

# THE JOURNAL OF LAW, MEDICINE & ETHICS

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# Health Justice: Engaging Critical Perspectives in Health Law and Policy



GUEST EDITED BY Lindsay F. Wiley,  
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Symposium Articles

**Health  
Justice:  
Engaging  
Critical  
Perspectives  
in Health Law  
and Policy**

Guest Edited by  
Lindsay F. Wiley,  
Ruqaiyah Yearby,  
Brietta R. Clark, and  
Seema Mohapatra

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*Letter from  
the Editor*

Cover image ©Getty Images

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**Introduction**

*Lindsay F. Wiley, Ruqaiyah Yearby,  
Brietta R. Clark, and Seema Mohapatra*

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**The Social Determinants of Health,  
Health Disparities, and Health Justice**  
*Ruqaiyah Yearby*

Although the federal government and several state governments have recognized that structural discrimination limits less privileged groups' ability to be healthy, the measures adopted to eliminate health disparities do not address structural discrimination. Historical and modern-day structural discrimination in employment has limited racial and ethnic minority individuals' economic conditions by segregating them to low wage jobs that lack benefits, which has been associated with health disparities. Health justice provides a community-driven approach to transform the government's efforts to eliminate health disparities, by acknowledging the problem of structural discrimination; empowering less privileged groups to create and implement structural change; and providing support to redress harm.

650

**Respect for Communities in Health  
Justice**

*Charlene Galarneau and  
Patrick T. Smith*

Health justice seeks, both conceptually and in practice, to strengthen community engagement and empowerment as an integral means of addressing health disparities. In this essay, we explore the nature of communities and their roles in health care/public health. We propose that an ethical *principle of respect for communities* is a requisite part of health justice. It is this respect for communities that ethically grounds health justice's calls for greater community engagement and empowerment. Conceptions of health justice, we claim, will gain ethical power and coherence as this principle is more clearly recognized and further developed.

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**Health Justice Through the Lens of  
Power**

*Jamila Michener*

Health justice is an aspirational north star for scholars, practitioners, and anyone who refuses to accept the harms and inequities of the status quo. But what does health justice mean? How ought we conceptualize it? There is no correct answer to these questions, but any robust rendering of health justice must account for power and politics. This article posits that the path to health justice requires political struggle taking (at least) two forms: (1) building power and (2) breaking power. Building power for health justice means cultivating the political capacity of people who are disproportionately harmed by health inequity, and who therefore have the most at stake. Breaking power involves weakening and destabilizing the economic and political configurations that perpetuate health inequity. By surfacing and elaborating crucial modes of political struggle, this article points to a way forward for achieving health justice.

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**Locating Disability Within a Health  
Justice Framework**

*Jasmine E. Harris*

This Article explores the connections between disability and health justice in service of further tethering the two theories and practices. The author contends that disability should shift from marker of health inequity alone to critical demographic in the analytical and practical application of health justice. This theoretical move creates a more robust understanding of the harms of health injustice, its complexities, and, remedially, reveals underexplored legal and policy pathways to promote health justice.

674

**Health Justice and Just Transition**

*Aysha Pamukcu and Angela P. Harris*

Just Transition, an organizing and policy framework that has emerged from the climate justice movement, is a powerful upstream response to health disparities created by structural subordination. As the public health field pushes itself to address the "cause of causes" of unjust health disparities, Just Transition offers new possibilities for partnership and collective action. We introduce the Just Transition framework, explain its relevance to the concerns of health justice advocates, and provide some examples of how the two movements might work together.

682

**A Critique of Expertise for Health Law**

*Aziza Ahmed*

A health justice approach requires a progressive critique of expertise. This article considers two recent high-profile cases – the mask mandate and medication abortion – to understand how we should think the mobilization of expertise in the context of public health law. Following from this, the article offers news ways to better understand how to think of the relationship between health law, expertise, and politics.

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**The Anti-Transgender Medical Expert Industry**

*Alejandra Caraballo*

Civil rights attorneys challenging laws restricting transgender rights and access to healthcare often encounter anti-transgender medical experts in litigation at various stages. The experts often maintain dubious credentials in the relevant area of medical or scientific expertise which presents a challenge that undermines equitable access to justice by introducing pseudo-science into court proceedings. This commentary will discuss the phenomenon and propose a normative path forward.

