9. K. S. Tsosie et al., "We Have 'Gifted' Enough: Indigenous Genomic Data Sovereignty in Precision Medicine," *American Journal of Bioethics* 21, no. 4 (2021): 72-75, at 73.

10. E. Ahmed and M. Shabani, "DNA Data Marketplace: An Analysis of the Ethical Concerns regarding the Participation of the Individuals," *Frontiers in Genetics* 10 (2019): doi:10.3389/fgene.2019.01107. For instance, a company called Luna DNA offers shares in the company in exchange for data, outlining in the consent form how the process of revoking consent works (resulting in the return of data and the canceling of shares).

11. Munung and De Vries, "Benefit Sharing for Human Genomics Research"; Walker, "Into the Machine."

12. M. S. Creary, "Bounded Justice and the Limits of Health Equity," *Journal of Law, Medicine & Ethics* 49 (2021): 241-56.

13. A. C. F. Lewis et al., "Getting Genetic Ancestry Right for Science and Society," *Science* 376 (2022): 250-52.

14. D. D. Dolan, S. S.-J. Lee, and M. K. Cho, "Three Decades of Ethical, Legal, and Social Implications Research: Looking Back to Chart a Path Forward," *Cell Genomics* 2 (2022): doi:10.1016/j.xgen.2022.100150.

Cultivating Peace and Health at Community Health Centers

by CAROLYN P. NEUHAUS

Bioethics is currently reorganizing itself around an emphasis on justice, a move that is overdue but nonetheless embraced by many in the field. Scholars in bioethics who are committed to redressing health injustices can learn much from our colleagues in community health who have made justice the centerpiece of their mission from the get-go. In creating primary health care centers whose mission it is to provide care for underserved and marginalized populations, health center leaders and advocates have attempted answers to questions like these: What does an organization and a movement that makes health equity its goal look like? What does it mean to enact a right to health care? How can health care organizations effectively address social drivers of health? In a series of projects on bioethics community health, my colleagues and I have looked at contemporary issues in community health, like genomics research, Covid vaccination, and sources of funding.[1] Here, I share some reflections on the history of community health centers based on my recent reading of two books: one an institutional history of an individual center and the other a more general history of the health center movement.

Peace & Health: How a Group of Small-Town Activists and College Students Set Out to Change Healthcare, by Charles Barber, tells the history of Community Health Center, Inc., founded in Middletown, Connecticut, in 1972.[2] The book recounts the story of its charismatic and dedicated founder, Mark Masselli, and the people who worked with him to build one of the largest and most influential community health centers (CHCs) in the United States. The book details the center's impressive achievements, including vaccinating half a million Connecticut residents during the Covid pandemic, as well as the political battles and financial struggles that shaped the institution's trajectory.

CHCs provide high-quality, primary and preventive health care, dental care, and behavioral health services to medically underserved populations. As independent nonprofit organizations, CHCs are organizationally distinct from ambulatory care clinics of hospital systems, government health departments, private walk-in urgent-care clinics, or pharmacy clinics. They are also distinct from free clinics that do not charge patients or insurers for their services. Instead, CHCs charge patients' insurance when applicable and use a sliding payment scale for nonreimbursed portions of bills. A subset of CHCs called "federally qualified health centers" (FQHCs) receive funding from the U.S. Health Resources and Services Administration to provide care for underinsured and noninsured individuals and to offer nonreimbursable goods like access to food banks and housing and transportation resources. Most CHCs are led by consumer-majority boards, meaning that patients make up 51 percent or more of their governing bodies.

In 2023, the existence of health care organizations that provide high-quality medical and social services regardless

Carolyn P. Neuhaus, "Cultivating Peace and Health at Community Health Centers," *Hastings Center Report* 53, no. 5 (2023): 13-16. DOI: 10.1002/hast.1512

© 2023 The Hastings Center. Permission is required to reprint.

of patients' ability to pay and are governed by patients is remarkable, but this was even more radical in the 1960s and '70s, when CHCs got their start. Masselli was a twenty-year-old college dropout when he opened Community Health Center, Inc. It began with one volunteer dentist on the second floor of a youth crisis center run by current and former Wesleyan students. Masselli got the idea to add health care adjacent to the drop-in center after connecting young adults' sense of abandonment, addiction, and anger at older generations to poverty, racism, disenfranchisement, and lack of access to respectful health care. Opening Community Health Center, Inc. went fast; however, planning came to a halt when Masselli began facing opposition from local physicians and the state medical board. This would not be the last time he would go up against entrenched policies and bureaucracies to save the center.

That initial battle, though, motivated Masselli to organize local community members in support of his mission. His strategy worked. The people he brought on board in those early days would become some of the longest-serving board members, staff, and donors to Community Health Center, Inc. The health center became *of* Middletown, not just *in* Middletown. Masselli's capacity to bring people together and inspire them has been a factor at every point in the center's history, including during the Covid pandemic, as Barber details in the last chapter of *Peace & Health*.

