# Health Equity, History, and a New Presidential Bioethics Commission: Lessons from the "Lost" Reports



Laura Kolbe, MD<sup>1,2</sup> and Joseph J. Fins, MD, MACP, FRCP<sup>1,3,4</sup>

<sup>1</sup> Division of Medical Ethics, Department of Medicine, Weill Cornell Medical College, 435 E. 70th Street, 29JK, New York, NY, USA; <sup>2</sup>Hospital Medicine, Department of Medicine, Weill Cornell Medical College, New York, NY, USA; <sup>3</sup>Solomon Center for Health Law and Policy, Yale Law School, New Haven, CT, USA; <sup>4</sup>Rockefeller University, New York, NY, USA.

Convening a national bioethics commission has historically been one of the most powerful bioethical legacies a US presidential administration can undertake. The Biden Administration has not yet created such a commission; here we argue that centering health equity and healthcare access would provide a vital framework for a new commission's legacy. Moreover, we demonstrate two crucial historical episodes when American presidents appointed commissions to examine the practical and ethical implications of these very issues. We turn first to the 1952 President's Commission report on "Building America's Health," a lofty vision of universal healthcare access stymied by both political conflict and unaddressed problems of racism in the era's legislation. Its rich yet incomplete account of American health inequities serves as a valuable forerunner to questions of justice in bioethics. We then explore the President's Commission's 1983 report "Securing Access to Healthcare: A Report on the Ethical Implications of Differences in the Availability of Health Services." This report took up the mantle of equity in healthcare access, again with mixed results. Only by understanding the checkered history of these overlooked, practically "lost" reports can a new era in American bioethics successfully re-center the goal of equitable health for all.

J Gen Intern Med 37(13):3471–4 DOI: 10.1007/s11606-022-07733-9 © The Author(s), under exclusive licence to Society of General Internal Medicine 2022

#### INTRODUCTION: A COMMISSION FOR OUR TIME

When, and with what priorities, will the Biden administration at last undertake a national bioethics commission to take on the enormous issues of our moment? To answer this question, we look to two commissions from twentieth-century American history, both "bioethical" in spirit though one predates the formation of bioethics as a field. These reports have much to teach us about what makes such commissions succeed or fail when the central agenda is—and we will argue that Biden's must be—health equity. Many think of the 1974 National Commission, which produced the famous Belmont Report,

Received April 23, 2022 Accepted June 28, 2022 Published online July 26, 2022 as the first commission to address the nation's pressing concerns in biomedicine. But by looking to two lessfrequently scrutinized commission reports, we have the opportunity to recover lost opportunities, and lost historical lessons, that the Biden administration would do well to heed.

## FORGOTTEN PRECEDENTS: THE "RIGHT" TO HEALTH CARE AND THE 1952 PRESIDENT'S COMMISSION REPORT

It is often thought that the nation's first bioethics commission was the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, convened in 1974 as part of the National Research Act.<sup>1</sup> This was the groundbreaking commission that produced the famous Belmont Report,<sup>2</sup> which, galvanized in part by the aftermath of the horrific Tuskegee Syphilis Study, outlined protections for human research subjects. The real history of federal commissions addressing subjects of bioethical significance, however, is much older. While the term "bioethics" had multiple near-simultaneous coinages around 1970,<sup>3-5</sup> a synthesis made possible by converging pressures and attitudes towards technology, risk, and vulnerability, the spirit of a protobioethics was already at work long before. This is particularly evident when we hear echoes of that era's broader emphasis on whole-person, whole-community health and justice as one of the emerging discipline's overarching concerns.

It may surprise clinicians, for example, to find language in a federally appointed commission as far back as 1952 calling health care "a basic human right,"<sup>6</sup> echoing similar language in the 1946 Constitution of the World Health Organization (WHO).<sup>7</sup> Yet the President's Commission on the Health Needs of the Nation, appointed by Harry S. Truman, did just that. This important document marks the first serious federal investigation of the rights, obligations, capabilities, and interdependencies of all Americans with respect to health.

The commission delivered its report in December 1952, a month after the election of Eisenhower during Truman's final lame-duck weeks. The Truman administration had earlier attempted to introduce a universal, compulsory health insurance scheme, but this had failed roundly in Congress. The commission was one last attempt to yield a systematic investigation of other alternatives that might similarly improve healthcare access, assessing these on their philosophical, economic, and clinical merits. This initial framework for debate helped normalize the idea—if not yet the practice—of universal access to adequate, equitable health care as an aspiration of American society.

