

INTRODUCTION

Invoking Health and Human Rights in the United States: Museums, Classrooms, and Community-Based Participatory Research

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The United States is rough terrain for those aiming to stake health-related human rights claims on domestic soil. Less than a decade ago, the passage of the 2010 Patient Protection and Affordable Care Act (ACA), which was designed as a massive expansion of insurance-based health coverage, led some health and human rights scholars to wax optimistic. The ACA—the Obama administration’s signature piece of legislation—passed by a razor-thin margin in US Congress. For human rights optimists, this legislation deserved praise for adopting “significant national reforms consistent with human rights norms” in a manner “Corresponding with international law, [and] following both the spirit and substance of the UDHR [Universal Declaration of Human Rights] and ICESCR [International Covenant on Economic, Social, and Cultural Rights].”¹ As pessimists were quick to point out, however, the ACA’s protections have always been “inherently unstable.”² First, this market-based arrangement grounds access to health care in a statutory right—in other words, a right that can be modified or revoked. In addition, it sidesteps international norms and commitments precisely “by avoiding the specific language of rights and obligations of international law.”³

Early predictions of the ACA’s promise from a human rights standpoint are thus difficult to reconcile with current realities. Some aspects of the law have gained wide popularity, especially its requirement to ensure health coverage for people with “pre-existing conditions.” During the first two years of the Trump administration, however, the Republican-led Congress sought repeatedly to undermine the ACA and erode its protections through court challenges, budgetary obstruction, and obfuscation about the nature and stipulations of the law itself. Numerous attempts to “repeal and replace” the ACA failed, and these efforts effectively stopped after the Democratic party took control of the US House of Representatives in the 2018 midterm elections. Meanwhile, arguments supporting a human right to health have gathered support from a small, politically liberal segment of the US electorate, especially since the presidential election of 2016.⁴

Although the country’s overall legal and policy climate is no more hospitable to health-related human rights claims now than before the passage of the ACA, this special section shares evidence that human rights can “travel” and transform even in settings where they lack legal traction, including the United States.⁵ As these papers demonstrate, human rights can function beyond the spheres of law and policy as a power-

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ful “idiom of social justice mobilization for health” by introducing new terms and concepts, deepening awareness of historical legacies, and proposing new narrative frames for interpreting current and past situations of disparity and injustice.⁶

This special section looks beyond the juridical domain to explore three cases in which unconventional encounters with human rights spurred non-specialists—that is, members of the American public—to contemplate the relationship between health and human rights. In the first case, I write about an exhibition with a provocative title at a federal museum: “Health Is a Human Right: Race and Place in America.” This exhibit was designed to commemorate the 25th anniversary of the Office of Minority Health and Health Equity at the US Centers for Disease Control and Prevention (CDC) in 2013. In the second paper, Bisan Salhi and Peter J. Brown analyze a pedagogical attempt to spark engagement with human rights concepts among US undergraduate students of global health. In the third paper, Nadia Gaber investigates two efforts to use community-based participatory research strategies to help protect and fulfill residents’ right to water in the American cities of Flint and Detroit, Michigan. Authors of all three papers are medical anthropologists with cross-training in public health or clinical medicine, and all employ qualitative research methods, including audio-recorded interviews, open-ended surveys, and participant observation.

By exploring how human rights principles and logics can reverberate in extra-juridical spaces, papers in this section draw on critical human rights scholarship to train their gaze on what anthropologist Richard Wilson calls the “social life of rights.” For Wilson, it is necessary to “look beyond the formal, legalistic, and normative dimensions of human rights, where they will always be a ‘good thing,’” and consider “how rights are transformed, deformed, appropriated, and resisted by state and societal actors when inserted into a particular historical and political context.”⁷ In a similar vein, Peggy Levitt and Sally Engle Merry call attention to the “vernacularization” of human rights discourse by local actors, and Mark

Goodale advocates for a “skeptical distance from the exalted claims of human rights” while analyzing the “different registers through which the idea of human rights is conceived.”⁸

By exploring the social life of rights in museum, classroom, and citizen-science contexts, this special section sheds light on the potential as well as the limits of human rights frames in confronting health inequities and injustices in the United States. Through their analyses, the authors engage several important questions: What’s at stake in invoking the human right to health in conversations about health inequities in the United States? What obstacles do US researchers, public health professionals, and activists face in attempting to confront domestic health inequities and injustices using a human rights idiom? Finally, what new opportunities do these US engagements with human rights language reveal, and what lessons do they offer the health and human rights community more broadly?