Although there are many shareable moments, two moments in the institution's history struck me. First, in 1974, Community Health Center, Inc. was approved by Medicaid and Medicare to receive reimbursement for patient visits. The decision to accept payment for services and to partner with federal payers shifted the institution's course from a free clinic to a CHC. This helped establish Community Health Center, Inc., as a powerful, mission-driven organization that had a sustainable business model. Second, in 2007, the center founded the Weitzman Institute, a partner organization that conducts research on primary care innovation and provides training and educational resources to primary care providers and health centers. It is truly one of a kind. The Weitzman Institute illustrates that, with sufficient funding and support, health centers can do more—more research, more education, more advocacy. In the book, Barber reports the observation of a Community Health Center, Inc., board member that, "without margin, there's no mission" (p. 91). Founding the Weitzman Institute was possible partially because of the expansion of federal funding for CHCs in the early 2000s. Masselli is described as asserting, "Those of us involved in primary care have an obligation to improve it" (p. 108). Health centers need the financial margins to follow through on their mission.

While Barber's book stands alone as an institutional history and inspiring story, readers interested in learning more about how Community Health Center, Inc., fits into the broader CHC movement should also read *Community Health Centers: A Movement and the People Who Made It Happen*, by Bonnie Lefkowitz.[3] Published in 2007, it provides a political history of federal funding for CHCs, detailing in chapter 1 the first grants for "neighborhood health centers" out of the Office of Economic Opportunity during President Johnson's War on Poverty, the creation of the FQHC in landmark legislation passed during the George H. W. Bush administration, and the bipartisan-backed expansion of the health center program during the George W. Bush administration. What's happened in the sixteen years since—notably, the passing of the Affordable Care Act, Medicaid expansion, the opioid epidemic, and the Covid pandemic—will have to wait for another volume.

The remaining chapters of Community Health Centers are each dedicated to a state, city, or region that is home to one or more of the earliest health centers: Mississippi's Delta Health Center and Jackson-Hinds Health Center; Boston's neighborhood health centers starting with Columbia Point, the nation's first CHC; South Carolina Low Country's Comp Health; New York City's William F. Ryan CHC; and the Texas Rio Grande Valley's Su Clinica and Brownsville health centers. *Peace & Health* can be read as another chapter of *Community Health Centers*. *Peace & Health* is longer than any individual chapter in *Community Health Centers* but is written in very much the same spirit: as an institutional history, a personal history of the institution's founders and influencers, a political background of the region, and a celebration of what each center has achieved. Each story also includes examples of plans that were not realized and important lessons learned. While reading *Peace & Health*, I wondered if Masselli was in touch in the 1970s or 1980s with other people at these or other CHCs. The lack of attention to other health centers or the national political landscape is understandable given the provenance and goal of the book. *Peace & Health* was commissioned and published by Community Health Center, Inc., in celebration of their fiftieth anniversary, in 2022, and the author is a writer in residence at nearby Wesleyan University. The book focuses on the health center and surrounding community.

As I consider the histories told in *Peace & Health* and *Community Health Centers* along with my research with CHCs, some through lines are apparent. First, ideas matter, especially ideas that challenge the status quo. All the CHCs were founded on the idea that everyone deserves respectful, good-quality health care and that addressing the social drivers of health—like access to food, water, education, and stable housing—is within the remit of a health care organization. This simple but radical idea is at the heart of every health center. It's also what ruffled the most feathers politically as several centers got their start. Groups opposed to the somewhat scrappy, community-based medical practice argued that the delivery of health care should not happen outside the walls of venerable hospitals or private practices. Those opposed to CHCs sensed a threat to their health care business model—and, in many cases, their racist, classist beliefs. Too often, the greatest opposition to CHCs came from within the medical community.

Appreciating both the history and present impact of CHCs may help bioethicists forge alliances with community health organizations to address social drivers of health—without needing to reinvent the wheel.

Second, the people matter. The histories of these institutions are inextricable from the individual stories of the people who built them. Community Health Center, Inc., would not be what it is today without Masselli or Margaret Flinter, his long-time colleague. Delta Health Center in Mound Bayou, Mississippi, was a deeply collaborative and community-based effort. The medical doctors who secured the first federal funding for CHCs, Jack Geiger and Count Gibson, were critical, but so were L. C. Dorsey, Ollye Shirley, and Aaron Shirley, Black Mississippians who were active, grassroots community organizers and became critical leaders and supporters of the newly founded organizations. At times, personal and institutional histories are hard to parse out, and I had to read some paragraphs of *Community Health Centers* several times, reminding myself of each person's connection and contribution to their CHC. This speaks to the realness of the stories: these are just people, not heroes or characters, who bring their whole, complicated selves to their work. They are friends, former colleagues and classmates, and volunteers who happened to be in the right place at the right time to build an organization.