Although the aspirations of the commission's report were virtuous, the parallel political reality taking shape concomitantly was more troubling. For while the commission's report, called "Building America's Health," gave pluralistic attention to "grass roots" Americans "from all walks of life," "from the big cities and from the forks of the creek,"<sup>8</sup> in practice the related legislation prompted by Truman's call had opposing effects for different "kinds" of Americans. In fact, the 1946 Hospital Survey and Construction Act, more commonly known as the Hill-Burton Act, intensified the practice and effect of structural racism in health care.<sup>9</sup> The Hill-Burton Act provided federal funding for the construction of muchneeded new hospitals, with crucial consequences. In choosing federal funding targets, the Act had key conditions: new hospitals must not discriminate by patients' race in providing care, must agree to provide a "reasonable volume" of free care to "persons unable to pay," and must be built on "economically viable" sites in communities able to provide a certain degree of matching local funding.<sup>10</sup>

The results of these stipulations were depressingly predictable: proving discrimination was rarely undertaken and rarely successful. Moreover, hospitals could be excused from providing free care if it was "not feasible from a financial standpoint," a vague and exploitable phrase. The stipulation that stuck, however, was the requirement that sites have "economic viability." This meant that redlined and ghettoized communities did not get sorely needed new facilities, while affluent and white areas experienced the bulk of this bounty.<sup>11,12</sup> Some African-American communities actually declined to accept funding, outraged by the legislation's implicit bias.<sup>13</sup> As former Senate Majority Leader Tom Daschle has noted before, this was part of a history of predictable political maneuvering, with Southern legislators of the mid-twentieth century "fear[ing] that federal involvement in health care would lead to federal action against segregation."<sup>14</sup>

The 1952 Commission's work is generally forgotten when we recall bioethical milestones of the twentieth century. And yet the positive, visionary aspects of the commission's inclusive ambitions to establish a right to healthcare—along with the bias and structural violence embedded in its execution—make this report ripe for reevaluation.

## MARGINALIZED BUT VISIONARY: THE PRESIDENT'S COMMISSION'S 1983 "SECURING HEALTHCARE ACCESS" REPORT

Another report too often forgotten in the history of medical ethics is "Securing Access to Health Care," written by the 1978–1983 President's Commission, formed during the Carter administration. The Presidential Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, as it was formally known, again took on the task of formulating a sweeping vision of accessible health care as a duty of government and a right of its citizens. Like the report of 1952, though, the 1983 report on "Securing Access to Health Care" also found itself sidelined by changing political winds and a fatal inability to tackle the contradictions and inequities embedded in the health system it sought to describe. It, too, was something of a "lame duck" report, situated at the cusp of the Reagan Revolution.<sup>15</sup> Yet the report's vision of true universal healthcare access-not just on paper, but as a lived experience-is one we would do well to see to fruition today. Perhaps this time around, we might make good on the promises that the 1978-1983 Presidential Commission did not keep—that of fulfilling a duty "of all to all."<sup>16</sup>

The report made the powerful case for the role of "intermediary institutions," to use the phrase coined by Senator Daniel Patrick Moynihan, as important agents of health and health equity.<sup>17</sup> Intermediary institutions, such as civic and religious organizations, educational groups—entities larger than individuals and households but smaller than governments—are, in the Report's language, more likely to understand and respond to the "special interpersonal significance" of health care, reflecting a society's "most basic attitudes about what it is to be a member of the human community," and particularly to provide "solidarity in the face of suffering and death."<sup>18</sup>

Beyond these poetic words, the report also directed analysis and praise towards specific kinds of innovative intermediary institutions seen as especially promising. One was the neighborhood health center of the 1970s (NHCs), revised and renamed as the community health centers (CHCs) of the 1970s onwards. NHCs were federally funded healthcare sites in low-income areas aimed at "promoting a health local environment, generating employment, increasing job skills, and serving as a focal point for community activity."<sup>19</sup> Far more than typical primary care, they took an integrative approach to medicine that included day care, child development, nutrition, and job training. Moreover, data showed that NHCs increased access to primary care in their communities,<sup>20</sup> improved regional and economic disparities in dental care access,<sup>21</sup> and often offered care superior to academic or group-practice settings based on studies of audited medical records.<sup>22</sup> However, funding for this ambitious vision soon expired under a new presidential administration,<sup>23</sup> and individual sites struggled to continue. The CHCs which replaced them, while vital for clinical care, did not offer such bold and innovative approaches.

Recalling these histories can help us revive the art of bigpicture, holistic thinking about community health. More than ever, the pandemic has revealed that community health should mean more than discrete activities like providing medications or vaccines. It means working within a preexisting social fabric to make its services trustworthy, accessible, and useful to a community. By highlighting the roles that community-centered institutions can play, the 1983 report on "Securing Access to Healthcare" brings these matters out of the realm of pure policy. It reframes them as the ethical issues they are: which kinds of spaces can best serve those who seek care? What makes community-specific institutions most effective and just? These activating questions remain potent and unanswered.