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**It's Not Irony, it's Interest Convergence:  
A CRT Perspective on Racism as Public  
Health Crisis Statements**

*Tomar Pierson-Brown*

Racism as a Public Health Crisis Statements (RPHCs) acknowledge the reality that racism must be eradicated to ensure health justice: a fair and just opportunity for all individuals to be healthy. Scholars of critical race theory (CRT) have expressed doubt when it comes to the capacity of law-related institutions to catalyze or sustain anti-racist efforts. These strains of skepticism underscore the question of whether so many RPHCs were adopted precisely because, in many instances, they were merely symbolic acts. This commentary argues that the trend in adopting RPHCs carries signs of interest convergence, and asserts that the alliance between government and the movement for health justice reflected in this phenomenon falls short of the substantive anti-racist action needed to realize health justice. The spate of RPHC adoption, in lieu of passing anti-racist policy or meaningfully empowering people of color, signifies that the movement for health justice must be strategic in determining whether to leverage, or be wary of, the power dynamics which shape political change. The health justice framework must expand its toolkit to include CRT.

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**(Im)Balancing Acts: Criminalization and  
De-Criminalization of Social and Public  
Health Problems**

*Keon L. Gilbert and Robert S. Chang*

Racially disparate policing, prosecution, and punishment harm individuals, families, and communities. These practices must be understood within the context of the development

of the criminal legal system as a means of racialized social control. This context permits a critical examination of the way criminalization has been and is still deployed to subject poor and racialized communities to systemic injustices. This commentary frames a call for interventions to integrate a health justice approach to ensure that they advance racial and health equity to promote the well-being of individuals, families, and communities.

711

**Food Oppression in a Pandemic**

*Andrea Freeman*

COVID-related racial disparities represent a spectrum of injustices and inequalities. Focusing on food oppression, this essay argues that racism infuses food law and policy in ways that contribute to racially disparate COVID deaths and severe illnesses. USDA nutrition program participants were at a nutritional disadvantage when COVID hit. Yet, government responses focused on food insecurity, not nutritional quality. Racism against a predominantly Black and brown labor force of essential food workers – from fields to meat plants to grocery stores – created tolerance for the administration's failure to protect or compensate some of the country's most vulnerable workers. When COVID-driven supply issues threatened to narrow white people's activities and choices, the favored response was to keep their options open by sacrificing Black and brown workers. A food oppression lens – understanding how corporate interests drive food policy – is necessary to achieve food equality in this pandemic and beyond.

719

**Stemming the Shadow Pandemic:  
Integrating Sociolegal Services in Contact  
Tracing and Beyond**

*Medha D. Maklouf*

The COVID-19 pandemic has shed light on the challenges of complying with public health guidance to isolate or quarantine without access to adequate income, housing, food, and other resources. When people cannot safely isolate or quarantine during an outbreak of infectious disease, a critical public health strategy fails. This article proposes integrating sociolegal needs screening and services into contact tracing as a way to mitigate public health harms and pandemic-related health inequities.

726

**We Charge Vaccine Apartheid?**

*Matiangai Sirleaf*

Vaccine apartheid is creating conditions that make for premature death, poverty, and disease in racialized ways. Invoking vaccine apartheid as opposed to euphemisms like vaccine nationalism, is necessary to highlight the racialized distributional consequences of vaccine inequities witnessed with COVID-19. This commentary clarifies the concept of vaccine apartheid against the historical and legal usage of apartheid. It reflects on the connections and important disjunctions between the two. It places the intellectual property regime under heightened scrutiny for reform and transformation. This commentary finds that drawing on the intersections between a human rights and health justice approach can provide creative and novel approaches for anti-subordination. It concludes that acknowledging and naming

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the structural injustice of vaccine apartheid is only the first step towards providing redress.

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**Cooperative Ownership as a Health Justice Intervention: A Promising Strategy to Advance Health Equity Through the U.S. Childcare System**

*Kimberly Libman, Sabrina Adler, and Pratima Musburger*

In their article “The Civil Rights of Health,” Harris and Pamukcu offer a framework connecting civil rights law to unjust health disparities with the aims of creating broader awareness of subordination as a root cause of health inequities and inviting policymakers to create new legal tools for dismantling it. They close with a call to action. Here, we take up their call and propose cooperative enterprises as a health justice intervention. To illustrate this conceptualization, we focus on childcare as a system with robust connections to social, economic, and health equity for children, workers, and families.

