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Introduction: Access to Healthcare Symposium

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INTRODUCTION: ACCESS TO HEALTHCARE SYMPOSIUM

Yvonne Lindgren*

The four Articles in this Access to Healthcare symposium edition address the different ways that the U.S. healthcare delivery system is failing marginalized communities, including individuals who are disabled, who are birthing, who are women of color or represent another marginalized group, or who live in poverty. The result is a rich conversation that uncovers the complex systems that contribute to unequal access to health care and unjust disparities in health outcomes in the United States. Several themes emerge across the four Articles. First, at the highest level, each of the Articles uses the COVID-19 pandemic as an opportunity to consider what the pandemic reveals about what is broken in the U.S. healthcare system. Second, each of the Articles address how the infrastructure and financing of health care contributes to inequality in access and unjust disparities in health outcomes. Third, the Articles examine how health care inequality is the result of discrimination, including racial, gender, income, and disability. Finally, the Articles describe how the COVID-19 pandemic revealed inequality in new ways and offered opportunities to consider health care reforms that would enhance health equity.

The four Articles reflect the type of critical legal undertaking reflected in the health justice framework.[1] Health justice has been described as an emerging framework that addresses unjust health disparities by addressing their underlying social causes including discrimination, poverty, and other forms of subordination.[2] The authors in this symposium edition situate health care access within the framework of social justice to consider how multiple axes of oppression—including gender, race, class, disability, and other characteristics—may deprive individuals and communities of fully experiencing health care equity. The works examine the ways that health care outcomes are shaped by more than poverty or genetics, rather, the works consider the ways that external forces such as social structures of discrimination, economic systems, and governmental institutions may work to deny individuals and communities meaningful access to health care. One of the central themes that ties the papers together is how the infrastructure of health care contributes to health care inequality. As Professor Elizabeth Kukura describes in her article, *Rethinking the Infrastructure of Childbirth*, "all infrastructure is fundamentally health infrastructure."[3] She argues that the very infrastructure of the

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[1] *See* Emily A. Benfer et al., *Health Justice Strategies to Combat the Pandemic: Eliminating Discrimination, Poverty, and Health Disparities During and After COVID-19*, 19 YALE J. HEALTH POL'Y, L. & ETHICS 122, 128 n.20 (2020); Angela P. Harris & Aysha Pamukcu, *The Civil Rights of Health: A New Approach to Challenging Structural Inequality*, 67 UCLA L. REV. 758, 806 (2020) (describing the emerging framework of 'health justice," that "places subordination at the center of the problem of health disparities"); *see also* Emily A. Benfer, *Health Justice: A Framework (and Call to Action) for the Elimination of Health Inequity and Social Injustice*, 65 AM. U. L. REV. 275, 278 (2015).

[2] Benfer et al., *supra* note 1, at 128 n.20.

[3] Elizabeth Kukura, *Rethinking the Infrastructure of Childbirth*, 91 UMKC L. REV. 497, 500 (2023)

U.S. birthing system leads to poor outcomes with the highest rates of maternal and infant mortality rates among peer industrialized nations, with the rate three- to four-times higher for Black women and women of color.[4] Her Article unearths how the birthing infrastructure in place which is seen as normal in the United States was actually shaped and influenced by political and legal maneuvering by doctors' organizations, insurers, and hospitals. The result is a medical system that financially rewards intervention and dissuades birth outside of hospitals and the use of midwives, even though those practices all contribute to better birth outcomes, especially for Black women and women of color. Thus, the infrastructure itself has "reshaped childbirth in the United States as a medicalized, pathologized, and technocratic process with high reported rates of coercion, mistreatment, and trauma."[5] She concludes that the maternal health care crisis is the result of *systemic* choices and failures, arguing that the perinatal care system is driven by "ignorance, paternalism, profit-seeking, and racism."[6]

Professor Marilyn Uzdavines' article, *Unforgiveable Lapses in Care: Our Failing Home and Community-Based Care System Discriminates Against People with Disabilities*, also examines how the infrastructure that provides care for people living with disabilities results in people with disabilities being placed in institutional care instead of independent living arrangements. Despite the fact that home- and community-based care services (HCBS) are more cost-effective—costing usually less than half the cost of institutional care—individuals with disabilities are being placed in institutional care because of the financial and reimbursement systems that pay for care. Medicaid's bias toward institutional care and poor pay for in-home workers as well as state caps on HCBS mean that states are more likely to place individuals in long term care instead of in-home and community based placement. She concludes that the systemic failures that force individuals with disabilities into institutionalized care deprive them of "dignity, equality, empowerment, self-determination, . . . and inclusion."[7] Finally, in his article, *Reference-Based Price Health Plans: A Necessary Approach to Exorbitant Health Care Prices*, Professor George Nation argues that the way the nation pays for healthcare and financially rewards behaviors of insurance companies and hospitals leads to inequality because it comes at the steep cost to the health and quality of life of those who rely on those systems, especially those with the least ability to pay.