## CAUTIONARY TALES AND CONTEMPORARY BIOETHICS: MOVING FORWARD WITH PURPOSE

What cautionary lessons can we learn from these two "lost reports"? One important lesson from the "Securing Access" report was the dilution of its ambit of concerns. To avoid this fate, Biden's bioethics commission needs clear goals. Equity in health and healthcare access provides a solid framework for a host of issues better understood in the context of historical inequities that have diminished, disrupted, and fragmented American health. Linking the work of a bioethics commission to the larger national conversation around the history and present state of American health inequities will ensure its broad relevance.

A second cautionary lesson is that political divisiveness-much like that of our own time, particularly as the electoral midterms loom-ultimately sank both reports: "Building America's Health" in 1952 and "Securing Access to Healthcare" in 1983. "Securing Access to Healthcare" was written by a high-turnover commission of 11 members (serving for 2- to 4-year terms only). It also took place against a national political backdrop of marked partisanship, affecting the commission's ability to issue strong statements or impact national policy. Whereas the appointments of the National Commission were widely seen as having based appointments on professional and academic credentials, the President's Commission had to negotiate the Carter and Reagan administrations, the latter of which notably exchanged eight seasoned appointees for new ones with "stronger political than substantive qualifications."<sup>24</sup> For a contemporary bioethics commission to avoid this fate and achieve broad impact, an emphasis on diverse stakeholder membership and on a bipartisan commission may help to maintain public trust.

More specifically, the particular events towards the end of the "Securing Access" report's drafting encapsulate the partisan and philosophical divisions that still exist today. In a rare move, three members of the commission—John J. Moran, Bruce K. Jacobson, and H. Thomas Ballantine—threatened to withhold their signatures (Ballantine, in fact, did) because it "appeared to advocate national health insurance" and had too many "anecdotes of failure" about the current healthcare system.<sup>25</sup> For the more conservative members of the commission, there was simply not enough of an ethical problem with healthcare access to warrant sweeping systemic change. Similar doubts remain current in American political discourse, and it will take a concerted effort to make the case for health equity a compelling bioethical mandate.

#### HISTORY AS TUTOR, BIOETHICS AS TELOS

What can a new bioethics commission for our time teach health policy makers, and how can it avoid becoming mere dusty archival material? A strong, unified, thematic framing around equitable healthcare access can meet today's needs, including the issues of distributive justice the COVID-19 pandemic made so clear. Bioethics discourse at the national level matters more than ever. Misinformation on matters of medicine and health policy is rampant,<sup>26,27</sup> but a bioethics commission able to communicate clearly and accessibly may be able to break through the noise of punditry that has diluted the impact of expertise.<sup>28</sup>

The "lost" commission reports of 1952 and 1983 on healthcare access and its inequities have much to teach us. As one of us has written, bioethics has overemphasized doctor-patient and researcher-subject relationships, which ignore others affected by those oversimplified dyads.<sup>29</sup> Moreover, as the COVID-19 pandemic has tragically demonstrated, health and equity are global concerns that do not respect national borders. Now is our chance: knowing our bioethical history when it comes to health equity can provide us the necessary humility and clear-eyed determination if we are to care justly for all.<sup>30</sup>

**Corresponding Author:** Laura Kolbe, MD; Division of Medical Ethics, Department of Medicine, Weill Cornell Medical College, 435 E. 70th Street, 29JK, New York, NY 10065, USA (e-mail: lek4002@med. cornell.edu).

#### REFERENCES

- 1. National Research Act. Public Law 93-348. July 12, 1974.
- National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. Department of Health, Education and Welfare. The Belmont Report. Washington, D.C.: United States Goverment Printing Office; 1978.
- Wilson D. The Making of British Bioethics. Manchester (UK): Manchester University Press; 2014. Introduction. Available from: https://www.ncbi. nlm.nih.gov/books/NBK248687/.
- 4. Jonsen AR. The birth of bioethics. Hast Cent Rep. 1993;23(6):S1–S4.
- Baker R, Porter D, Porter R. Introduction. In: Baker R, Porter D, Porter R, eds. The Codification of Medical Morality: Historical and Philosophical Studies of the Formalization of Western Medical Morality in the Eighteenth and Nineteenth Centuries. Dordrecht: Kluwer Academic Publishers; 1993:1–14. (p. 2).
- Building America's Health : A Report to the President. Washington: U.S. Govt. Print. Off., 1953. Print. Available from: https://babel.hathitrust. org/cgi/pt?id=mdp.39015072170932&view=1up&seq=3.
- Constitution of the World Health Organization. Bulletin of the World Health Organization. 2002 80.12: 983-84. Web. Available from: https:// apps.who.int/gb/bd/PDF/bd47/EN/constitution-en.pdf?ua=1.
- Building America's Health : A Report to the President. Washington: U.S. Govt. Print. Off., 1953. Print. Available from: https://babel.hathitrust. org/cgi/pt?id=mdp.39015072170932&view=1up&seq=3.
- 9. Hill-Burton Act. Public Law 79-725. August 13, 1946.
- Securing Access to Healthcare: Ethical Implications of Differences in the Availability of Health Services. Washington: U.S. Govt. Print. Off., 1983.