745

**Trauma Informed Delinquency Interventions for Native Children**

*Addie C. Rolnick and Hon. Patricia Sekaquaptewa*

Recognizing the links between childhood trauma and delinquency, many juvenile delinquency systems now emphasize trauma-informed care. This commentary examines established and emerging research on childhood trauma among American Indian and Alaska Native children and contrasts the development and implementation of “trauma-informed” approaches in state and tribal juvenile systems. It identifies three key innovations present in tribal models and calls for further research to identify best practices that work for Native children and tribal communities.

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**A Health Justice Agenda for Local Governments to Address Environmental Health Inequities**

*Gregory Miao, Katie Hannon Michel, and Tina Yuen*

Law plays a large role in creating the conditions in which health inequities exist and persist. Unjust laws, policies, and practices shape our physical, social, and economic environments, codifying discrimination and disenfranchisement. Environmental policy is one place where these issues play out, with environmental injustices resulting from policies and initiatives over multiple generations at all levels of government.

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**Data Sharing to Combat Segregation**

*Courtney Lauren Anderson*

Data sharing between housing and education agencies will provide housing agencies with resources to assist them with efforts to decrease segregation and mitigate the adverse health outcomes experienced by people of color. The Fair Housing Act has the potential to fulfill its original integrationist purpose if housing and education agencies combine resources and data to create and implement fair housing plans. The Biden Administration’s restored rule to affirmatively further fair housing pursuant to the Fair Housing Act of 1968 which seeks to reduce segregation and increase housing equity. However, it omits most of the processes set forth by the Obama Administration whereby federal agencies provide the proper tools to housing agencies so that they are able to make data-based decisions about housing policies. This article advocates for the sharing of data between housing and education agencies to optimize the positive impact of fair housing not only within housing, but also on the education, employment, and health opportunities for communities of color.

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**Critical Perspectives to Advance Educational Equity and Health Justice**

*Yael Cannon and Nicole Tuchidna*

Although education is an under-examined social determinant of health, it is central to health and well-being. Those with more years of schooling are more likely to have higher income, better physical and mental health, and a longer lifespan. As highlighted by the Covid-19 pandemic, schools are also important sources of wellbeing as spaces for social and emotional development, building relationships and community, and obtaining food and limited health care. Nevertheless, children can suffer from discrimination, exclusion, fear, or violence in schools due to the school-to-prison pipeline, school brutality, inequitable investment of resources, and other systemic problems. Exposure to such problems significantly increases a child’s risk of experiencing poor health during and after childhood. Calling attention to these severe consequences should strengthen arguments made by advocates and policymakers to eliminate these educational inequities. Further, it is time for scholars, advocates, and policymakers to fully acknowledge that education is a critical component of health justice, a framework that aims to leverage law and policy to advance health equity. Health justice requires an exploration of how structural racism, ableism, and other systemic barriers manifest in education and drive health disparities so that these barriers can be removed. Critical perspectives, including Critical Race Theory and Dis/ability Critical Race Studies, enhance this exploration. Action towards both health equity and educational equity, including reform of law and policy and enforcement of existing laws, should be built on a health justice approach that is informed by critical perspectives and recognizes the deep interconnectedness of educational and health inequities.

## Independent Articles

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### **Assessing the Governance of Digital Contact Tracing in Response to COVID-19: Results of a Multi-National Study**

*Brian Hutler, Alessandro Blasimme, Rachel Gur-Arie, Joseph Ali, Anne Barnhill, Amelia Hood, Jeffrey Kahn, Nancy L. Perkins, Alan Regenber, and Effy Vayena*

This paper describes the results of a multi-country survey of governance approaches for the use of digital contact tracing (DCT) in response to the COVID-19 pandemic. Of the nine countries surveyed, four enacted laws requiring that DCT comply with their data protection regimes, and each of these countries released a voluntary DCT mobile phone app with built-in privacy protections. Four other countries authorized DCT under their emergency response laws and employed a network-based DCT surveillance system that allowed for collection of identifiable user data from mobile phones without consent. (One country, the United States, did not to enact legislation authorizing DCT, and did not implement a national DCT system.) We argue that the countries in our survey represent two distinct models of DCT governance, both of which are flawed. The “data protection model” emphasizes privacy protections at the expense of public health benefit, while the “emergency response model” sacrifices transparency and accountability, prompting concerns about excessive governance surveillance. The ethical and effective use of DCT in the future requires a new governance approach that is better suited to this novel use of mobile phone data to promote public health.