Before summarizing the papers themselves, I provide a brief historical overview of American presidential administrations’ resistance to confronting health issues in a human rights idiom.

Health and human rights in the United States: Legacies and missed opportunities

Under different circumstances, the vision of President Franklin Delano Roosevelt and human rights pioneer Eleanor Roosevelt might have propelled the United States to an enduring leadership role in refining and implementing international commitments to health as a human right. FDR’s 1941 “Four Freedoms” speech, for instance, introduced the notion that states are obligated to provide for the health of their people. On the domestic front, his 1944 State of the Union address called for a “second Bill of Rights” promising every American citizen the “right to adequate medical care and the opportunity to achieve and enjoy good health.”⁹ Four years later, Eleanor Roosevelt represented the United States at the deliberations culminating in the 1948 Universal Declaration of Human Rights (UDHR), which affirmed that, “Everyone has the right to a standard of living adequate for the health

and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services.”¹⁰

Rather than carry this legacy forward, however, the United States retreated. During the Cold War, the world was divided—in effect, into countries rallying behind civil and political rights, led by the United States, and advocates of economic and social rights, led by the Soviet Union. This sharp distinction faded with decolonization and the end of the Cold War, and more than 150 countries have now ratified the International Covenant on Economic, Social Cultural Rights (ICESCR), although the United States still has not. Neither has the United States ratified most other international treaties that include a right to health commitment. Instead, successive American presidential administrations have sought to avoid incurring obligations relating to the right to health or other economic, social, and cultural rights, and the country has promoted a raft of neoliberal strategies in its foreign policy that push in the opposite direction.¹¹ Given its general unwillingness to join “with other countries in advancing and adhering to the international framework of human rights laws,” some human rights experts have characterized the United States as a “rogue state” in human rights terms.¹²

Meanwhile, on the domestic front, a variety of obstacles have impeded efforts since the 1940s to enshrine right to health commitments in US law.¹³ These factors range widely, from the individualist approach to rights within the Anglo-American tradition to the resistance of powerful stakeholders (including the American Medical Association and the private health insurance industry); the rise of neoliberal economic policy under the Reagan administration; and the willingness of left-leaning Democrats to entertain market-based solutions to universal health coverage rather than pushing harder for a “single-payer” solution or “public option” during the ACA debates.¹⁴ Despite strong legacies of civil society struggle against the egregious health disparities that persist in the United States even post-ACA, human rights claims have been invoked only infrequently by those commit-

ted to combating the country’s health inequities, and only with moderate, typically localized (such as state-level) success.¹⁵ Although the notion that all Americans possess a basic human right to health may be gaining some popularity since the 2016 presidential election cycle, the impact of this shift on both national and local politics remains to be seen. For the time being, most struggles against health inequities in the United States employ other “idioms of social justice mobilization.”¹⁶ Some of these idioms, like “health disparities” and the “social determinants of health,” aim for descriptive neutrality or scientific objectivity. Others, such as “health inequities” and, increasingly “structural racism,” involve built-in forms of political critique.

Overview of the papers

The original catalyst for this special section was the aforementioned museum exhibition “Health Is a Human Right: Race and Place in America,” which was created to commemorate the 25th anniversary of the Office of Minority Health and Health Equity (OMHHE) at CDC. During the seven months it was on display at the Smithsonian-affiliated David J. Sencer Museum, located on CDC’s main campus in Atlanta, Georgia, the exhibition attracted nearly 50,000 visitors. The special section itself began as an invited panel at the 2016 American Anthropological Association Annual (AAA) Meetings in Minneapolis, Minnesota. Although the original panel included companion perspectives on the exhibition from its originators at CDC, the shifting political landscapes limited their inclusion in this section.

In the first paper, I examine the origins, aims, and content of the CDC Museum’s exhibition and the apparent contradiction it embodies. The paper asks three questions: First, how can this exhibition, in this particular locale, be reconciled—if at all—with the absence of any firm right to health commitment in the United States? Second, what does the exhibition reveal about the “social life” of health-related human rights claims? Finally, what might we learn from the exhibition about the potential role of museums and museology in sparking

public engagement with health and human rights issues, especially in settings where human rights have some rhetorical power, but lack legal or political traction?