Print. Available from: https://repository.library.georgetown.edu/ bitstream/handle/10822/559375/securing\_access.pdf?sequence=1.

- Smith DB. Health Care Divided: Race and Healing a Nation. Ann Arbor, MI: University of Michigan Press; 1999.
- Thomas KK. The Hill-Burton Act and civil rights: expanding hospital care for black southerners, 1939-1960. J South Hist. 2006;72(4):823– 870.
- Largent EA. Public health, racism, and the lasting impact of hospital segregation. Public Health Rep. 2018;133(6):715-720. https://doi.org/ 10.1177/0033354918795891.
- Fins JJ. Critical: What We Can Do About the Health-Care Crisis. JAMA. 2009;301(13):1384–1385. https://doi.org/10.1001/jama.2009.382.
- Perlstein R. Reaganland: American's Right Turn 1976-1980. New York: Simon & Schuster; 2020.
- Abram M. 1983 March 28 [letter]. Available from: https://repository. library.georgetown.edu/bitstream/handle/10822/559375/securing\_access.pdf?sequence=1.
- Fins JJ, Leiman JM, Pardes P. Primum non nocere: Daniel Patrick Moynihan and the defense of academic medicine. The Pharos. 2017 Spring:11-20. Available from: https://alphaomegaalpha.org/pharos/ 2017/Spring/2017-2-Fins.pdf.
- Securing Access to Healthcare: Ethical Implications of Differences in the Availability of Health Services. Washington: U.S. Govt. Print. Off., 1983. Print. Available from: https://repository.library.georgetown.edu/ bitstream/handle/10822/559375/securing\_access.pdf?sequence=1.
- Securing Access to Healthcare: Ethical Implications of Differences in the Availability of Health Services. Washington: U.S. Govt. Print. Off., 1983. Print. Available from: https://repository.library.georgetown.edu/ bitstream/handle/10822/559375/securing\_access.pdf?sequence=1.
- Moore GT, Bernstein R, Bonanno RA. Effect of a neighborhood Health Center on Hospital emergency room use. Med Care. 1972;10(3):240-247.
- Reynolds, RA. Improving access to Health Care among the poor: the Neighborhood Health Center experience. The Milbank Memorial Fund Quarterly. Health Soc, Winter. 1976;54(1):47-82.

- Morehead MA, Donaldson RS, Seravalli MR. Comparisons between OEO neighborhood health centers and other health care providers of ratings of the quality of care. Am J Public Health. 1971;67(7):1294-1306.
- Sardell, A. Neighborhood Health Centers and community-based care: federal policy from 1965 to 1982. J Public Health Policy. 1983;4(4):484-503.
- 24. Institute of Medicine (US) Committee on the Social and Ethical Impacts of Developments in Biomedicine; Bulger RE, Meyer Bobby E, Fineberg HV, eds. Society's Choices: Social and Ethical Decision Making in Biomedicine. Washington (DC): National Academies Press (US); 1995. Bioethics Commissions: What Can We Learn from Past Successes and Failures? Available from: https://www.ncbi.nlm.nih.gov/books/ NBK231978/.
- Jonsen A. The Birth of Bioethics. New York: Oxford University Press; 1998. 431 pp.
- Cinelli M, Guattrociocchi W, Galeazzi A, Valensise CM, Brugnoli E, Schmidt AL, Zola P, Zollo F, Scala A. The COVID-19 social media infodemic. Sci Rep. 2020;10(1):16598. https://doi.org/10.1038/s41598-020-73510-5.
- Scales D, Gorman J, Jamieson KH. The COVID-19 infodemic applying the epidemiologic model to counter misinformation. N Engl J Med. 2021;385(8):678-681. https://doi.org/10.1056/NEJMp2103798.
- Scales D, Gorman S, Gorman J. Resist pseudoscience with respect, not ridicule. Nature. 2020;582(7810):32. https://doi.org/10.1038/d41586-020-01626-9.
- Fins JJ. COVID-19 makes clear that bioethics must confront health disparities. The Conversation [web]. 2020 Jul 8. Available from: https:// theconversation.com/covid-19-makes-clear-that-bioethics-must-confront-health-disparities-142136.
- 30. Fins JJ. History and bioethics. Hast Cent Rep. 2021;51(2):3.

**Publisher's Note** Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.