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On the personhood of marginalized communities: a Maritainian rights-based approach to the moral wrong of U.S. health disparities in maternal mortality, and to moral repair through targeted policy measures

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ON THE PERSONHOOD OF MARGINALIZED COMMUNITIES: A MARITAINIAN RIGHTS-BASED APPROACH TO THE MORAL WRONG OF U.S. HEALTH DISPARITIES IN MATERNAL MORTALITY, AND TO MORAL REPAIR THROUGH TARGETED POLICY MEASURES

by

SHAUNESSE' A. JACOBS PLAISIMOND

B.A., Emory University, 2014
M.T.S., Emory University, 2016
M.A., Emory University, 2016

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Approved by

First Reader

Wesley J. Wildman Ph.D.
Professor of Philosophy, Theology, and Ethics, and of Computing and Data Sciences

Second Reader

Wylin D. Wilson, Ph.D.
Assistant Professor of Theological Ethics
Duke Divinity School, Duke University

We love Black mamas and approach this work with generosity towards all who are working for Black maternal health, rights, and justice. There is much to do: we need many voices and perspectives at the table.
— Black Mammas Matter Alliance

DEDICATION

I dedicate this work to my great-grandmother, Lucille Jenkins Yearling. She remains my best model of kindness, betterment, and love. Her sacrifices have allowed me to become her faith made flesh.

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ON THE PERSONHOOD OF MARGINALIZED COMMUNITIES: A MARITAINIAN RIGHTS-BASED APPROACH TO THE MORAL WRONG OF U.S. HEALTH DISPARITIES IN MATERNAL MORTALITY, AND TO MORAL REPAIR THROUGH TARGETED POLICY MEASURES

SHAUNESSE' A. JACOBS PLAISIMOND

Boston University School of Theology, 2023

Major Professor: Wesley J. Wildman, Professor of Philosophy, Theology, and Ethics, and of Computing and Data Sciences

ABSTRACT

Health disparities are differences in disease prevalence, mortality rates, and adverse health outcomes across social demographics. The prevalence of health disparities stems from sociopolitical inequities that contribute to the ongoing marginalization of different communities, the majority of which occur along racial and ethnic lines in the United States. As moral wrongs in need of moral repair, health disparities can be addressed in one of six ways, articulated in the scholarship of Margaret Urban Walker: (1) holding wrongdoers responsible; (2) addressing the harms imposed on victims; (3) instating moral terms and standards into harmed communities to regain their trust in social mechanisms meant to protect them; (4) recreating trust among harmed communities rooted in new norms; (5) nourishing hope; and (6) bringing together victims and wrongdoers. This dissertation engages the aforementioned morally reparative steps to redress the moral wrong of health disparities in the United States through proposed policy, educational, and clinical interventions.

This dissertation examines health disparities from four perspectives. First, it employs a sociohistorical lens to chart the history of health disparities in the United States and the complex social factors contributing to their prevalence. Second, it uses international rights rhetoric of the United Nations and its supporting committees to examine methods of accountability from the United States aimed at reducing disparities and inequities. Third, the dissertation applies the lens of Jacques Maritain's ontologically informed personalism to reclaim personhood as a viable concept that attends to the sacrality of humanity and our status as social and political beings. Fourth, the dissertation applies the historical, rights, and personalist perspectives in a case study centering black birthing people as an exemplary demographic plagued by racially impacted health disparities and in need of moral repair.

This dissertation uses the four-perspective approach to conclude with a morally reparative framework aimed at eliminating health disparities through constructive healthcare policy, practice, and educational measures affirming personhood, human dignity, universal human rights, and health for all people.

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LIST OF ABBREVIATIONS

CDC	Centers for Disease Control and Prevention
CEDAW	Convention on the Elimination of all Forms of Discrimination against Women
CERD	Convention on the Elimination of all Forms of Racial Discrimination
CMQCC	California Maternal Quality Care Collaborative
DOJ	Department of Justice
eGFR	Estimated Glomerular Filtration Rate
HCUP	Healthcare Cost and Utilization Project
HDI	Human Development Index
HELPP	Hemolysis, Elevated Liver enzymes, and Low Platelets
HEW	Department of Health, Education, and Welfare
HHS	Department of Health and Human Services
ICESCR	International Covenant on Economic, Social and Cultural Rights
ICG	Institute for Gender and Culture
NIH	National Institutes of Health
OHCHR	Office of the United Nations High Commissioner for Human Rights
OHRP	Office for Human Research Protections
PMSS	Pregnancy Mortality Surveillance System
SES	Socioeconomic Status
TOLAC	Trial of Labor After Cesarean

UDHR	Universal Declaration of Human Rights
UN	United Nations
U.S.	United States
USPHS	United States Public Health Service
VBAC	Vaginal Birth After Cesarean

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GLOSSARY

Black birthing people is a "gender-inclusive term referring to people who identify racially as black and have the physiologic capacity for pregnancy and childbirth." This includes, but is not limited to, black cisgendered women, black transgendered men, black gender nonconforming people, black genderqueer people, and black nonbinary persons. Black birthing people is the term most used in this work to remain as inclusive as possible; however, women will occasionally be used when referencing specific datasets or quotes given the binary language of health data.

Health disparities are "differences in the incidence, prevalence, mortality, and burden of disease and other adverse health conditions that exist among specific population groups in the United States."

Maternal morbidity "describes any short or long-term health problems that result from being pregnant and giving birth."

Maternal mortality is the death of a birthing person "from complications of pregnancy or childbirth that occur during pregnancy or within 6 weeks after the pregnancy ends."

Moral repair is "the task of restoring or stabilizing – and in some cases creating – the basic elements that sustain human beings in a recognizably moral relationship."

Moral wrong involves actions that individuals ought not perform due to social codes of conduct or the consequences those actions bring about. Some moral wrongs require legal punishment, others are not legally punishable but are unethical behaviors that cause individual and social harm, leading to moral damage.

Obstetric violence is “the appropriation of the body and reproductive processes of [birthing people] by health personnel, which is expressed as dehumanized treatment, an abuse of medication, and to convert the natural processes into pathological ones, bringing with it loss of autonomy and the ability to decide freely about their bodies and sexuality, negatively impacting the quality of life of [birthing people].”

Pregnancy-related complications are “physical and mental conditions that affect the health of the pregnant or postpartum person, their baby, or both. [These conditions] may start before, during, or after the pregnancy.” Common complications include anemia, anxiety, depression, diabetes, heart conditions, high blood pressure, hyperemesis gravidarum, infections, and weight.

INTRODUCTION

Global and Domestic Importance of Health Disparities

In February 2023, the World Health Organization (WHO) released a report detailing trends in maternal mortality from 2000 to 2020. Approximately 800 birthing people around the world die daily from preventable pregnancy and delivery-related complications.[1] One month later, data from the United States (U.S.) revealed that maternal mortality rates in 2021 were the highest in decades and largely informed by generations-long health disparities negatively impacting marginalized communities.[2] Whereas 861 U.S. birthing people died in 2020, 1,205 died in 2021.[3] Black birthing people had the highest maternal mortality rate of all racial and ethnic groups—"69.9 deaths per 100,000 lives births, 2.6 times the rate for non-Hispanic White women (26.6)."[4] While the mortality statistics are egregious, their source—health disparities—is a moral wrong.

Research efforts to examine "the multiple ways in which racism can adversely affect health" have gained traction in recent decades.[5] These efforts include identifying the most negatively impacted demographics and the specific systemic and individual

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[1] *Trends in maternal mortality 2000 to 2020: estimates by WHO, UNICEF, UNFPA, World Bank Group and UNDESA/Population Division* (Geneva: World Health Organization, 2023).

[2] Donna L. Hoyert, "Maternal Mortality Rates in the United States, 2021," NCHS Health E-States 2023, https://dx.doi.org/10.15620/cdc:124678.

[3] Hoyert, "Maternal Mortality Rates in the United States."

[4] Hoyert, "Maternal Mortality Rates in the United States."

[5] David Williams et al., "Racism and Health: Evidence and Needed Research," *Annual Review of Public Health* 40, no. 1 (2019): 106.

contributors to their disparities and inequities. As this dissertation will explore, identifying harmed groups and the many contributing factors informing their harm is only part of a larger solution to reducing and eradicating health disparities and inequities in one of the wealthiest developed nations in the world.

Separate from the first step of identifying inequities, international advisory bodies and Catholic ethicists have mapped an ideal society informed by respect for persons' universal rights. This dissertation takes these separate steps further and merges the international rights documents crafted by the United Nations and its supporting committees—primarily from the Universal Declaration of Human Rights (UDHR)—and Jacques Maritain's personalism to articulate the moral wrong of health disparities in the U.S., and also proposes solutions for moral repair inclusive of health policy, healthcare professional training, and clinical practice.

While some may argue that the secular ethics of the UDHR is sufficient to address health disparities, the worsening state of health in the U.S. suggests we need more. In the U.S., health disparities among black birthing people are not improving despite the U.S.'s agreement to international treaties protecting their rights to health and adequate health care. Technical policies are insufficient in the absence of an ontological vision of human persons that undergirds human rights, assesses moral wrongs, and most importantly, catalyzes positive action and inspires moral repair. In this dissertation, I argue that Maritain's personalism offers these necessities. Maritain provides the nation urgent moral motivation and a profound vision of the sacredness of every human life that aligns with U.S. culture and ways of thinking. There are many resources that can ground the sacrality

of life and focusing Maritain does not depreciate these alternatives. Rather, I aim to present a particular philosophy of personalism that both helps to inspire U.S. citizens' revolutionary use of international rights instruments and, even now, inspires a revolution in U.S. healthcare policy that improves the lived conditions of black birthing people.

Statement of the Problem: Health Disparities as Moral Wrongs

Contemporary healthcare research in the U.S. suggests that health disparities are undesirable side effects of complex social dynamics. Yet action to eliminate these disparities is slow-moving and limited to surface-level health measures as opposed to a comprehensive overhaul of the current ways we engage health systems and practice healthcare. This dissertation argues for the necessity of far-reaching systemic diagnosis and repair to end violations of universal human rights, specifically those rights attending to health and a good life, and to redress attacks on personhood among identifiable marginalized communities, attacks implied in the prevalence and persistence of health disparities and inequities.

To engage medical ethics communities, scholars, and policy developers interested in rights-based approaches, diagnosis and repair can be conducted at the level of human rights—inclusive of rights to the highest attainable standard of health and to adequate health care outlined in the UDHR and the United Nations' supporting conventions and committees—providing opportunities for analysis and application across cultures and traditions. Such engagement is inclusive of numerous societies, religious and theological traditions, and philosophical perspectives that can provide appropriate nuances for those marginalized in their communities of concern. This is a secularized, rights-based

approach that allows individual wisdom traditions to privately generate their own internal reasons for endorsing rights-based achievements, and thus it is the level at which most policy debates operate.

From within Christian ethics, however, there is a deeper story to tell. Christian personalism provides a more profound analysis of the problem of systemic and structural health disparities that moves the diagnosis of moral wrong beyond a violation of rights to a violation of the very dignity of persons, and of marginalized groups of persons. While the ethics of Christian personalism may not find resonance among all within the medical ethics community, it does articulate, for Christians and possibly other monotheistic religious communities, the deep wrong and urgency for repair associated with violating God-ordained personhood.

An abundance of personalist frameworks can be chosen to articulate the ethics of personhood, including the Boston Personalists' approach to social ethics. This dissertation centers the personalism of twentieth-century French Catholic philosopher Jacques Maritain for his indirect role in the philosophical framing of the moral consciousness required to craft a universal declaration of human rights, relevance for Catholic medical ethics, and majestic ontological vision of personhood rooted in natural law as an expression of God's intentionality in creating humanity. While innumerable theological approaches exist, all capable to an extent, of yielding moral frameworks proportional to Maritain's ontology and personhood—from Louisiana Black Baptist traditions to the United Methodist Church—Maritain's personalism aligns well with the goals of this dissertation.

A primary goal of this dissertation involves moving beyond the rights framework of the international community without contradicting it towards reframing the ills of health disparities by invoking an ontological Christian personalism. Such personalism is particularly beneficial for the case study of maternal mortality and morbidity among black birthing people this dissertation will employ. By painting a more descriptive portrait of the challenging lives and health of black birthing people in the U.S., the dissertation moves toward the goal of initiating an ethic of accountability for the U.S. that leads to practical steps improving the health of marginalized communities in this nation. This secondary goal attends to the sociocultural context of the U.S. and aims to invite more interdisciplinary interlocutors to the proverbial table to expand discourse and actions improving health outcomes beyond our current medical model. Because health is not relegated to the absence of disease, I follow emilie m. townes in addressing "the personal and public dimensions of health…dependent on social networks, biology, and environment," including spiritual, mental, and physical health.[6]

As a medical ethics project informed by theological ethics, this dissertation has three aims. First, it aims to reclaim "personhood" as a useful concept for bioethics. Since the early 1970's, "personhood" has been incorporated in medical ethics arguments to determine who is entitled to full moral rights.[7] A contemporary example of this position

[6] emilie m. townes, *Breaking the Fine Rain of Death: African American Health Issues and a Womanist Ethic of Care* (Eugene, OR: Wipf and Stock Publishers, 1998), 2.