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### **COMMENTARY**

*Ryan Calo*

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### **A Strategy to Improve Knowledge about Health Policies and Evidence Based Medicine for Federal Magistrates in Health Litigation**

*Bruno Barcala Reis, Marcus Carvalho Borin, Marcelo Dolzany da Costa, Renato Luís Dresch, Osvaldo Oliveira Araújo Firmo, Melissa Cordeiro Guimarães, Carla Barbosa Morais Alves, Nelio Gomes Ribeiro Junior, Ludmila Peres Gargano, Túlio Tadeu Rocha Sarmiento, Pâmela Santos Azevedo, Isabella de Figueiredo Zuppo, Carolina Zampiroli Dias, Vania Cristina Canuto dos Santos, Juliana Alvoares-Teodoro, Francisco de Assis Acurcio, Augusto Afonso Guerra, Jr.*

**Context:** Several countries maintain universal health coverage, which implies responsibility to organize delivery formats of healthcare services and products for citizens. In Brazil, the health system has a principle of universal access for more than 30 years, thus many deficiencies remain and Country observes a day practice of those seeking judicial decisions to determine provision of healthcare. The National Council of Justice supports the parallel production of scientific evidence to contribute to health rights litigation, despite efforts of ealth authorities. The strategy to promote knowledge to magistrates about evidence-based-medicine (EBM) and health policies occurs through media and courses/conferences, but may it happen personalized with academic detailing (AD)? AD is a method that combines interactive education outreach with noncommercial evidence-based information. This study evaluated the AD strategy aimed at federal magistrates and their perception about authority of individual prescribers versus regulatory agencies.

**Methods:** AD intervention combined with an exploratory study describing magistrates’ perceptions of the health authority of prescribers versus federal agencies using case study based on decision-making scenarios, survey and messages about EBM process from technologies approval to health services incorporation.

**Results:** Based on a workshop we organize key messages in three bulletins and boards containing EBM information and an algorithm from approval to incorporation of technologies. We made 61 visits to judges: 64% men; 36% women; mean age of 45 years and 14 years of magistracy covering all regional courts with at least one state from each. The case study reveal magistrates’ decisions favors prescribers’ authority over regulatory agencies in individual demands. The magistrates’ satisfaction survey indicated effectiveness of AD to deepening EBM knowledge.

**Conclusions:** AD strategy showed potential to improve EBM and health policies knowledge to magistrates and contributing for harmonizing decisions between health agencies and judiciary. We observed that magistrates tend to make decisions in the sense of preserving medical authority and providing medicines with public funds, even when in opposition to regulatory agencies.

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**An Examination of the Ethical and Legal Limits in Implementing “Traceback Testing” for Deceased Patients**

*Jessica Martucci, Yolanda Prado, Alan F. Rope, Sheila Weinmann, Larissa White, Jamilyn Zepp, Nora B. Henrikson, Heather Spencer Feigelson, Jessica Ezzell Hunter, and Sandra Soo-Jin Lee*

This paper examines the legal and ethical aspects of traceback testing, a process in which patients who have been previously diagnosed with ovarian cancer are identified and offered genetic testing so that their family members can be informed of their genetic risk and can also choose to undergo testing. Specifically, this analysis examines the ethical and legal limits in implementing traceback testing in cases when the patient is deceased and can no longer consent to genetic testing. In preparation for our own traceback study of ovarian cancer patients in the Kaiser-Permanente Health system, we sought to develop an ethical and legal framework for doing this kind of work. In doing so we turned to the established literatures on cascade screening and return of research results, as well as an examination of existing healthcare privacy laws in order to identify the ethical and legal possibilities for moving forward with traceback testing when the patient is deceased. After a detailed, historically-informed discussion of the ethical and legal frameworks that exist to guide this work, we propose and critically examine a series of practical solutions for doing this work.

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**Ethical and Public Health Considerations for Integrating Physicians with Mental Disability into the Physician Workforce**

*Amalia R. Sweet, Omar Sultan Haque, and Michael Ashley Stein*

Stigma against mental disability within the medical field continues to impose significant barriers on physicians and trainees. Here, we examine several implications of this stigma and propose steps toward greater inclusion of persons with mental disabilities in the physician workforce.

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*Steven Solomon*

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A Symposium Guest Edited by Michael R. Ulrich