The second paper, by Salhi and Brown, approaches the CDC museum exhibition from a different angle: exploring the reactions of university students who visited as part of a semester-long course on global health. Drawing on written student assessments and their own long-term teaching experience in American university settings, the authors describe the exhibition as a rude awakening for many students. In particular, many were surprised to discover a long history of health-related human rights violations within the United States, ranging from 20th century legacies of eugenics and forced sterilization, to systemic violations whose effects persist until today, including “redlining,” the dumping of toxic waste near residential communities, and lack of access to safe water and/or basic sanitation, especially among impoverished communities of color.¹⁷ Student-visitors to the exhibition, the authors write, “displayed an intuitive sense of—and support for—certain human rights” even as they lacked “the vocabulary or framework to anchor these sentiments” and arrived “unaware that human rights are dynamic legal tools and principles that apply in regional, national, and international spheres.” The authors acknowledge the power of a well-curated exhibition to spark new thinking about health and human rights in two ways: by showing that health-related violations can, and do, happen on American soil, and by demonstrating the relevance of human rights laws and logic for domestic efforts to name injustices and mobilize for change.

Finally, Gaber’s paper addresses one of the exhibition themes of greatest concern to Salhi and Brown’s students: contemporary violations of the human right to water. Although 99% of US residents have safe access to drinking water and 89.5% have safe access to sanitation, water insecurity is increasingly a problem, not just for rural communities but also in urban settings.¹⁸ Drawing on ethnographic fieldwork involving community-based participatory research (CBPR) projects in the cities of Flint and

Detroit, Michigan, Gaber argues that human rights frameworks are growing more important as citizens mobilize for water justice despite the lack of a human right to water under US law. In their efforts to “generate data in the absence of credible, public information about the water crises,” CBPR projects in Flint and Detroit show how health evidence can “play a unique role in protecting the human right to water ... by supporting ethical demands, policy recommendations, and local organizing efforts with robust, reliable data.” Moreover, Gaber shows how CBPR findings framed in a human rights idiom can influence how violations and questions of redress are debated in the court of public opinion. In all, her paper suggests an important role for CBPR in certain kinds of human rights claims-making in the United States, given its ability to bring community member voices, values, and demands into political and even legal conversations that presumed experts might otherwise dominate.

Conclusion

As the first United Nations Special Rapporteur on the right to health Paul Hunt and colleagues have observed, there are many ways to assess “how human rights are making a difference for health.”¹⁹ Certainly this assertion is true, and its meaning may be even broader than its authors originally intended. For those who fall on what Mark Goodale describes as the “establishment” side of the human rights enterprise, opportunities to help human rights make a difference are increasingly well-defined; these include strategies to improve the effectiveness of legal interventions; strengthen claims for institutional legitimacy; and develop clearer lines of accountability.²⁰ Goodale contrasts this “establishment” orientation with what he calls an “alternative” position espoused by those for whom “the status of human rights remains as ‘unsettled’ (Sarat & Kearns 2001) as ever.”²¹ Although he and others in this “alternative” camp might remain “agnostic about the underlying value claims and political aspirations that ground existing human rights activism,” they are not inclined to abandon the human rights project altogether. Rather, they

see the need for a “reconfigured theory and practice of human rights that is pluralist, decentralized, and perhaps even ‘de-juridified.’”²² Among other things, Goodale’s proposal for radical reconfiguration clarifies the extent to which human rights can, and do, travel meaningfully beyond spaces of law. In addition, it invites reflection on other ways in which human rights can make a difference for health—even in places where the “non-practice” of human rights is more common than its practice.²³

In such places, non-specialist members of the public may have little or no understanding of what human rights entail, or how rights violations and health inequities are interconnected. This specialized language may someday catalyze new ways of thinking—but first, citizens and community members will need an introduction. Unconventional invocations of human rights like those explored in this special section—especially in museums and community-based participatory research settings—may effectively serve this role. By showing how human rights can be meaningful, timely, and relevant even in countries lacking formal human rights commitments, such informal encounters can spark creative thinking and help expand public imaginings of how human rights can make a difference for health.

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