[7] Mary Anne Warren first used personhood in a bioethical analysis of the legal status of persons in 1973, concluding fetuses were humans but not persons; therefore, fetuses were not entitled to full moral rights. *See* Mary Anne Warren, "On the Moral and Legal Status of Abortion," *The Monist* 57, no. 1 (1973): 43–61.

can be seen throughout abortion debates in the U.S. as state courts and communities continue fighting to determine how the potential personhood of those *in utero* compares to the personhood of the birthing person.[8] The lack of agreement in ethical debates regarding who is a person with full moral rights has led some scholars to call for the "end of personhood."[9]

Others persist in using personhood but argue for additional specificity about its philosophical import.[10] Yet others argue for broadening the community of interlocutors, reviving the efficacy of personhood by engaging communities whose personhood has been threatened through arbitrary lines of marginalization that have historically and negatively impacted minoritized groups.[11] While acknowledging the difficulties personhood poses for ethics, this dissertation takes the latter approach through a Christian personalism that simultaneously attends to the sacrality of humanity and our status as social and political beings.

Second, the dissertation proposes to utilize both an international rights-based framework and a theologically specific Maritainian personalism to craft a path from

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[8] Bloomberg Law, "Beyond Abortion: The Fight over Fetal Personhood is Here," filmed January 12, 2023 at The National Library of Medicine, Washington, D. C., video, 6:19, https://youtu.be/J-9Evt6j8SQ.

[9] Jennifer Blumenthal-Barby, *"*The End of Personhood*," The American Journal of Bioethics* (published online ahead of print, January 12, 2023): 1-10, https://doi.org/10.1080/15265161.2022.2160515.

[10] Francis J. Beckwith, "Taking Abortion Seriously: A Philosophical Critique of the New Anti-Abortion Rhetorical Shift," *Ethics & Medicine: An International Journal of Bioethics* 17, no. 3 (Fall 2001): 155-166.

[11] Jennifer Elyse James, "Black Feminist Bioethics: Centering Community to Ask Better Questions," in *A Critical Moment in Bioethics: Reckoning with Anti-Black Racism through Intergenerational Dialogue,* ed. Faith E. Fletched et al., special report *Hastings Center Report* 52, no. 2 (2022): S21-S23.

discerning moral wrong to articulating relevant moral repair as it relates to health disparities in the U.S. There are innumerable, complex potentials for establishing moral repair, including policy and healthcare-practice measures. But this dissertation's two lenses establish principles for interpretation that can clarify the policy-and-practice landscape. Moreover, these lenses are capable of inspiring novel scholarly understandings of the ways communities have been marginalized by health systems in the U.S., thereby inspiring transformations of healthcare policy and practice that can eventually eliminate these health crises.

Third, this dissertation aims to clarify the role of medical and theological ethics in U.S. healthcare praxis and policy. For many bioethicists, ethical dilemmas and deliberations are addressed using the four-principle-model—autonomy, non-maleficence, beneficence, justice.[12] These four principles have demonstrated their efficacy on a plethora of moral concerns, including the moral status of sentient beings, the impact of overconsumption on diverse members of communities, research contributions to future generations that reduce and eliminate disparities, and the virtues held within socially marginal beings.

In contrast, Christian theological ethics remains increasingly sidelined in policy debates, partially due to the secularity of the public square that deems religion-specific

[12] Tom Beauchamp and James Childress set out their four *prima facie* principles following W.D. Ross's distinction between *prima facie* and absolute principles. They suggest the four principles serve as norms, more than an ethical framework, which can be applied as guidance with proper specification to ethical analysis. Critics challenge the absolutism of their principlism, but the four principles are largely accepted by bioethicists as the norms by which we measure and conduct medical analyses. *See* Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics*, 7th ed. (New York: Oxford University Press, 2009).

outlooks ill-suited for public moral reasoning and partly due to the harm Christian ethics has posed in policy measures, directly violating the aforementioned principles. This dissertation puts forth that Christian ethics can serve a reparative role with future health policies by incorporating the four-principle-model in considering how to affirm personhood, human dignity, universal human rights, and health for all people. Through this incorporation, Christian theological ethics can provide constructive contributions to healthcare policy and praxis impacting the daily lives and health of vulnerable communities in need of their personhood restored through the elimination of health disparities. This dissertation does not aim to provide comprehensive answers to these morally and bioethically relevant questions and distinctions. Instead, it aims to demonstrate the theological and ethical *significance* of attending to the ways theologically informed bioethicists are uniquely suited to inform policy measures addressing health disparities and the ways healthcare professionals are involved in reducing said disparities.

Significance of the Problem Internationally and Domestically

The State of Health Disparities in the U.S.

In 2016, the National Institutes of Health (NIH) conducted a national landscape analysis surveying the breadth and clarifying the sources of health disparities in the U.S, which was published as *Communities in Action: Pathways to Health Equity*.[13] Health

[13] The NIH articulates that health disparities "stem from health inequities—systematic differences in the health of groups and communities occupying unequal positions in society that are avoidable and unjust." *See* National Academies of Sciences, Engineering, and Medicine et al., "The State of Health Disparities in the United States," in *Communities in Action: Pathways to Health Equity* (Washington D.C.: National Academies Press, 2017).

disparities exist across numerous identifiers and demographics—gender and sexuality, indigenous versus nonindigenous, LGBTQIA+ versus heterosexual, disability versus ability, veteran versus civilian, and rural versus urban, to name a few. However, racial and ethnic identifiers remain the focus of the majority of this research field given the lasting impact of historic and systemic racist measures that continue to plague U.S. society.[14] Alongside this lasting impact is the vast amount of empirical research proving socioeconomic factors are not the primary cause of disparities along racial and ethnic lines. Racism is a primary determinant driving adverse health outcomes.

> As a structured system, racism interacts with other social institutions, shaping them and being reshaped by them, to reinforce, justify, and perpetuate a racial hierarchy…Thus, structural racism exists within, and is reinforced and supported by, multiple societal systems, including the housing, labor, and credit markers, and the education, criminal justice, economic, and health care systems.[15]

> [Racism] goes beyond prejudice or even bigotry by binding negative or vicious feelings or attitudes to the exercise of putatively legitimate power. Racism is both an ideology and a set of practices. It does not rely on the choices or actions of a few individuals; rather, racism infiltrates, permeates, and deforms the institutions of politics, economy, culture, even religion. Racism exploits the interdependence of individuals in and upon society through the formulation of ideology. Ideology as a mental construction may be defined as a biased way of thinking, which justifies and maintains an iniquitous way of living. Not only does racism ignite pseudo-rationality, incite vicious practices and violent acts, it poisons the racist—crippling [a person's] potential for authentic religious, cultural, social, moral, psychological, and spiritual growth. As intrinsic evil, racism is lethal to bodies.[16]

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[14] National Academies of Sciences, Engineering, and Medicine et al., *Communities in Action.*

[15] David R. Williams et al., "Racism and Health: Evidence and Needed Research," *Annual Review of Public Health* 40 (2019): 106.

[16] M. Shawn Copeland, *Enfleshing Freedom*: body, race, and being (Minneapolis, MN: Fortress Press, 2010), 109.

As an ideology and structured system, racism remains at the root of the obstacles to good health marginalized communities in the U.S. encounter as they try to assert their rights to health and healthcare. While there are significant gaps in disparities research, enough is known about the prevalence of disparities along racial and ethnic lines to understand the intersectional impacts of health disparities with gender, socio-politics, culture, identity, and history.

Further, the landscape analysis demonstrated the complexity of the interaction between racial and ethnic markers and health outcomes. Despite race and ethnicity being markers for negative organ, infant, and prenatal health, with people of color faring worse than white groups, Latino/a, African, and Afro-Caribbean communities give rise to the "immigrant paradox," initially experiencing better health outcomes than white communities. Unfortunately, the longer generations of immigrants remain in the U.S., the worse their communal health outcomes become.[17] Other indicators reflecting declining disparity gaps along racial and ethnic lines exist due to declining health among dominant white groups.

For example, in recent years white women have experienced increased suicide and alcohol-related deaths. Their increased deaths close statistical gaps across broad death statistics along racial and ethnic lines; however, people of color continue to fare disproportionately worse when encountering systems meant to protect and promote their

[17] National Academies of Sciences, Engineering, and Medicine et al., *Communities in Action*; Marielena Lara et al., "Acculturation and Latino health in the United States: A review of the literature and its sociopolitical context," *Annu Rev Public Health* 26 (2005): 367-397.

health.[18] While the landscape disparities survey captures the positive and negative epidemiological and clinical complexities of health disparities in the U.S., it does not account for health among intersecting identities, *e.g.*, being black and having a uterus.

The NIH's analysis concludes by asking future researchers to expand definitions, metrics, and indicators of health to capture added nuances of health equity as well as to pursue studies examining how singular factors influence multiple health outcomes.[19] This call-to-action sparks vital questions for this dissertation: How can the Universal Declaration of Human Rights and its supporting committees be used to articulate and redress health disparities? What does the UDHR tell us about how we understand individual and communal health, and our duties to promote both?[20] Can we identify consistent health rights that ground moral duties in the form of policy measures that can

[18] National Academies of Sciences, Engineering, and Medicine et al., *Communities in Action*; Anne Case and Angus Deaton, "Rising morbidity and mortality in midlife among white non-Hispanic Americans in the 21st century," *Proceedings of the National Academy of Sciences of the United States of America* 112, no. 49 (2015): 15078–15083.

[19] National Academies of Sciences, Engineering, and Medicine et al., "*Communities in Action.*"

[20] Three concepts for understanding health are at the fore of five international documents: 1) States must ensure a right to adequate care for all citizens. If this responsibility is not upheld, the international community is responsible to ensure this right. 2) States are responsible for ensuring state action does not deprive citizens of a right to health. 3) The right to adequate health is guaranteed to every citizen regardless of demographic identifier and communal standing. *See* UN General Assembly, *Universal Declaration of Human Rights*, 10 December 1948, 217 A (III), available at: https://www.refworld.org/docid/3ae6b3712c.html; UN General Assembly, *International Convention on the Elimination of All Forms of Racial Discrimination*, 21 December 1965, United Nations, Treaty Series, vol. 660, p. 195, available at: https://www.refworld.org/docid/3ae6b3940.html; UN General Assembly, *International Covenant on Economic, Social and Cultural Rights*, 16 December 1966, United Nations, Treaty Series, vol. 993, p. 3, available at: https://www.refworld.org/docid/3ae6b36c0.html; UN General Assembly, *Convention on the Elimination of All Forms of Discrimination against Women*, 18 December 1979, A/RES/34/180, available at: https://www.refworld.org/docid/3b00f2244.html; World Health Organization (WHO), *Constitution of the World Health Organization: Basic Documents* (Geneva: World Health Organization, 1946).

apply to any identifiable group experiencing suboptimal health in the U.S.? And how might honoring these rights improve health and health equity?

Engaging international rights rhetoric with health praxis promotes clearer articulation of moral duties within the U.S. healthcare system. Further, the NIH landscape analysis prompts Christian theological ethics to put forth its resources to address the problem of systemic health disparities. And this dissertation engages Maritainian personalism as the primary theological resource, leveraging its revolutionary ontological understanding of human persons and human dignity, derived from participation in God's creation and divine love.

Health Disparities Impacting Black Birthing People

In 2020, the mortality and morbidity statistics for black birthing people equated to 55.3 deaths per 100,000 live births, 2.9 times the rate for white birthing people.[21] This death rate was the highest in fifty years, and sixty percent were preventable.[22] Unfortunately, deaths in 2021 surpassed those in 2020, creating a new record of maternal mortality among black birthing people. Regardless of age, educational attainment, and income level, black birthing people's mortality statistics around pregnancy, labor, and

[21] WHO defines maternal death as "the death of a woman while pregnant or within 42 days of termination of pregnancy, irrespective of the duration and the site of the pregnancy, from any cause related to or aggravated by the pregnancy or its management, but not from accidental or incidental causes," calculated as "the number of maternal deaths per 100,000 live births." Given the binary nature of the definition, there exists a tension between the clinical language and evolving socially inclusive language. As such, I will quote binary language related to health disparities, when necessary, but more often I will use gender-inclusive language such as birthing people. *See* Donna L. Hoyert, "Maternal Mortality Rates in the United States, 2020" NCHS Health E-Stats 2022, https://dx.doi.org/10.15620/cdc:113967.

[22] Centers for Disease Control and Prevention, "Health of Black or African American non-Hispanic Population," NCHS, last modified April 7, 2021, https://www.cdc.gov/nchs/fastats/black-health.htm.

delivery remain higher than all other racial and ethnic groups in the U.S. Further, of all developed nations in the world, the U.S. has the highest mortality and morbidity rates among birthing communities despite possessing the highest global spending rate on healthcare.[23]

This reality is statistically captured in a 2023 WHO report, which found a 77.9% increase in the U.S.'s maternal mortality rate between 2000 and 2020.[24] The following year's mortality rates surpassed this already historic high with black birthing people experiencing mortality rates at approximately seventy deaths, 2.6 times higher than white women. In just a year, with the same reporting measurements in place, fourteen percent of the birthing population experienced rates of preventable maternal deaths almost triple their population. This reality moves maternal mortality among black birthing people beyond a public health crisis. Their deaths are morally reprehensible.

These alarming statistics alone suggest a violation of universal rights to health and adequate healthcare. This could be explained several ways, including some ways that do not present the urgency of this health crisis as a moral wrong. This dissertation argues that part of the explanation for the disproportionate death rates for black birthing people

[23] Samantha Artiga et al., "Racial Disparities in Maternal and Infant Health: An Overview," KFF, last modified November 10, 2021, https://www.kff.org/report-section/racial-disparities-in-maternal-and-infant-health-an-overview-issue-brief/.; Organisation for Economic Co-operation and Development, "OECD Health Data 2009– Frequently Requested Data," last modified November 30, 2009, http://www.oecd.org/document/16/0,3343,en _2649_33929_2085200_1_1_1_1,00.html.

