariate analyses on their own data (to separate out the confounding influences of class, education, geography, and insurance status) or delete all findings of disparity.⁹

New multivariate analyses were not a realistic option. Thus, the December version greatly downplayed the evidence of disparities that AHRQ had marshaled. Rather than setting forth detailed findings of health care disparity, the December rewrite interpreted the researchers’ data as mere evidence of health care “differences.”⁴

By insisting that the AHRQ researchers treat the existence of racial disparities as an unproven hypothesis rather than an established premise for their report, those who ordered the rewrite imposed their politics on federal science. Had earlier versions of the report not been leaked to Congress and others, embarrassing top DHHS officials, the rewrite would have stood.¹¹ Some suggest that this sort of intrusion of politics into science is business as usual, or even that it represents legitimate partisan “spin.” Business as usual it may be, in view of the larger pattern of the Bush Administration’s manipulation of government science to support its positions on public health, environmental protection, and national security,^{12,13} but legitimate it isn’t.

It is important not to lose sight of why the epi-

sode so embarrassed the DHHS. If Americans generally believed that cherry-picking of facts and findings to support government positions is legitimate when federal research agencies report on controversial matters, the leaking of earlier versions would not have posed such a problem for the department. The affair was embarrassing because Americans expect scientific rigor, not aggressive advocacy, from federal research agencies.

So did Congress, in this case. Congress can (and often does) confer political discretion on the leaders of cabinet departments and regulatory agencies by making them responsible for issuing findings. But the statutory provision that called for the disparities report made the director of the AHRQ exclusively responsible for submitting it to Congress.¹⁴ The DHHS officials who insisted on the rewrite had no legal authority to do so. Technically, AHRQ Director Carolyn Clancy could have acted on her own to release the report last July (although the administration’s budgetary and other powers over the AHRQ would have made such defiance costly).

Congress’s signal was clear: it wanted a scientific assessment of “prevailing disparities”¹⁴ from the nation’s health services research agency. In the words of Representative Danny K. Davis (D-Ill.), who sponsored the provision that mandated the report, this assessment was meant to provide Congress with “adequate and accurate information on which to base policy and budgetary decisions.”¹⁵ To allow partisan advocacy to interfere in such cases would cut Congress off from a highly capable source of impartial fact-finding. It would also put public service at odds with the scientific community’s professional values, making it harder to attract scientists into government. At best, legislators would be less well informed than they are today about technical matters; at worst, they would be more vulnerable to influence by interest groups.

Popular confidence in science is also at stake. There would be a crisis of credibility if the tailoring of scientific reports to suit presidential policy became the norm. Confidence in science is essential to democracy’s ability to manage fears of environmental disaster, epidemic disease, and bioterrorism and to profit from the opportunities of scientific progress.¹⁶

This is hardly to claim that scientific research is a value-free endeavor. Those who frame research questions, fund investigators, gather data, and debate their meaning all have points of view. Social norms and values affect the questions researchers

ask, the categories they create, the standards of proof they insist on, and the inferences they draw from circumstantial evidence. But peer review, if balanced and done well, can keep norms and values within bounds. It can push government researchers to be explicit about their premises when they are potentially controversial, and it can encourage them to address the implications of contrary premises. Above all, it can discourage the dressing up of policy preferences as data-driven findings.

Such peer review is a far cry from the overtly political appraisal to which the AHRQ disparities report was subjected. When Congress asks a federal research agency to examine an issue and report on it impartially, peer review must not be confounded by political spin management. Self-restraint in the executive branch should be enough to ensure this. But given the bitterly partisan mood that prevails in Washington today, legislation ought to require it.

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