The symposium Articles address inequality in access to health care as the result of discrimination, including racial, gender, income, and disability. Professor Kukura's Article, *Rethinking the Infrastructure of Childbirth*, addresses the issue of racism on the maternal and infant mortality rates in the United States. She explains that "obstetric racism" has resulted in negative birth experiences and

(quoting Bhav Jain et al., *All Infrastructure Is Health Infrastructure*, 112 AM. J. PUB. HEALTH 24, 24 (2021)).
[4] *Id.* at 503.
[5] *Id.* at 500.
[6] *Id.* at 499.
[7] Marilyn Uzdavines, *Unforgiveable Lapses in Care: Our Failing Home and Community-Based Care System Discriminates Against People with Disabilities*, 91 UMKC L. REV. 627, 632 (2023).

higher rates of maternal death and morbidity among Black women.[8] As she describes, poor birth experiences and outcomes are the result of the history of "medical exploitation of Black women upon which the field of gynecology was built, revealing the 'continuity of reproductive subordination' and the pathologization of Black women's bodies that contributes to the overmedicalization of Black women's childbearing."[9] Thus, poor outcomes for Black birthing people cannot be explained solely by poverty or biology; rather, the nation's legacy of slavery has resulted in structural inequality that shapes health outcomes.[10] Professor Uzdavines describes that unnecessarily segregating people with disabilities in institutional care is a form of discrimination, citing the Supreme Court's decision in *Olmstead v. L.C. ex rel. Zimring*,[11] which recognized that "unjustified isolation is properly regarded as discrimination on bases of disability."[12] Thus, Professor Uzdavines' Article is more than a call for legal reform to enhance healthcare access, but also argues that denial of access is a form of discrimination based on disability that deprives individuals of dignity, equality, empowerment, and self-determination.[13]

At the highest level, each of the authors describes how the COVID-19 pandemic laid bare what had been pervasive but hidden problems in the U.S. healthcare system. Brenna M. Moreno and Molly J. Walker Wilson's Article, *The Psychology of Science Denialism and Lessons for Public Health Authorities*, addresses the growing phenomenon of science denialism—the use of purportedly legitimate arguments to raise doubts about scientific consensus—which had been on the rise for decades. The authors argue that the need to squarely confront science denialism became clear during the pandemic because it undermined the efficacy of public health campaigns to combat the spread of the virus. Similarly, Professor Nation's call for reference-based pricing to help control the exorbitant hospital pricing that essentially requires patients to sign a "blank check" upon admission to the hospital grew in part out of the financial pressures surrounding COVID-19 that have led employers to look for new ways to contain health care costs.[14]

The symposium Articles also argue that the pandemic put health disparities into sharp relief. Professor Uzdavines observed that the COVID-19 pandemic shed light on how critical it is to allow people to live in community-based and home settings, describing that hundreds of thousands of people living in institutional settings died due to exposure to the virus in nursing homes and other institutional care settings. The disproportionate loss of life for people who lived in institutional settings revealed that "[i]nclusion of people with disabilities is not only a matter of human dignity, . . . it is a matter of life and death."[15] The pandemic

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[8] Kukura, *supra* note 3, at 508-09.
[9] *Id.* at 509 (quoting Colleen Campbell, *Medical Violence, Obstetric Racism, and the Limits of Informed Consent for Black Women*, 26 MICH. J. RACE & L. 47, 70 (2021)).
[10] *Id.*
[11] Olmstead v. L.C. *ex rel.* Zimring, 527 U.S. 581 (1999).
[12] *Id.* at 597.
[13] Uzdavines, *supra* note 7, at 627.
[14] George A. Nation III, *Reference-Based Price Health Plans: A Necessary Approach to Exorbitant Health Care Prices*, 91 UMKC L. REV. 585, 590 (2023).
[15] Uzdavines, *supra* note 7, at 631.

also allowed the rest of the population to experience firsthand how damaging isolation is for people's physical and mental health.[16] When nursing home visitation was severely curtailed, the toll of isolation on those in institutional care who lived and died alone, away from family, revealed that when people with disabilities are in "institutions isolated from their loved ones and community . . . [they] decline in mental and physical health because of their segregation."[17]

Professor Kukura's Article examines how the pandemic not only shed light on health disparities, but in some cases, the pandemic also offered glimpses of how the healthcare system could be reconfigured to enhance equal access and ensure better outcomes. She explains that the pandemic increased demand for decentralized stand-alone birth centers and home births as patients sought to avoid giving birth in hospitals filled with COVID-19 patients.[18] As a result, during the pandemic, many states relaxed interstate licensure rules and physicians, midwives, nurses, and doulas often cooperated in delivering care to ensure safe childbirth outside of the hospital setting.[19] The pandemic also revealed the heavy toll of living in institutional facilities in isolation and may help those advocating for people who are disabled to demand inclusion and connection to the community in housing as well as in social and workplace settings.

The wake of the COVID-19 pandemic is the ideal moment to consider inequality in access to health care and to envision ways to make the U.S. healthcare system more equitable and inclusive. The Articles offer ways to do so, from drawing upon psychological science to address science denialism and looking to the human rights framework for inspiration to solve intractable problems of inequality plaguing the U.S. healthcare system. The Articles reveal the many dimensions of inequality in the U.S. healthcare system. Inequitable health care outcomes cannot be explained by individual biology or insurance status. Rather, as these Articles describe, inequality in access and outcomes in health care is the result of economic systems, governmental institutions, and social structures of discrimination. The very infrastructure that undergirds the healthcare system perpetuates inequality in health care access and inequitable outcomes. Discrimination based on race, class, gender, and ability is both the source and the driver of health inequity. It is a critical moment to address the U.S. healthcare system because, as the Articles in this symposium edition describe, health care is one of the foundational requirements for human beings to be able to live lives of dignity, autonomy, and equality.

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[16] *Id.*
[17] *Id.* at 632.
[18] Kukura, *supra* note 3, at 501.
[19] *Id.* at 502.