[24] WHO's 2023 *Trends in maternal mortality 2000-2020* revealed maternal mortality rates and maternal death rates across the globe. The U.S. was one of eight countries, most importantly the only developed nation, that experienced significant percentage increases in maternal mortality and one of twenty-four countries that experienced COVID-19 contributing to at least ten percent of maternal deaths. *See, Trends in maternal mortality 2000 to 2020.*

is their exclusion from being considered full persons to whom society owes rights commensurate with their dignity as persons. It is this potential exclusion that I investigate as a theologically trained bioethicist, exploring how black birthing people's exclusion from full personhood manifests in medical policy and praxis in the U.S. healthcare system.

Existing scholarship has acknowledged that maternal mortality among black people is a public health crisis in the U.S. This framing is critical, yet detrimental. Crisis becomes the primary lens through which black birthing people are engaged, placing them in a "nontime and nonplace, one that is thought to be qualitatively different from the here and now of the contemporary United States…as noncitizens, as historical actors who do not fit into the present moment...describing Black mothers as analogous with non-US women."[25] Several journalists and scholars have compared the mortality and morbidity statistics among black birthing people to those in developing nations as though the mortality rates abroad are acceptable.

The crisis framing has led to some mitigating proposals prioritizing improved black birthing experiences, largely by focusing on statistical analyses and promoting anti-racist clinical and social practices through additional anti-bias trainings and education. However, these interventions have yet to mitigate the moral wrong. Meanwhile, minimal attention has been given to the violations of black birthing people's personhood and

[25] Jennifer C. Nash, *Birthing Black Mothers* (Durham, NC: Duke University Press, 2021), 12.

rights to health that inform these health disparities. These violations lead to detrimental patterns in healthcare decisions that are challenging to identify and correct.

Such difficulties sustain the moral wrong despite the efforts of policies meant for redressal. The history of increasing deaths afforded by ongoing public health analysis provides ample evidence that current policy measures are not having the intended impact. Following Jennifer Nash's critique of crisis, which has become the U.S.'s norm to express epistemological limits, crisis "contains an implicit ethical demand for another kind of future and for immediate intervention to transform the conditions of the present into a different kind of future" that radically breaks from the present state of compassion-turned-neglect once the urgency has passed.[26] It is critical for new policies to invoke the judgment that health disparities are a moral wrong that will likely persist until serious and sustained moral repair is instituted. This dissertation proposes both the UDHR and Maritainian personhood as complementary bases for diagnosing moral wrong and articulating moral repair, both in theory and in practice, aiming for the reparative transformation of healthcare policy and practitioner decision processes that radically break from our present healthcare system.

Although investigating the role personhood can play in protecting health and health rights is understudied—the gap in which this dissertation stands—several disciplines have done important work to address some of the social ills that contribute to the maternal mortality and morbidity crisis. Bioethicists have addressed the historic

[26] Nash, *Birthing Black Mothers*, 14.

suffering experienced by black communities leading to centuries of medical mistrust and the necessity of institutional and communal healing as a form of social justice.[27] International bioethics scholarship has also examined the unethical treatment of birthing people in developing nations (*e.g.*, Nigeria and Sudan).[28]

Feminist scholarship addresses the failures in healthcare experienced by non-men (most often discussed are cis-gendered women) and the long-term social damage caused by neglecting symptoms, minimizing expressed health concerns, and ignoring demands for gender health equality. Feminist theologians go a step further, analyzing the complex spectrum of sexualization experienced by black women that informs social biases limiting the care they receive.[29] Bioethics and feminist scholarship have united to address reproductive rights as human rights, analyzing international documents outlining rights owed to members of participating nations.[30] Finally, religion scholars have adequately

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[27] Michael Byrd and Linda Clayton, *An American Health Dilemma: A Medical History of African Americans and the Problem of Race: Beginnings to 1900* (New York: Routledge, 2012); Kelvin Calloway, "Bioethical Issues Confronting the African American Community," *Bioethics Forum* 11, no. 2 (1995): 31-34; Patricia King, "Race, Equity, Health Policy, and the African American Community," in *African American Bioethics: Culture, Race, and Identity*, ed. Edmund Pellegrino and Lawrence Prograis (Washington, D.C.: Georgetown University Press, 2008); Harriet A. Washington, *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present* (New York: Doubleday, 2006).

[28] Bolatito A. Lanre-Abass, "Poverty and maternal mortality in Nigeria: towards a more viable ethics of modern medical practice," *International Journal for Equity in Health* 7, no. 1 (2008): 1-9; Vedran Stefanovic, "Education in developing countries and reducing maternal mortality: a forgotten piece of the puzzle?," *Journal of Perinatal Medicine* 49, no. 9 (2021): 1042-1047; Susan Dodds et al., *Linking visions: feminist bioethics, human rights, and the developing world* (Lanham: Rowman & Littlefield Publishers, 2004).

[29] Delores Williams, "Women's Oppression and Lifeline Politics in Black Women's Religious Narratives," *Journal of Feminist Studies in Religion* 1, no. 2 (1985): 65.

[30] Rebecca J. Cook et al., *Reproductive Health and Human Rights: Integrating Medicine, Ethics, and Law* (Oxford: Oxford University Press, 2003); Michael Grodin, *Health and Human Rights in a Changing World* (New York: Routledge, 2013).

attended to the social and theological aspects of morality, but have yet to move towards engaging in compliance and violations of morally informed human actions and rights.

Connected to bioethics and feminist studies, public health scholarship addresses the social determinants of health that can promote health equity. The field of public health also gathers and analyzes statistical data to uncover patterns in maternal mortality, health complications, and ignored symptoms experienced by black birthing communities.[31] For example, the Centers for Diseases Control and Prevention (CDC) annually report birth and death certificate data from forty-eight participating states to track mortality rates across birthing people in their Pregnancy Mortality Surveillance Systems.[32]

Moral Implications of Health Disparities

While research has effectively identified the depth and complexities of disparities in the U.S., including those impacting black birthing people, the path from disparity to health remains a live and unresolved debate. This dissertation contributes to this ongoing debate by proposing policy interventions informed by both an international rights-inspired approach and a Maritainian-personhood approach. This dual approach is capable of diagnosing moral wrong at the broad level of health policy debates and at the more niche level of Christian theological ethics. Simultaneously, this approach is capable of

[31] Donald Barr, *Health Disparities in the United States: Social Class, Race, Ethnicity and Health*, 2nd ed. (Baltimore: Johns Hopkins University Press, 2014).

[32] Centers for Disease Control and Prevention, "Pregnancy Mortality Surveillance System," last modified November 25, 2020, https://www.cdc.gov/reproductivehealth/maternal-mortality/pregnancy-mortality-surveillance-system.htm.

supporting moral repair at both levels, leading to policy frameworks and interventions that can positively impact clinical care, thereby alleviating health disparities.

Engaging international rights rhetoric within the secular context of healthcare policy is well understood, whereas the Christian theological ethics of personalism is largely unfamiliar except to those theologically trained policy professionals. Despite the potential lack of familiarity with Christian theological ethics, this dissertation argues that building Maritainian personalism into policy contexts can have positive impacts due to its ability to highlight systemic violations of human dignity inherent in health inequities. Further, Christian theological ethics writ large is uniquely capable of illuminating the relationship between victims of disparities and larger offending societies to encourage new norms aimed at moral repair. This approach goes beyond naming the violation of rights, although this should be enough to identify a moral wrong and define strategies for moral repair, but in fact the crisis is not being eliminated. Something more is needed to spark right action and effective change.

Employing Maritain's personhood and international rights rhetoric together, the dissertation seeks a novel way to capture the moral successes, failures, and duties at stake in advancing health in the U.S. Maritain's personalism provides an energized theological stance on human dignity rooted in divine creation and love, and an evocative ontological vision of natural law that increases sensitivity to the immorality of health inequities, thus strengthening desire and determination to seek specific actions for moral repair. What is owed to humans as social and political beings—outlined in the UDHR, a universal bill of rights supported by the United States—is a catalyst for new conversations.

But Maritain's personalism goes further. His theological engagement with the social dimensions of individuals and persons provides fertile ground for applying these philosophical and theological concepts to practical areas of political and social life, including health disparities among black birthing people, which is a problem Maritain did not address. Maritain's ontological vision of human dignity strengthens the necessity and urgency of moral repair rooted in the restoration of personhood for marginalized communities, and this has the potential to spark greater change than a rights framework alone.

Method of Investigation and Sources of Study

This dissertation exists at the intersection of bioethics and theological ethics.[33] Bioethical works examine moral questions related to the sharing of embodied lives and biologically complex environments on this planet and frequently engage in interdisciplinary philosophical, ethical, religious, and judicial dialogue. In this dissertation, I engage bioethics in an interdisciplinary conversation with selected philosophers, theologians, and healthcare policy experts working on the questions of rights, personhood, and the morality of equitable health.

This work of engaging interdisciplinary interlocutors serves two aims: to interrogate and assert universal rights to health as standard practice in the U.S., and to

[33] Many branches of bioethics exist, creating rich dialogue, important differences, and critical overlap. Despite this rich history, I was trained within the principlist approach of Beauchamp and Childress, surveying the ethical theories that best protect the four principles of autonomy, justice, beneficence, and nonmaleficence. As such, their frameworks, methodologies, and approaches, along with those scholars who informed them, can be found throughout this work. *See* Beauchamp and Childress, *Principles*.

draw attention to the critical methods the discipline of bioethics possesses for pursuing important ethical questions and healthcare policy solutions that center personhood as a means of reducing health disparities. Fulfilling these aims requires integrative analysis of philosophical and moral concepts of personhood; dialogues between ethicists, theologians, and healthcare policy experts; and investigating practical implications of personhood through measurable policy actions in the form of a case study on black birthing people and maternal mortality.

The conceptual frameworks of deontology, moral rights, and principlism—following the lineage of Tom Beauchamp and James Childress—are critical to my aims.[34] Deontology, specifically a deontological ethic informing moral rights and principles, determines the rightness or wrongness of actions based on the rational identification of universalizable principles that increase the common and individual good. Moral rights imply corresponding positive and negative duties for individuals and societies in which individuals live and contribute.[35] Moral-rights dialogue seeks to understand what constitutes personal and communal interests in need of protection. Beauchamp and Childress's principlism puts forth that morally informed persons share a common morality guided by *prima facie* principles—such as the four-principle model of

[34] Guyer and Wood, *The Cambridge Edition of the Works of Immanuel Kant*.

[35] Lisa Kearns and Maya Grunschlag, "Conceptual Foundations of Bioethics," NYU Grossman School of Medicine Division of Medical Ethics, last modified June 25, 2020, https://med.nyu.edu/departments-institutes/population-health/divisions-sections-centers/medical-ethics/sites/default/files/medical-ethics-conceptual-foundations.pdf.

autonomy, beneficence, nonmaleficence, and justice—which serve as useful tools for decision-making, including in relation to clinical decisions impacting health equity.[36]

These conceptual resources sometimes require integration with other bioethical resources (*e.g.*, virtue ethics and ethics of care) to recalibrate in the face of new health concerns. Still, deontology, moral rights, and principlism lay necessary groundwork for understanding how healthcare functions in the U.S. and where it has demonstrably failed to generate equitable health outcomes.

I bring the forgoing conceptual resources for understanding morality and duty into conversation with Jacques Maritain's concept of personhood. There are four critical texts of Maritain's that are analyzed: *The Person and the Common Good*, *Man and the State*, *The Rights of Man and Natural Law*, and *Natural Law: Reflections on Theory and Practice.* Each of these texts together present the most thorough articulation of Maritain's Thomist moral consciousness that guides his articulation of the importance of respect of persons and their inalienable rights. International rights rhetoric is primarily derived from the 1948 Universal Declaration of Human Rights (UDHR), but four additional international documents expound on the rights in the UDHR. These include the World Health Organization's constitution, Convention on the Elimination of all Forms of Discrimination against Women, Convention on the Elimination of all Forms of Racial Discrimination, and International Covenant on Economic, Social and Cultural Rights.

[36] Beauchamp and Childress, *Principles*.

I have selected these texts because of their relation to one another—Maritain's definition and understanding of natural law is a grounding philosophy of the UDHR's approach to positive and negative human rights—as well as their importance as inclusive documents that are transferable across cultures.[37] Further, although many personalists could be chosen, Maritain's ontological approach to understanding human beings strengthens the moral aims of this project in addressing harmful historic marginalizations experienced by racial and ethnic minorities in the U.S., thus allowing this dissertation to analyze new ways of positively approaching the health of black birthing people and generating new models of care that bring attention to the U.S.'s need for moral accountability in protecting the rights of all its citizens.

While international rights rhetoric and Maritainian personalism cover much ground, secondary material on personhood, health, and disparity written by clinicians, health policy experts, feminist scholars, and theologians must be integrated. These secondary materials serve the purpose of providing the most robust and complex picture possible to diagnose the moral wrong health disparities represent and articulate opportunities for repair that can only be achieved when these different social actors come together to honor the personhood and rights of black birthing people.