Personal connections and community organizing are just as important in 2023. Studying access to genomics services for FQHC patients, for example, my colleagues and I have learned that referral networks among FQHCs, regional hospitals, and community-based organizations often depend on personal and professional ties among particular individuals.[4] Savvy chief executive officers, providers, and community health workers "know who to call" to advocate for their patients.

Third, place matters. I've been told that "when you know one FQHC, you know one FQHC," meaning that each center is unique because every CHC responds to the *local* community's needs and the *local* political and social milieu. South Carolina's Low Country and barrier islands faced water deprivation and sewage issues, and community health organizers there galvanized around access to clean water and laid the groundwork for the founding of Comp Health. Health centers in the Rio Grande Valley in Texas began as a group of people dedicated to supporting migrant and seasonal farmworkers. Building a CHC is a constant balance between figuring out how to meet the needs of the community and navigating the local, state, and national sociopolitical climates to create key partnerships capable of achieving desired health and social outcomes.

The dance between holding oneself to ideals of justice and equity but also fighting tooth and nail to make incremental, if insufficient, progress will be familiar to many in bioethics. I think it's why I find the stories told in these books so compelling. But there are also practical reasons for bioethicists to improve their understanding of the community health sector. Appreciating both the history and present impact of CHCs may help bioethicists forge alliances with community health organizations, including individual centers, regional hubs, and their national association, to address social drivers of health—without needing to reinvent the wheel. There are already health care organizations doing this quite well, and probably close by. Today, CHCs serve over 30 million people in more than 14,000 rural and urban communities across the country.[5]

For those inclined to do some reading, I recommend starting with the opening chapter of *Community Health Centers* and then diving into the individual stories of health centers, either in the later chapters of *Community Health Centers* or with *Peace & Health*. Additionally, The Hastings Center's projects on Bioethics in Community Health provide a starting point for people in bioethics who want to learn from and with people in community health and vice versa.[6]

Anyone seeking careers in community organizing, public health, or social justice who may face an uphill battle against entrenched bureaucracies, policies, or ways of thinking could also get a shot of courage from *Peace & Health*. The book closes with a quotation from John Hickenlooper, one of Masselli's close friends and critical supporter in the early days of Community Health Center, Inc., who would go on to become mayor of Denver, governor of Colorado, and United States Senator from Colorado. He said in 2021, "If we had known then what we know now, we would have never done it, and what a shame that would have been." We are led today to think that more information is always better, that risk must be measured and managed, that work can happen in isolation at home. The stories of CHCs told in *Peace & Health* and *Community Health Centers* provide concrete, detailed examples of how small, diverse groups of people dreamed up and slowly built mission-driven, innovative, community-based and community-led health care organizations. Lefkowitz writes in her preface that CHCs are a testament "to the social contract that many have forgotten" (p. vii). They may even provide hope to the most cynical among us that the American health care system, however

broken, already contains what's needed to bring medical care and social services—and maybe peace and health—to all.

Acknowledgment

Support for writing this essay came from The Greenwall Foundation, and I report findings of research funded by the National Human Genome Research Institute of the National Institutes of Health and the NIH's Office of the Director under award number R21HG010531. Many thanks to Danielle Pacia for suggestions and edits to this manuscript.

1. "Bioethics in Community Health," The Hastings Center, accessed September 11, 2023, https://community.thehastings-center.org.

2. C. Barber, *Peace & Health: How a Group of Small-Town Activists and College Students Set Out to Change Healthcare* (Middletown, CT: Community Health Center, Inc. and OctoberWorks, 2022).

3. B. Lefkowitz, *Community Health Centers: A Movement and the People Who Made It Happen* (New Brunswick, NJ: Rutgers University Press, 2007).

4. C. P. Neuhaus et al., "*All of Us* and the Promise of Precision Medicine: Achieving Equitable Access for Federally Qualified Health Center Patients," *Journal of Personalized Medicine* 13, no. 4 (2023): doi:10.3390/jpm13040615.

5. "Health Center Program: Impact and Growth," Health Resources and Services Administration, accessed September 11, 2023. https://bphc.hrsa.gov/about/healthcenterprogram/index.html.

6. "Bioethics in Community Health," The Hastings Center.

ERRATUM

In the July-August 2023 issue, the editors' blurb on the first page of the article "Risk-Sensitive Assessment of Decision-Making Capacity: A Comprehensive Defense," by Scott Y. H. Kim and Noah C. Berens, incorrectly represents the article (*Hastings Center Report* 53, no. 4 [2023]: 30-43, doi:10.1002/hast.1500). The blurb should have said, "Should an evaluation of decision-making capacity factor in the risks of the given decision? In a lengthy debate, critics have warned that this approach is paternalistic and that it creates a problem of asymmetry: someone could be competent when she consents to X but not when she refuses X. Yet a comprehensive look at the debate shows how a variable-threshold model of risk-sensitive DMC promotes autonomy, is coherent, and enables greater certainty about DMC than does a fixed-threshold model."

DOI: 10.1002/hast.1506