An important concern of projects at the intersection of bioethics and theological ethics is the development of a sustained critique of absolutist moral principles that conflict across communities. For example, clinically, should the duty to protect life

[37] William Sweet, "Jacques Maritain," *The Stanford Encyclopedia of Philosophy*, Summer 2022 Edition, ed. Edward N. Zalta, last modified May 1, 2019, https://plato.stanford.edu/entries/maritain/.

outweigh the duty to ensure fair distribution of resources in an underfunded trauma center that serves multiple counties?[38] Conversely, theologically, there is a serious problem absolutizing a theistic vision of personalism given the plurality of religious traditions, including nontheists who also have an equal stake in human rights. Such concerns are live and valid, and the bioethics framework of the proposed dissertation is sufficient for managing them.

Limitations

I have limited my project to a specific lineage of personalism that naturally relates to the social issue of health disparities, though other philosophical lineages could be analyzed in later works. I have also limited myself in the case study to a specific social justice issue plaguing a specific community, namely maternal mortality among black birthing people. While these limitations create particular boundaries, they also increase the control of the proposed dissertation.

A third limitation is prioritizing the social benefits gained from attending to health rights for marginalized communities. Numerous challenges exist to actualizing the rights to health and healthcare in a nation as diverse as the U.S. For example, should black and indigenous communities be given the largest health discounts and vouchers to account for historic traumas? How can a decent minimum of care for all citizens be created that avoids racial and ethnic identifiers? How should resources be justly allocated without replicating harms along racial and ethnic lines? How can the health system be funded to

[38] Kearns and Grunschlag, "Conceptual Foundations of Bioethics."

support citizens and immigrants? These questions are critical when seeking to protect rights to health in a diverse nation; however, they will not be engaged in this work. This work is limited to uncovering the social benefits gained from attending to the rights to health and health care through morally reparative actions for one marginalized social demographic, black birthing people.

A fourth limitation is the specific rights outlined in international rights rhetoric. In examining the International Bill of Rights, dozens of positive and negative rights are listed, many of which intersect with and/or inform individual and communal health. However, this work specifically analyzes those rights explicitly naming health and healthcare. A human rights approach cannot solve every problem connected to health disparities, but it can begin a necessary conversation centered on protecting and promoting rights to health owed to all communities, a conversation which Christian theological ethics can positively contribute to in theory and praxis.

Finally, I have limited my intended audience to bioethicists, theological ethicists, clinicians, and health policy experts. Many communities and vocations may find value in this dissertation, but the primary practical implications implore the intended audience to understand that personhood remains a vital concept for health praxis and policy, benefitting practitioners and patients alike.

Outline

The introduction has articulated the problem of health disparities impacting marginalized communities, a framing which is insufficient to fully mitigate the problem. Escalating the need to frame health disparities as a moral wrong, a broad range of

solutions have been offered through international advisory bodies and Catholic personalism, including new and reformed policies, social dynamics, and clinical educational frameworks. Beginning to analyze the moral dimensions of health disparities provides space for the remainder of the dissertation to invoke theological ethics to propose an in-depth diagnosis of moral wrong and repair alongside rights-based diagnoses more often explored in healthcare ethics and policy sources. Both approaches will offer solutions to restoring personhood to marginalized communities, specifically black birthing people, impacted by historic disparity.

In the first chapter, the dissertation performs a thorough analysis of the problem of health disparities in the U.S. Examining the history of disparities and clinician involvement dating back to chattel slavery, this chapter narrates how historically impacted communities struggled with poor health and limited healthcare. Historical narratives are then brought to the present through the analysis of contemporary health statistics that reveal the plight of many marginalized communities' poor health, resulting from intersecting systems that also negatively impact the entire nation. Contemporary data is then briefly put in conversation with black women to offer a glimpse of the health disparities impacting them as a result of historic systems and choices, as well as racial hierarchies placing them at the bottom of the social totem pole—the worst position for health outcomes in the U.S. The narratives and data of health disparities and structural health inequities are then philosophically framed as moral wrongs causing moral damage, leaving society desperately in need of moral repair.

Chapter two performs a landscape analysis of the application of morality and duty found in international rights rhetoric informing positive and negative rights to health and healthcare. The chapter begins with the difficulties associated with implementing a rights framework in the U.S. followed by a close analysis of international documents, which the U.S. supports. These include the Universal Declaration of Human Rights, Convention on the Elimination of all Forms of Discrimination against Women, Convention on the Elimination of all Forms of Racial Discrimination, and International Covenant on Economic, Social and Cultural Rights, as well as sources challenging the implementation of an idealized framework and criticizing the universality of human rights. This chapter concludes with morally reparative actions that can be developed from international rights rhetoric focused on bettering the health and lived experiences of marginalized communities, specifically black birthing people. As such, the international documents serve as a secular source for moral repair in the presence of health disparities impacting black birthing people.

The third chapter conducts a thorough analysis of Jacques Maritain's concept of personhood as a part of the natural law lineage of Boethius and Thomas Aquinas. Charting the history and development of personhood, both from functionalist and inherent perspectives, the chapter then engages criticisms of personhood and its limitations in addressing social issues. Following these criticisms, the novel approach of Maritainian personalism is explored beginning with the Thomist influences that ground his concept. These influences are followed by a thorough analysis of Maritain's construction of personhood across four critical texts to grasp the ways he viewed

humanity and how these views could be bolstered in society to uplift all demographics. Maritain seeks the conditions to activate full humanity without diminishing individual value. Through these conditions, he acknowledges that private goods remain subordinate to the common good of community, and simultaneously insists that communal good remains subordinate to the spiritual good and supernatural end of persons. The chapter concludes putting Maritainian personalism in conversation with health disparities to theologically critique the systems that contribute to prevailing inequities and offer theologically informed moral repair.

The penultimate chapter develops disproportionately high mortality among black birthing people in the U.S. as a detailed case study to capture the ways they are not accounted for in health systems. As a public health crisis with deep and troubling roots in U.S. history, black maternal mortality is representative of the complexities of disparities and intersectionality of identities that exacerbate these disparities throughout the U.S. I begin with two narratives of maternity and mortality to provide nuance to the lived experiences and ongoing advocacy of black birthing people navigating U.S. healthcare systems. These portraits are then strengthened by the numerous statistics across the stages of pregnancy and postpartum care that depict a health system failing a specific demographic most in need of good care. Addressing the limitations of their care and the social burdens they carry, black birthing people's maternity and mortality is then explored through a morally reparative lens that engages education, policy, and society. This chapter attends to the duty to a reclaimed notion of personhood as a means of informing practices involving healthcare practitioners and recipients. Invoking

international rights rhetoric and Maritainian personalism allows this chapter to conclude with means of restoring and reclaiming personhood and equitable health for black birthing people through specific proposed policy measures aligned with existing Congressional recommendations.

The conclusion provides a summary of the argument concerning personhood in matters of health and communal duties related to moral rights as has been laid out in the preceding chapters. I offer my final thoughts on a world free of health disparities in which black birthing people and all other presently marginalized communities can move through society respected as persons with full moral status having their inherent rights protected. In part, this world is grounded in educational, clinical, and social policies that respect and protect rights and personhood, while always revisiting the present moral consciousness required to maintain such a society.

CHAPTER ONE: Uncovering the Moral Wrong of Health Disparities

"Health disparities are the civil rights issue of the 21st century."

—Donna Christian-Christensen, M.D.

The landscape of health disparities in the United States (U.S.) covers wide and troublesome terrain. While all would agree health disparities are a moral wrong, insufficient measures have been taken to eliminate them and bring impacted demographics to a base level of health. A harsh reality informing health disparity in this country is its intricate connection to historic and systemic racism.[1] This truth informs the following narrative of the complex social, political, and economic factors historically and contemporarily influencing health disparities, allowing us to better understand them as morally wrong and desperately in need of moral repair.

[1] Throughout this chapter, I follow social scientist Thomas Pettigrew in defining racism as, "a doctrine that holds that the world's human population consists of various 'races' that are the primary determinants of human traits and capacities. This doctrine typically regards one's own race as superior to other races. Intergroup hatred and discrimination generally accompany racist doctrines. Social science investigates racism at three interrelated levels. First, *individual racism* involves those individuals who hold racist beliefs. Here racist ideas often overlap with such concepts as prejudice, xenophobia, bigotry, and intolerance. But the key distinguishing feature of individual racism is that the group differences are viewed as innate and unchangeable. If assimilation or conversion is viewed as possible, then intolerance is involved but not racism. Second, *situational racism* occurs when racist behavior is shaped by the social context. This occurs when face-to-face situations are patterned, based on racist beliefs, to place one group in an inferior position in intergroup interaction. This occurs, for example, when one racial group in a situation possesses most of the resources that emphasize the status differences between the groups. Finally, third, *structural and cultural racism* results when a society's institutions are shaped by racist beliefs and results in group discrimination. Indeed, racism's effects can invade virtually all of a society's institutions. Thus, racism differentiates human beings from one another by presumed 'races,' and this leads to unequal access to resources and opportunities as well as to other forms of inequality such as gender-, ethnic-, and class-based inequity." Structural and cultural racism will be the definition most often implied as the connection between health disparities and policies are further elucidated. *See* Thomas F. Pettigrew, "Racism," In *obo* in Sociology, last modified November 24, 2020, https://www.oxfordbibliographies.com/view/document/obo-9780199756384/obo-9780199756384-0162.xm

Health Disparities and Health Inequities

In a 2017 report performing a landscape analysis of the state of health disparities in the U.S., the National Institutes of Health's (NIH) National Academies of Sciences, Engineering, and Medicine defined the term as "differences that exist among specific population groups in the United States in the attainment of full health potential that can be measured by differences in incidence, prevalence, mortality, burden of disease, and other adverse health conditions."[2] While the term is a relatively recent construct, stark differences in health outcomes between wealthy and poor, and white and non-white communities have existed for generations.

Yet, health disparities are only the beginning of the poor health outcome continuum. When "disparity" is coupled with racial and ethnic groups, "it describes the increased presence and severity of certain diseases, poorer health outcomes, and greater difficulty in obtaining healthcare services for these races and ethnicities."[3] Disparities progress to health inequities when systemic barriers create differences across social groups' opportunities to achieve health, resulting in unfair health outcomes.[4] The NIH has determined two clusters of root causes of health disparity and inequity. They encompass,

[2] "Health disparities 2014," National Institutes of Health, last modified November 2, 2016, http://www.nhlbi.nih.gov/health/educational/healthdisp.

[3] "Racial and Ethnic Health Care Disparities 2020," Center for Medicare Advocacy, last modified December 8, 2022, https://medicareadvocacy.org/medicare-info/health-care-disparities/#articles.

[4] "Racial and Ethnic Health Care Disparities 2020"; National Academies of Sciences, Engineering, and Medicine et al., "The State of Health Disparities in the United States," in *Communities in Action: Pathways to Health Equity* (Washington D.C.: National Academies Press, 2017), 100.

1. Intrapersonal, interpersonal, institutional, and systemic mechanisms (also referred to as structural inequities) that organize the distribution of power and resources differentially across lines of race, gender, class, sexual orientation, gender expression, and other dimensions of individual and group identity.
2. The unequal allocation of power and resources—including goods, services, and societal attention—which manifests itself in unequal social, economic, and environmental conditions, also called the determinants of health.[5]

The identifiable characteristics of individuals and social groups that structure the differences and systemic barriers they encounter include, "race and ethnicity, gender, employment and socioeconomic status, disability and immigration status, geography."[6] These characteristics inform structural inequities when systems use the associated identities to unfairly distribute resources and access to care, resulting in negative impacts to these groups' health and health outcomes.

It is important to note the paradoxical and controversial nature between identities and barriers that uphold structural inequities. People and communities must accept and align with the social identities and characteristics systems have hierarchized, an alignment which implicitly and partially determines their health outcomes. Alternatively, those who reject social characteristics are still imperiled depending on the characteristics forced upon citizens in this country, *e.g.*, formerly incarcerated person, veteran, immigrant. For example, when completing demographic data at a physician's office, the patient who selects a race, ethnicity, gender, and disability status has sorted themselves into statistical clusters informing their care, which becomes further complicated by the

[5] National Academies of Science, Engineering, and Medicine et al., *Communities in Action*, 7.

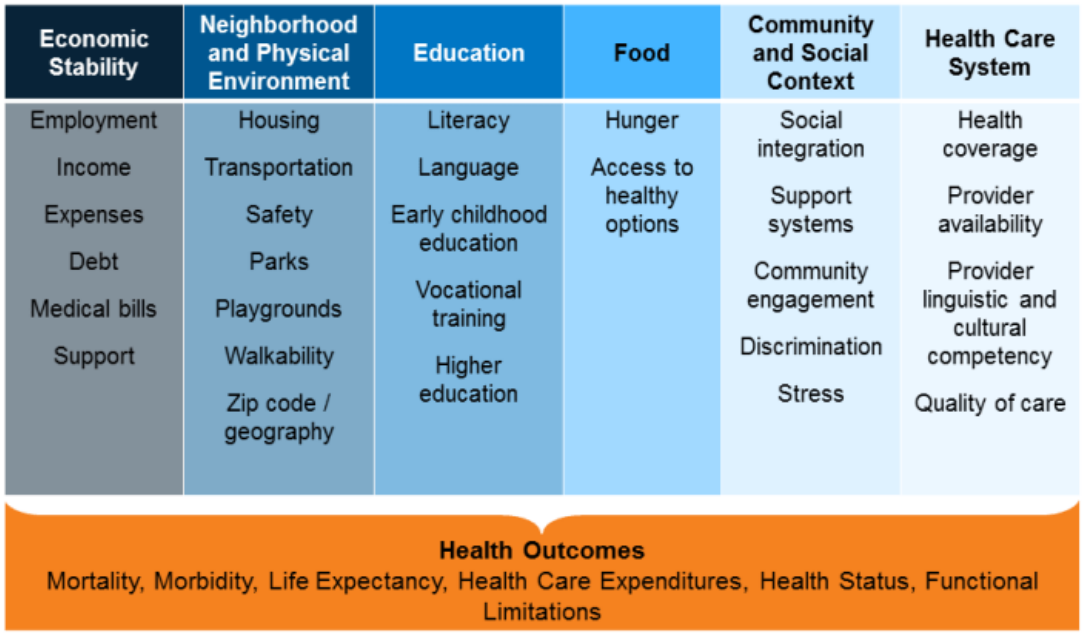
[6] National Academies of Science, Engineering, and Medicine et al., *Communities in Action*, 100.

systemic barriers challenging those identities, as well as the implicit biases of the care provider. Conversely, a patient who avoids aligning themselves with demographic identifiers may delay the onslaught of systemic barriers until social characteristics are forced upon them by representatives of various social systems. In this case, the representative being the care provider.

Structural inequities are maintained by policy measures at all levels of government, which further determine socioeconomic, cultural, and environmental health outcomes. The following chart from the Kaiser Family Foundation captures high level and lower-level social determinants of health that regularly inform quality of life and health.

Figure 1

Social Determinants of Health



KFF [7]

An example of how structural inequities impact social determinants of health can be seen in the penal system. As of 2019, my native state of Louisiana had the highest incarceration rate in the United States.[8] In a state whose population is just over 4.6 million people, thirty-three percent of whom are black, Louisiana "imprisons 683 inmates

[7] Samantha Artiga and Elizabeth Hinton, "Beyond Health Care: The Role of Social Determinants in Promoting Health and Health Equity," KFF, last modified May 2018, https://www.kff.org/racial-equity-and-health-policy/issue-brief/beyond-health-care-the-role-of-social-determinants-in-promoting-health-and-health-equity/.

[8] Kristen Lewis, *The Measure of America Series: A Portrait of Louisiana 2020 Human Development in an Age of Uncertainty* (New York: Measure of America, Social Science Research Council, 2020), 9.

per 100,000 residents."[9] Of those imprisoned, fifty-two percent of people in jail are black (2015) and sixty-seven percent of people in prison are black (2017).[10] Incarceration has been found to disrupt education, reduce job prospects, increase poverty, and negatively affect a person's ability to maintain insurance coverage and access to healthcare options. Studies have revealed past incarcerations can reduce earnings by eleven percent, annual employment by nine weeks, and annual earnings by forty percent.[11]

When looking more closely at the state, the highest rates of incarceration are found in the poorest performing zip codes, impacting already-struggling families and communities. The following chart, shared from *A Portrait of Louisiana 2020*'s report, reveals that the lower the human development index (HDI), the higher the incarceration rate.[12] Averaging the health and wellbeing of citizens in all sixty-four parishes compared with those persons incarcerated, this data reveals the ripple effect of incarceration. The penal system—especially in a state like Louisiana that charges children as adults, has an underfunded public defender system that has insufficient resources for poor community

[9] Lewis, *A Portrait of Louisiana 2020,* 36.

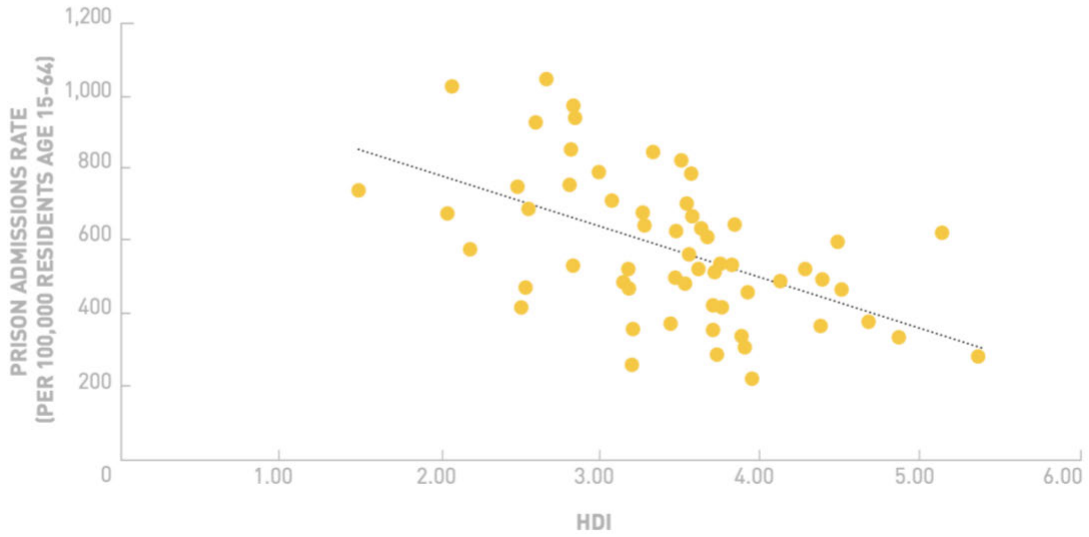
[10] Lewis, *A Portrait of Louisiana 2020*, 36.

[11] Lewis, *A Portrait of Louisiana 2020*, 113.

[12] Rooted in the research of Mahbub Ul Haq and Amartya Sen, the Human Development Index (HDI) is "a composite index measuring average achievement in three basic dimensions of human development—a long and healthy life, knowledge, and a decent standard of living." Health is calculated by one's life expectancy at birth. Knowledge is calculated by "mean of years of schooling for adults aged 25 years and more and expected years of schooling for children of school entering age." Standards of living are calculated by a nation's gross national income. The three scores are then aggregated into a composite index. HDI is most often used to assess policy choices and priorities between nations with similar indices. Other reports and composites are needed to find nuances in inequalities and disparities. *See* "What is Human Development?," United Nations Development Programme Human Development Reports, last modified 2023, https://hdr.undp.org/about/human-development.

members, and relies on economic interests in prison labor and for-profit private prisons—is negatively impacting health and contributing to deeper and widening disparity.[13]

FIGURE 9 Prison Admissions Rate Is Higher in Low HDI Parishes



[14]

Those of Louisiana's structural inequities that are rooted in the penal system, and their subsequent impact on social determinants of health, symbolize a larger, more daunting picture of the nation's health because the disparities stemming from these inequities follow impacted demographics from birth to death.

> For example, African American women are more likely to give birth to low-birthweight infants, and their newborns experience higher infant death rates that are not associated with any biological differences, even after accounting for socioeconomic factors (Braveman, 2008; Hamilton et al., 2016; Mathews et al., 2015)…In elementary school there are persistent differences across racial and

[13] Lewis, *A Portrait of Louisiana 2020*, 36-37.

[14] "Incarceration Trends: Prison Incarceration Rate, 2014," Vera Institute of Justice, last modified June 20, 2023, http://trends.vera.org/incarceration- rates?data=prison&year=2014; Lewis, *A Portrait of Louisiana 2020*, 38.

ethnic divisions in rates of discipline and levels of reading attainment, rates that are not associated with any differences in intelligence metrics (Howard, 2010; Losen et al., 2015; Reardon et al., 2012; Skiba et al., 2011; Smith and Harper, 2015)…One of the strongest predictors of life expectancy is high school graduation, which varies dramatically along class and race and ethnicity divisions, as do the rates of college and vocational school participation—all of which shape employment, income, and individual and intergenerational wealth (Olshansky et al., 2012). Structural inequities affect hiring policies, with both implicit and explicit biases creating differential opportunities along racial, gender, and physical ability divisions. Lending policies continue to create differences in home ownership, small business development, and other asset development (Pager and Shepherd, 2008). Structural inequities create differences in the ability to participate and have a voice in policy and political decision making, and even to participate in the arguably most fundamental aspect of our democracy, voting (Blakely et al., 2001; Carter and Reardon, 2014). And implicit biases create differential health care service offerings and delivery and affect the effectiveness of care provided, including a lack of cultural competence (IOM and NRC, 2003; Sabin et al., 2009).[15]

[15] National Academies of Science, Engineering, and Medicine et al., *Communities in Action,* 101-102; Paula Braveman, "Racial disparities at birth: The puzzle persists," *Issues in Science and Technology* 24, no. 2 (2008): 23–30; Brady E. Hamilton et al., "Births: Preliminary Data for 2015," *Natl Vital Stat Rep* 65, no. 3 (2016): 1-15; T. J. Mathews et al., "Infant Mortality Statistics from the 2014 Period Linked Birth/Infant Death Data Set," *Natl Vital Stat Rep* 64, no. 9 (2015): 1-30; T.C. Howard, *Why race and culture matter in schools: Closing the achievement in America's Classrooms* (New York: Teachers College Press, 2010); Daniel Losen et al., *Are We Closing the School Discipline Gap?* (Los Angeles: University of California, The Civil Rights Project, 2015); Sean Reardon et al., "Patterns of Literacy among U.S. Students," *Future Child* 22, no. 2 (2012): 17-37; Russell J. Skiba et al., "Race is not neutral: A national investigation of African American and Latino disproportionality in school discipline," *School Psychology Review* 40, no. 1 (2011): 85-107; Edward J. Smith and Shaun R. Harper, *Disproportional Impact of K-12 School Suspension and Expulsion on Black Students in Southern States* (Philadelphia: University of Pennsylvania, Center for the Study of Race and Equity in Education, 2015); S. Jay Olshanky et al., "Differences in life expectancy due to race and educational differences are widening, and many may not catch up," *Health Aff (Millwood)* 31, no. 8 (2012): 1803-1813; Devah Pager and Hana Shepherd, "The Sociology of Discrimination: Racial Discrimination in Employment, Housing, Credit, and Consumer Markets," *Annu Rev Sociol.* 34 (2008): 181-209; T.A. Blakely et al., "Socioeconomic inequality in voting participation and self-rated health," *Am J Public Health* 91, no. 1 (2001): 99-104; Prudence L. Carter and Sean F. Reardon, *Inequality Matters* (New York: William T. Grant Foundation, 2014); Institute of Medicine and National Research Council, *From neurons to neighborhoods: The science of early childhood development* (Washington D.C.: National Academy Press, 2000); Janice A. Sabin et al., "Physicians' Implicit and Explicit Attitudes about Race by MD Race, Ethnicity, and Gender," *J Health Care Poor Underserved* 20, no. 3 (2009): 896-913.

These inequities are not limited to individuals but also shape communities since they are so intimately connected with zip codes and historic policy measures maintaining racial and economic segregation across public services.

A Fraught History Informing Health Disparities

Louisiana is a prime example that analyzing U.S. health disparities and inequities requires a multifactor view of individual health and health inequities, recognizing that health is a combination of individual action and systemic issues. These systemic issues cannot be separated from policy measures and cultural norms that have shaped health, access, and engagement for decades. Further, a multifactor lens provides insight to the ongoing stagnation of health disparities despite equitable progress in other areas of social life, most of which can be traced historically to racist measures aimed at devaluing enslaved Africans throughout the history of chattel to maintain the profitability of interconnected social institutions.

As an economic institution, the business of slavery thrived due to the involvement of physicians who were called upon by slave markets and owners to determine the value of people's bodies. From declaring the prices at which the enslaved should be sold to the amount of long-term, hard labor an owner could get from them and their potential offspring, physicians crafted an evaluative pseudoscience that soon evolved into scientific racism. One lasting result of this "science" was the establishment of a

hierarchy, relegating "blacks, other non-whites, and women…to the lower echelons of humanity."[16]

Declaring those who were enslaved partial persons also provided physicians free medical subjects "that fed the American medical research and medical training that bolstered physicians' professional advancement."[17] The lack of political power black people possessed simultaneously bound them in a system of medical neglect and medical abuse. Poor white people were also viewed as partial persons and became recipients of medical abuse at the hands of established and aspiring physicians. Throughout the nineteenth century, in states whose black populations were less than ten percent, poor white people were the primary source of grave medical experimentation, although it should be mentioned black people "were still used out of all proportion to their numbers."[18]

In her comprehensive history of medical harms, Harriet A. Washington shares the stories of Alexis St. Martin and Phineas Gage. St. Martin, "a poor, French-Canadian trapper, was harassed, pursued, and studied for years by a successful physician who wished to experiment on him after an unusual accident caused a permanent opening in his stomach. So was Phineas Gage, a laborer who survived an industrial accident but suffered

[16] Institute of Medicine Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care et al., *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* (Washington D.C.: National Academies Press, 2002).

[17] Harriet A. Washington, *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present* (New York: Anchor Books, 2006), 26.

[18] Washington, *Medical Apartheid,* 58.

severe brain damage, which was assiduously recorded and tested by a long series of physicians."[19] White medical subjects held minimal legal protections that provided them some measure of agency to leave abusive medical scenarios. However, their inferior status in the eyes of the medical establishment still made them susceptible to ongoing medical abuses at the hands of clinicians.

These narratives, along with countless others, were widely shared at medical conferences, in physicians' diaries, and in medical journals, articulating patterns of abuse against vulnerable populations who held no legal status nor protections. Relying on the ignorance of a socially dehumanized, illiterate populace, clinicians were allowed to harm communities of partial persons and avoid accountability for generations. While these abuses are egregious, many pre-twentieth century medical experiments pale in comparison to the horrors committed by "father of gynecology," J. Marion Sims.

Prior to becoming the father of gynecology, Sims was a plantation doctor. Believing that malnutrition-induced tetany among infants was the result of incorrectly placed skull bones, Sims subjected black infants to incisions in the scalp followed by prying the skull open with a cobbler's tool to reposition the bones. His belief that he could open black infants' skulls was based on the scientifically racist "myth that the bones of black infants' skulls, unlike white infants', grew together quickly, leaving the brain no space to grow and develop. This premature closing of the skull was held to cause low intelligence and perpetual childishness in adult blacks. When infants died, Sims

[19] Washington, *Medical Apartheid,* 58.

castigated the sloth and ignorance of their mothers and the black midwives who attended them."[20] Sims also tortured young adults in his "labs": a teenager who died from an unanesthetized bone segment removal; a man's near suffocation when Sims removed part of his jaw and forgot to remove a sponge from his mouth; another man's death after Sims unsuccessfully stopped a bleed out from his carotid artery.[21]

In 1845, Sims accelerated his medical abuses and purchased eleven enslaved women as medical subjects on which he could practice correcting the painful vesicovaginal fistulae they possessed, eleven women with no legal rights nor protections, eleven women subjected to horrible pain and dehumanizing experiments leading to medical miracles that would not benefit them nor their communities.[22] The eleven women experienced the violation of many Victorian social conventions of the day, including having their genitalia exposed to strange men and being stripped naked and placed upon medical examining tables. Sims used a personally invented speculum to fully open the women's vaginal areas allowing him to close the open sores, burn them, then suture them

[20] Sims ascribed neonatal tetanus to "the mothers' moral and intellectual failures," believing poverty, filth, laziness, and intellectual inferiority compounded the problem. However, neonatal tetanus "is caused by a bacterial infection with *Clostridium tetani,* which emanates from animal manure and thrives in wounds such as healing umbilical stumps." The geographic location of slave quarters amplified the problem because plantation owners often "built slave shacks on inferior lands near horse stables and other quarters and as far as possible from the whites' dwellings. Antebellum doctors' disdain for hand washing, as well as the midwifery practice of swaddling the umbilical cord with rags, raised the risk of infection." *See* Washington, *Medical Apartheid,* 62-63; J. Marion Sims, *The Story of My Life* (New York: D. Appleton, 1884).

[21] Washington, *Medical Apartheid,* 63.

[22] A vesicovaginal fistula occurs from vaginal tearing, usually after childbirth. The skin eventually erodes and creates tears between the vagina, bladder, and rectum. The openings allow urine to enter the tissue, causing infections, immense pain, and odor. Many women in the nineteenth century suffered from this condition, but "enslaved women had an especially high rate," possibly due to a confluence of malnutrition, vitamin D deficiency, and the use of forceps. *See* Washington, *Medical Apartheid,* 63-64.

each time the scars reopened and became infected, all of which was done without proper anesthetics for the medical subjects.

Refusing to offer his test subjects popular ethers because he believed black people did not experience pain in the same ways as white people, nor did he believe the procedures painful enough to require medication, Sims forced on them dangerously high doses of morphine, sometimes twice a day, leaving them drug-addicted, physically infected from overmedicalization, and in unending pain. Aware of the proper care to be given, which was extended to his white women patients, Sims deliberately built a legacy for himself through the destruction of the lives of eleven black women.[23]

The state of health for marginalized communities did not advance after enslavement legally ended, despite the medical and public health advancements resulting from the Civil War. In fact, the black population experienced higher mortality rates and poorer health outcomes due to "black social and economic collapse; health segregation, discrimination, and exploitation at all levels throughout the Civil War, Reconstruction, Gilded Age, and Progressive eras; collapse of the slave health subsystem; and refusal by the mainstream health system to incorporate Freedmen."[24] The rampant level of social rejection led Freedmen bureaus to create legislation and clinics serving the black population during Reconstruction to fight against their rapidly declining health. Unfortunately, these "Negro medical ghetto[s]" provided mainstream American society

[23] Washington, *Medical Apartheid,* 65-68.

[24] Institute of Medicine, *Unequal Treatment,* 502.

more reasons to keep systemic inequalities in place and bar black populations from the larger health system.[25]

Deep divisions persisted as scientific racism in medical society evolved into eugenics and social Darwinism in the twentieth century. Physicians began constructing,

> elaborate classifications for and predicted the imminent extinction of inferior "races" such as blacks, criminals, Jews, the Irish, the poor, and the insane. Much of the research and deprecation, especially with the rise of IQ testing, was directed at newly arrived white (e.g., Irish, Eastern European Jews) and non-white (e.g., Chinese, Mexicans, and Japanese) immigrant groups. Good breeding and sterilization of the "unfit" were posited as solutions to all social and many medical problems.[26]

These attitudes plagued medicine and healthcare institutions for decades because physicians medicalized social concerns, working to reduce the need for wider social programs since issues like poverty and disability were diagnosed as a result of human limitations, "limitations" most often stemming from race and ethnicity. This false medicalization further justified widespread sterilization, incarceration, displacement, and restrictions on immigration.[27] Because of these actions rooted in rampant discrimination and segregation, health among white communities soared drastically while the health of black and immigrant communities remained deficient.

The Tuskegee Syphilis Experiment is one of the most infamous cases in U.S. history exemplifying these sociomedical dynamics. Running 1932-1972, the U.S. Public Health Service (USPHS) recruited 600 black men for a syphilis study from a

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[25] Institute of Medicine, *Unequal Treatment*, 503.

[26] Institute of Medicine, *Unequal Treatment*, 503.

[27] Institute of Medicine, *Unequal Treatment*, 504.

predominantly African American community in Macon County, Alabama. Of the participants, 399 tested positive for syphilis. All participants received free medical exams, meals, and burial insurance.[28] While the study began with seeming integrity to monitor the natural progression of syphilis, roughly a decade into the study (1943) penicillin became available as a treatment. However, researchers and doctors did not offer penicillin to study participants but continued monitoring their symptoms. Decades passed before the study ended, only as a result of journalism revealing that the participants were harmed by having treatment withheld.[29] By that time innumerable community members became unknowingly infected with syphilis, geographically confined to a space with limited resources and poor health outcomes.

Health inequities persisted into the Great Depression and throughout World War II despite increased governmental presence in collapsing health institutions. The health of the entire country slowed, but major gaps remained between white and non-white communities due to the white medical establishment using its power to "fight against progressive health reform (other opponents included insurance companies, conservative series of Congresses, some members of the pharmaceutical industry, and white health

[28] Department of Health, Education, and Welfare, *Final Report of the Tuskegee Syphilis Study Ad Hoc Advisory Panel* (Washington, D.C.: Government Publishing Office, 1973); Memorandum "USPHS Study of Untreated Syphilis—the Tuskegee Study; Authority to Treat Participants Upon Termination of the Study," from Wilmot R Hastings to the secretary, March 5, 1973.

[29] "About the USPHS Syphilis Study" Tuskegee University Annual Public Health Ethics Intensive Course, last modified 2016, *https://www.tuskegee.edu/about-us/centers-of-excellence/bioethics-center/about-the-usphs-syphilis-study#:~:text=The%20PHS%20began%20working%20with,syphilis%20from%20Macon%20County%2C%20Alabama.&text=As%20part%20of%20the%20class,wives%2C%20widows%2C%20and%20children.*

professional organizations)."[30] These powerful obstacles remained overtly in place until 1964 with the passage of federal measures that ended segregation in federally-managed hospitals.

Even after 1964, opposition became more systemic as white doctors refused to accept government-sponsored insurance (*i.e.,* Medicaid) and marginalized demographics' health remained treatable only within the public sector where funding continues to vary drastically each year.[31] Despite the opposition, civil rights fights continued, eventually leading to the desegregation of medical schools and all hospitals, as well as improved health for black and immigrant communities. Unfortunately, the path to full health equity was thwarted by "unethical experimentation on blacks, incarcerated populations, military populations, infirm elderly, and other disadvantaged groups."[32]

Two egregious examples during the second half of the twentieth century must be brought to light to further underscore the levels of abuse experienced by vulnerable and marginalized communities, devoid of protections of their personhood and rights. Throughout the 1950's to 1970's, widespread dermatologic experiments were performed on prisoners in Philadelphia's Holmesburg Prison by Dr. Albert M. Kligman. Initially

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[30] Institute of Medicine, *Unequal Treatment*, 505.

[31] Institute of Medicine, *Unequal Treatment*, 506.

[32] Again, Harriet Washington poignantly captures the narratives of abused individuals during this time. "For example, in his memoir *As I Remember Him: The Story of R.S.*, Harvard microbiologist Hans Zinsser recalls that when he needed specimens of live lice for his research on typus, he approached a Boston policeman, who obligingly arrested 'the old coon that sells pencils down near the South Station,' forcibly taking the vendor to the station house. There, Zinsser retrieved his lice at leisure. Despite the man's protests that 'I'm an American citizen and I got my rights. I dunno what youse all talkin' bout de cause of science,' the police threatened him with jail if he did not permit Zinsser his lice for medical research." *See* Washington, *Medical Apartheid*, 354-355; Institute of Medicine, *Unequal Treatment*, 506.

brought to the prison to treat widespread athlete's foot among those incarcerated, Kligman began experiments far beyond the realm of dermatology, including, testing hundreds of experimental drugs; using cosmetics and powders that damaged the skin and caused baldness and scarring; removing fingernails; subjecting inmates to diseases like syphilis and *Staphylococcus*; covering inmates in industrial solvents; and, subjecting them to harsh chemicals, extreme temperatures, and hallucinogens.[33]

Although prisoners were commonly used for medical experimentation through the second World War, the U.S. was the only nation still using prisoners for medical experimentation well after the rest of the world denounced the practice. While Kligman's behavior was abhorrent, he was far from the only physician in prisons causing irreversible harm to vulnerable demographics. From injecting live cancer cells to flash burns and ineffective and cruel psychiatric treatment, incarceration centers all over the country have been and remain test sites for medical experimentation.[34]

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[33] Washington, *Medical Apartheid*, 248-252.

[34] While it is easy to assume that human experimentation on the vulnerable population of incarcerated persons is a past phenomenon, much experimentation continues throughout the carceral state. In the 1970's many journalistic exposés revealed the abusive state of prisoner experimentation, resulting in a massive reduction of the practice. The Department of Health, Education, and Welfare (HEW) later instituted strict regulations on human experimentation in 1978, followed by the publication of the Belmont Report in 1979 requiring researchers to receive informed consent from all test subjects, also known as the "Common Rule." The Department of Health and Human Services' Office for Human Research Protections (HHS OHRP) further outlined four categories of permissible research on prisoners: "that on the cause and effect of incarceration and crime; the study of prisons or of incarcerated persons; investigations of conditions that affect prisoners ['as a class for example, vaccine trials and other research on hepatitis which is much more prevalent in prisons than elsewhere'] en masse; and therapeutic studies." However, these regulations under Subpart C only apply to research conducted or supported by HHS.

Unfortunately, human experimentation in correctional facilities has seen a renaissance since in the 1980's. As such, "any prison studies that do not take place in a formal correctional facility are being conducted without review or approval by an IRB. Both public universities and drug companies regularly use prisoners and other incarcerated individuals as subjects in medical experiments. More than one-third of

Depending on the demographics, hospitals have been no different than prisons in the history of unethical medical experimentation. Henrietta Lacks may be the most widely known individual on whom unethical medical experimentation was performed. More than an example of unethical experimentation, Lacks represents the ways black people were used in the development of medical technologies yet continue benefiting from these technologies less than other racial and ethnic groups.

> In 1951, the science of cell-line culture was founded with usually long-lived cervical cells from black Baltimore housewife and cancer patient Henrietta Lacks. (Her cells were conventionally nicknamed HeLa, after the two initial letters of her first and last names.) Without the knowledge or consent of Lacks or her family, George Grey, M.D., of Johns Hopkins, harvested her cells and used them to transform medicine. Vaccines could now be tested and lengthy experiments completed that would have been unthinkable a few months earlier. One advance was immediate and dramatic: The Salk polio vaccine was tested and perfected with HeLa cells produced by Tuskegee Institute Laboratories in 1952, only a year

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these medical experiments take place in alternative corrections facilities, which include probation, residential drug treatment programs, parole, community corrections, home confinement, and boot camps for first-time drug users and sellers." In 2006 and 2008, five states recruited prisoners with addiction issues into experimental addiction treatment programs run by Hythiam. An extended release naltrexone is presently "being tested on pre-release and released prisoners through a study sponsored by the Friends Research Institute…For fifteen years, beginning in the 1990s, various scientific researchers tested AIDS drugs on hundreds of foster children [from infants to teenagers who were 'presumed' to be HIV positive] in studies funded by the NIH" across seven states.

Psychiatrists in California received $14 million from 2010 to 2013 if they prescribed psychotropics to foster children, with two doctors receiving over $2 million each for "research" because they prescribed the most psychotropics. In November 2019, the Department of Justice (DOJ) launched an investigation into an Iowa residential home that was the site of medical experiments on intellectually disabled patients to determine optimal sexual arousal and a correlation between hydration and pneumonia symptoms. In August 2021, a physician performed a medical experiment on Arkansan prisoners to determine the efficacy of ivermectin as a COVID-19 treatment, giving dosages three to six times the amount required per their body weight. These are but a handful of examples evidencing the varieties of harmful human experiments that occur beyond governmental oversight throughout the carceral system in the U.S. *See* Washington, *Medical Apartheid*, 244-270; "Subpart C—Additional Protections Pertaining to Biomedical and Behavioral Research Involving Prisoners as Subjects," U.S. Department of Health and Human Services, last reviewed March 10, 2021, https://www.hhs.gov/ohrp/regulations-and-policy/regulations/45-cfr-46/common-rule-subpart-c/index.html#46.306(a)(2); Laura I. Appleman, "The Captive Lab Rat: Human Experimentation in the Carceral State," *Boston College Law Review* 61, no. 1 (January 2020): 21-44; Maya Yang, "Arkansas jail's ivermectin experiments recall historical medical abuse of imprisoned minorities," *The Guardian*, February 14, 2022, https://www.theguardian.com/us-news/2022/feb/14/arkansas-prison-covid-19-ivermectin-experiment-minorities-medical-abuse.

> after Henrietta Lacks died. Today, the science of cell-line culture has enabled a cultivation and therapy with stem cells, immature cells that can develop into many other types of needed cells, including red blood cells, white blood cells, and platelets. Today, many Americans and most scientists hail research with stem cells as the key to taming disease; the only identified group to oppose stem-cell research are African Americans, 44 percent of whom are opposed to their use. This attitude may be driven by the racial disparity in current stem-cell treatments such as bone-marrow transplants, because African American patients are less likely than whites to match with a donor.[35]

From racial and ethnic minorities to immigrants to contemporary prisoners, the state of U.S. healthcare has a consistent history of failing marginalized communities. These demographics have been the subject of unethical and invasive medical experimentation, stripped of their individual health autonomy, and morally devalued as if their personhood were nonexistent. These issues are not issues of the past but remain prevalent today as seen in the ongoing health disparities that continue impacting identifiable demographics across the country.

Health Disparities Today

The U.S.'s narrative is often discussed within a past versus present paradigm with the Civil Rights Movements of the 1960's and 1970's marking the social transition point. Yet, it is reductionist and willfully ignorant to assume that our present is not also shaped by the social ills of our "pre-civil rights past." Enslavement, the near elimination of Indigenous communities, the long absence of women's rights, Jim Crow, immigration restrictions and nativist policies, and mass homophobia subjected the majority of the U.S. population to sub-citizen status for much of the country's history. And that history

[35] Washington, *Medical Apartheid*, 355.

continues to have an impact on the status and outcomes of health for these very demographics today.

Researchers have found that discrimination, segregation, and historical trauma are the three most prominent mechanisms influencing health outcomes today, and each of these mechanisms is a direct result of systemic racism.[36] While the personal experiences of racism are subjective, data reveals those discriminated against experience adverse health effects due to stress associated with chronic exposure to daily racist encounters (*e.g.*, microaggressions). "Thus, discrimination appears to exert its greatest effects not because of exposure to a single life traumatic incident but because people must mentally and physically contend with or be prepared to contend with seemingly minor insults and assaults on a near continual basis."[37] These ongoing insults negatively affect mental health, cardiovascular health, pregnancy-related health, and birth outcomes.

Segregation, most specifically residential segregation, also has direct bearing on health.[38] Disease load is exacerbated, and these communities' isolation reduces the urge

[36] National Academies of Science, Engineering, and Medicine et al., *Communities in Action,* 107.

[37] National Academies of Science, Engineering, and Medicine et al., *Communities in Action,* 108.

[38] "In the 2010 U.S. Census, residential segregation was at its lowest level in 100 years, and the decline in segregation was observed in all the nation's largest metropolitan areas. However, the recent declines in segregation have been driven by a few blacks moving to formerly all-white residential areas; the declines in segregation have had negligible impact on census tracts with a very high percentage of blacks, the residential isolation of most African Americans, and the concentration of urban poverty. Although segregation is increasing for Hispanics, the segregation of African Americans remains distinctive. In the 2000 census, middle-class blacks were more segregated than poor Hispanics and Asians, and the segregation of immigrant groups has never been as high as the current segregation of African Americans. Segregation affects health in multiple ways. First, it is a critical determinant of SES, which is a strong predictor of variations in health. Research has found that segregation reduces economic status in adulthood by reducing access to quality elementary and high school education, preparation for higher education, and employment opportunities. Schools in segregated areas have fewer high-quality teachers, lower levels of

and awareness for dominant and resource-rich communities to provide interventions to improve their health. Interestingly, racial neighborhood segregation differs from socioeconomic neighborhood segregation. Poor white people "are more likely to live in areas with a range of SES levels, which affords even the poorest residents of these communities access to shared resources that buffer against the effects of poverty" and poor health outcomes.[39] Unlike poorer white citizens, racial and ethnic minorities more often live in areas with concentrated poverty, contributing to limited financial resources in the community, reduced health care provider presence and access, food deserts, and increased exposure to environmental toxins.[40]

Returning to Louisiana, the state provides a horrible and apt example of environmental racism and racial neighborhood segregation that continues to negatively impact citizens' health. Cancer Alley, an eighty-five-mile stretch of land following the Mississippi River, sits between the southern cities of Baton Rouge and New Orleans. This land tract is home to "approximately 25% of the country's petrochemical production."[41] The historic black communities that settled this region and formed

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educational resources and per-student spending, and higher levels of neighborhood violence, crime, and poverty. Segregation also reduces access to employment opportunities by triggering the movement of low-skill, high-pay jobs from areas where racial minorities are concentrated to other areas and by enabling employers to discriminate against job applicants by using their place of residence as a predictor of whether the applicant would be a good employee. One national study found that the elimination of segregation would erase black-white differences in income, education, and unemployment and reduce racial differences in single motherhood by two-thirds." *See* Williams et al., "Racism and Health," 108.

[39] National Academies of Science, Engineering, and Medicine et al., *Communities in Action,* 111.

[40] National Academies of Science, Engineering, and Medicine et al., *Communities in Action,* 111.

[41] Julia Mizutani, "Notes: In the Backyard of Segregated Neighborhoods: An Environmental justice Case Study of Louisiana," *The Georgetown Envtl. Law Review* 31, no. 363 (2019): 372.

unincorporated towns following Emancipation remain on their land, now suffering "an acute vulnerability to noxious facility siting because they do not have the power to govern themselves."[42] They bear, "a cumulative risk to cancer of 16% more than in white-dominant areas, and low-income census tracts bear a 12% greater risk to cancer from air toxins. Spatial analyses show that the gradient of being both a majority-minority and a socioeconomically disadvantaged community magnifies the disparity for the most highly concentrated black areas."[43] As a state, Louisiana consistently ranks in the bottom of all national wellness categories, but Cancer Alley exemplifies how dire the disparities are within the state.

Discrimination and historical trauma also remain factors in the health and wellbeing gaps experienced across racial and ethnic lines. Currently, the U.S. attempts clarity around racial and ethnic groups in the Office of Management and Budget's "Revised Standards for the Classification of Federal Data on Race and Ethnicity" to better understand gathered data and potential disparities. However, maintaining a race-based system, especially one rooted in historical harms across generations, muddies the overlapping and intersectional health narratives that continue to harm many communities in the U.S.

[42] Mizutani, "Notes," 373.

[43] Mizutani, "Notes," 373.

BOX 1-1
Revised Standards for the Classification of Federal Data on Race and Ethnicity

Categories for Race:

American Indian or Alaska Native. A person having origins in any of the original peoples of North and South America (including Central America), and who maintains tribal affiliation or community attachment.

Asian. A person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam.

Black or African American. A person having origins in any of the black racial groups or Africa. Terms such as "Haitian" or "Negro" can be used in addition to "Black or African American."

Native Hawaiian or Other Pacific Islander. A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands.

White. A person having origins in any of the original peoples of Europe, the Middle East, or North Africa.

Categories for Ethnicity:

Hispanic or Latino. A person of Cuban, Mexican, Puerto Rican, South or Central American, of other Spanish culture or origin, regardless of race. The term "Spanish origin" can be used in addition to "Hispanic or Latino."

Not Hispanic or Latino.

[44]

Kidney disease and estimated glomerular filtration rate (eGFR) is a ripe example. Dating back to 1926, researchers have been studying rates of kidney filtration and reabsorption. These studies have led to various equations to determine eGFR as a diagnostic tool for managing kidney disease given over 37 million U.S. adults, the majority of whom are

[44] Institute of Medicine Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care et al., *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* (Washington D.C.: National Academies Press, 2002), 34.

racial and ethnic minorities, are living with some level of the disease.[45] The eGFR equation includes age, sex, body weight, and a race multiplier to approximate kidney functioning.[46]

The equation also "automatically assigns higher eGFR values to African-Americans," despite the majority of participants involved in historic clinical trials to strengthen the equation being overwhelmingly white.[47] Because researchers incorporated a social construction of race into the equation, and built that equation from studies involving a minimally diverse participant community, numerous racial and ethnic minorities have experienced misdiagnosed levels of disease and treatment due to the eGFR values. One 2020 study revealed if race were removed from the eGFR equation, approximately thirty-three percent of black patients would receive a more severe and chronic diagnosis of kidney disease with appropriate treatment to match.[48] The ongoing use of the equation results in large numbers of kidney patients not receiving appropriate kidney treatments because their treatment is informed by their race instead of their physiologic state. Following the study, the National Kidney Foundation has since

[45] "Removing Race from Estimates of Kidney Function," NKF, last modified March 9, 2021, https://www.kidney.org/news/removing-race-estimates-kidney-function.

[46] "Removing Race from Estimates of Kidney Function."

[47] Salman Ahmed et al., "Examining the Potential Impact of Race Multiplier Utilization in Estimated Glomerular Filtration Rate Calculation on African-American Care Outcomes," *Journal of general internal medicine*, 36, no. 2 (2021): 467; "A brief history on the estimation of Glomerular Filtration Rate," Gentian, last modified February 4 February 2021, https://www.gentian.com/news/cystatin-c-glomerular-filtration-rate.

[48] Ahmed et al., "Examining the Potential Impact of Race Multiplier," 466.

advocated the elimination of race modifiers in calculating kidney functioning and disease.[49]

eGFR equations are but one example of medical algorithms that continue to sort people into socially constructed categories to determine their health and care. While these algorithms can positively impact health and hold healthcare systems accountable, they remain rooted in past historic traumas and scientific racism, classism, and sexism. A major negative effect of this is the consistent undertreatment of black and Indigenous people, and women.

Until 1994, women and racial and ethnic minorities were excluded from being participants as research subjects in clinical trials. The NIH's publication guidelines that year including women and racial minorities are evidence of "the slowness with which the federal government officially recognized that the majority of the population in the United States must be included in research along with White males."[50] On average, women between ages 18 and 44 spend approximately $3,867 annually on personal healthcare compared to men's $2,097. Despite this eighty-four percent difference in care spending, most of which is related to childbirth,[51] U.S. women report some of the least positive

[49] "Removing Race from Estimates of Kidney Function."

[50] Patricia King, "Race, Equity, Health Policy, and the African American Community," in *African American Bioethics: Culture, Race, and Identity,* ed. Edmund Pellegrino and Lawrence Prograis (Washington, D.C.: Georgetown, University Press, 2008), 68.

[51] Amanda Bucceri Androus, "Here's How Much Your Healthcare Costs Will Rise as You Age," Registered Nursing, last reviewed March 16, 2023, https://www.registerednursing.org/healthcare-costs-by-age/.

healthcare experiences across developed nations.[52] Among eleven countries surveyed in 2018,

> Women in the U.S. reported a higher rate of having multiple chronic disease...One of five U.S. women reported having two or more chronic conditions, compared to one of 10 or less in Germany, the Netherlands, and Australia…Women in the U.S. had the highest rate of maternal mortality because of complications from pregnancy or childbirth…High rates of caesarean sections, lack of prenatal care, and increased rates of obesity, diabetes, and heart disease may be contributing factors to the high rate in the U.S.[53]

Not until January 2020 was it reported that the U.S. "standardized maternal mortality data from all 50 states," beginning with maternal mortality statistics in 2018.[54] These data revealed there were 17.4 deaths per 100,000 live births, totaling 658 maternal deaths.[55] Black birthing people's death statistics were 37.1 deaths per 100,00 live births that year.[56]

Just as with women, insufficient data gathering occurs among Indigenous communities, rendering them largely invisible in the U.S. healthcare system. Conversely, the majority of race-focused disparities research focuses black populations, charting centuries of disparities that have not been made better by social interventions. For example, black people have poor health outcomes across every stage of life, from the

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[52] Munira Z. Gunja et al., "What is the Status of Women's Health and Health Care in the U.S. Compared to Ten Other Countries?," Commonwealth Fund Issue Briefs, last modified December 19, 2018, https://www.commonwealthfund.org/publications/issue-briefs/2018/dec/womens-health-us-compared-ten-other-countries.

[53] Gunja et al., "What is the Status of Women's Health?"

[54] Elizabeth Chuck, "The U.S. finally has better maternal mortality data. Black mothers still fare the worst," *NBCNews*, January 30, 2020, https://www.nbcnews.com/health/womens-health/u-s-finally-has-better-maternal-mortality-data-black-mothers-n1125896.

[55] Chuck, "The U.S. finally has better maternal mortality data."

[56] Chuck, "The U.S. finally has better maternal mortality data."

highest death (lagging five to six years behind white communities) and cancer rates to the shortest survival rates of all racial and ethnic groups.[57]

> Historical demographers estimate that, in 1850, enslaved infants died before 1 year of age at a rate 1.6 times higher than that of White infants (340 vs 217 deaths per 1000 lives births). In comparison, Centers for Disease Control and Prevention figures from 2016 show that today non-Hispanic Black infant mortality is 2.3 times higher than mortality among non-Hispanic White babies (11.4 deaths and 4.9 deaths, respectively).[58]

The most recent data from 2019 maintains similar statistics, with 10.6 deaths versus 4.5 deaths between non-Hispanic black and non-Hispanic white infants, respectively.[59] The persistence of inequalities is pervasive to the extent that no period in U.S. history has witnessed equal health status between racial minority citizens and white citizens.[60]

[57] "NOTE: Measures are for the most recent year for which data are available. 'Better' or 'Worse' indicates a statistically significant difference from White people at the $p<0.05$ level. No difference indicates no statistically significant difference. 'Data limitation' indicates no separate data for a racial/ethnic group, insufficient data for a reliable estimate, or comparisons not possible due to overlapping samples. AIAN refers to American Indian or Alaska Native. NHOPI refers to Native Hawaiian or Other Pacific Islander. Persons of Hispanic origin may be of any race but are categorized as Hispanic for this analysis; other groups are non-Hispanic." *See* Latoya Hill et al., "Key Data on Health and Health Care by Race and Ethnicity," KFF, last reviewed March 15, 2023, https://www.kff.org/racial-equity-and-health-policy/report/key-data-on-health-and-health-care-by-race-and-ethnicity/.

[58] Deirdre Cooper Owens and Sharla M. Fett, "Black Maternal and Infant Health: Historical Legacies of Slavery," *American Journal of Public Health* 109, no. 10 (October 1, 2019): 1342-1345.

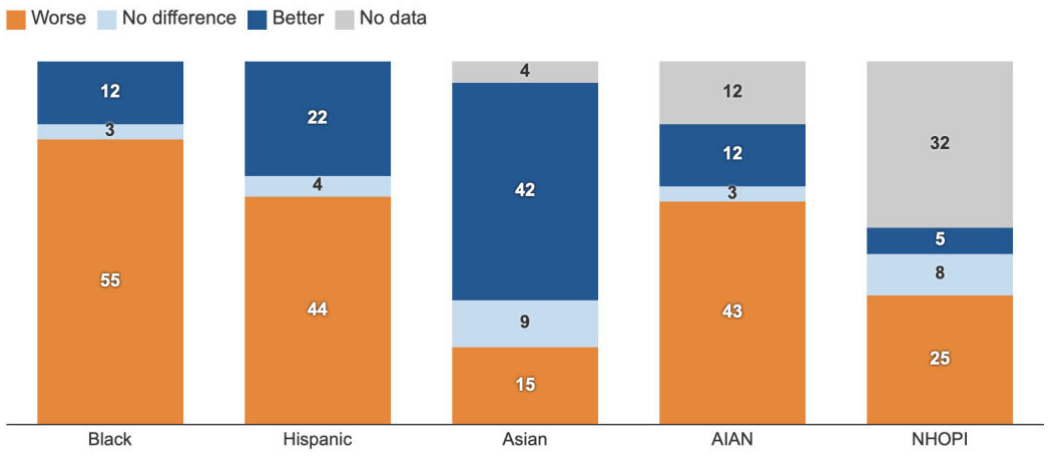
[59] "Infant Mortality," Centers for Disease Control and Prevention, last reviewed June 22, 2022, https://www.cdc.gov/reproductivehealth/maternalinfanthealth/infantmortality.htm.

[60] King, "Race, Equity, Health Policy, and the African American Community," 68.

Figure 1

Health and Health Care among People of Color Compared to White People

NUMBER OF MEASURES FOR WHICH GROUP FARED BETTER, THE SAME, OR WORSE COMPARED TO WHITE PEOPLE:

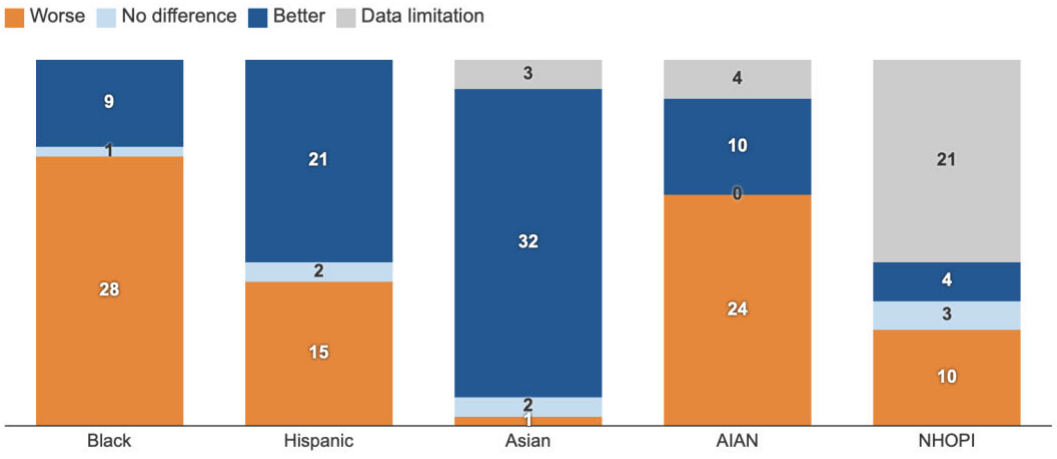


61

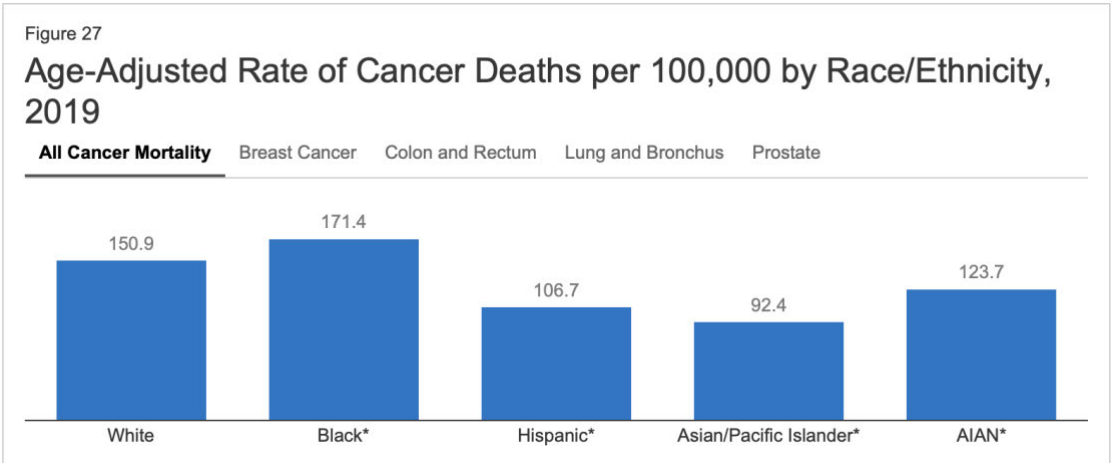
Figure 13

Health Status, Outcomes and Behaviors among People of Color Compared to White People

NUMBER OF MEASURES FOR WHICH GROUP FARED BETTER, THE SAME, OR WORSE COMPARED TO WHITE PEOPLE:



62



[63]

Health Disparities Impacting Black Women

The overall state of health disparities is dismal, but black women's health is particularly dangerous. Contemporarily, black "women are experiencing epidemic rates of medical conditions such as obesity, diabetes, hypertension, and HIV/AIDS, and higher mortality rates for nearly every major cause of death than any other racial/ethnic group."[64] The latest CDC health "fastats" numbers (2016-2018) revealed fifty-six percent of black women twenty or older are obese; fifty-eight percent of black women twenty or older have hypertension; and fourteen percent of adults between eighteen and sixty-four have no health insurance coverage.[65] These statistics support the lived reality that black

[61] Latoya Hill et al., "Key Data on Health and Health Care by Race and Ethnicity," KFF, last reviewed March 15, 2023, https://www.kff.org/racial-equity-and-health-policy/report/key-data-on-health-and-health-care-by-race-and-ethnicity/.

[62] Latoya Hill et al., "Key Data on Health and Health Care by Race and Ethnicity."

[63] Latoya Hill et al., "Key Data on Health and Health Care by Race and Ethnicity."

[64] Chanequa Walker Barnes, *Too Heavy A Yoke: Black Women and the Burden of Strength* (Eugene, OR: Cascade Books, 2014), 42.

women "are sicker during their lifetimes and younger when they die than any other racial/ethnic group in the United States, except for American Indians/Alaskan Natives."[66] Even when black women report less risky behavior, such as substance abuse, their health is disproportionately worse than most other racial and ethnic groups.

Across all of levels of education and income, black women have a lower life expectancy than white women at age twenty-five.[67] Residential segregation has had a direct impact on low birth weight and preterm birth, increased risk of stillbirths, later-staged cancer diagnoses, increased mortality rates, and lower survival rates for breast and lung cancers.[68] Black women receive fewer procedures, poorer quality care, and fewer diagnostic and treatment interventions than white women. Black children are three times more likely than white children to experience the death of their mother by age ten and by age thirty, black women are more than twice as likely to experience the death of a child.[69]

Many of these systemic health inequities coalesce around pregnancy and birthing care. The CDC's Pregnancy Mortality Surveillance System (PMSS) "defines a pregnancy-related death as the death of a woman while pregnant or within 1 year of the

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[65] "Health of Black or African American non-Hispanic Population," Centers for Disease Control and Prevention National Center for Health Statistics, last reviewed June 30, 2023, https://www.cdc.gov/nchs/fastats/black-health.htm.

[66] Wilhelmina Leigh et al., *Women of Color Health Data Book* (Bethesda, MD: National Institutes of Health, 2014), 27.

[67] David Williams et al., "Racism and Health: Evidence and Needed Research," *Annual Review of Public Health* 40, no. 1 (2019): 106.

[68] Williams et al., "Racism and Health: Evidence and Needed Research," 108.

[69] The authors importantly note that, "this elevated rate of bereavement and loss of social ties is a stressor that adversely affects levels of social ties and physical and mental health of blacks across the life course." *See* Williams et al., "Racism and Health: Evidence and Needed Research," 114.

end of pregnancy from any cause related to or aggravated by the pregnancy."[70] These deaths are measured by epidemiologists through a review and analysis of death, birth, and fetal records across participating states, New York City, and Washington, D.C., then ratioed to estimate annual pregnancy-related deaths for every 100,000 live births.[71] Throughout the nation, maternal mortality rates have doubled since 1987 with the latest CDC statistics from 2019 averaging 700 women annually dying from pregnancy and/or delivery related complications.[72] The ten states with the highest maternal mortality rates are Louisiana (58.1), Georgia (48.4), Indiana (43.6), Arkansas (37.5), New Jersey (36.2), Missouri (34.6), Texas (34.5), District of Columbia (29.4), South Carolina (27.9), and Tennessee (26.7).[73] Until recently, birthing people have been blamed for their maternal health outcomes because "they choose" to have children when they are older, fatter, and sicker[74]; but, of the top seven causes of pregnancy-related deaths—hemorrhage, cardiovascular and coronary conditions, cardiomyopathy, infections, embolism, mental health conditions, preeclampsia and eclampsia—all are preventable if birthing people are given access to quality healthcare.[75]

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[70] "Pregnancy Mortality Surveillance System," CDC, last modified November 25, 2020, https://www.cdc.gov/reproductivehealth/maternal-mortality/pregnancy-mortality-surveillance-system.htm.

[71] "Pregnancy Mortality Surveillance System."

[72] "Pregnancy Mortality Surveillance System."

[73] The Institute for Gender and Culture at the Black Women's Blueprint, "The Sexual Abuse to Maternal Mortality Pipeline: A Report by Black Women's Blueprint," July 2019, 12.

[74] Monica McLemore, "To Prevent Women from Dying in Childbirth, First Stop Blaming Them," *Scientific American* 320, no. 5 (2019): 48-51.

[75] IGC, "The Sexual Abuse to Maternal Mortality Pipeline," 13.

Such statistics are egregious in and of themselves, but they are more egregious for black birthing people who, regardless of age, educational attainment, geographic location, and income, fare three to four times worse than white birthing people.[76] Not only are maternal health outcomes worse, but a majority of birthing black people—seventy-five percent—deliver at hospitals serving predominantly black populations and these hospitals have higher rates of maternal complications.[77] One study from 2008 to 2011 examined,

> patient characteristics and performance on 15 delivery-related indicators with a quality-of-care component for primarily white-, black-, and Hispanic-serving hospitals in 7 US states. We found important differences in the composition of the obstetric population in the 3 types of hospitals: white-serving hospitals provided obstetric care to an overall older and wealthier population, black-serving hospitals to poorer women with a higher percentage of chronic medical conditions, and Hispanic-serving hospitals to younger women with a lower burden of chronic diseases…By and large, rates of the 15 delivery-related indicators in white-serving hospitals closely matched those in Hispanic-serving hospitals. Yet, black-serving hospitals performed worse than white- or Hispanic-serving hospitals on 12 of 15 indicators...Based on results from the fully-adjusted regression analyses, in all types of hospitals, non-Hispanic black women had higher risks of all complicated vaginal and complicated cesarean delivery, blood transfusion, and in-hospital mortality when compared to non-Hispanic white women.[78]

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[76] It is important to note that black and Indigenous birthing people have comparable maternal health outcomes across several demographic factors. Maternal mortality is a public health crisis that dually effects Indigenous birthing people and much more research is needed to determine best systemic and cultural advocacy strategies to better their maternal health outcomes and lived experiences. This author is not yet versed in Indigenous cultural and religious practices to contribute meaningfully to that conversation and advocacy work. *See* McLemore, "To Prevent Women from Dying in Childbirth, First Stop Blaming Them," 48-51.

[77] National Partnership for Women and Families, "Black Women's Maternal Health: A Multifaceted Approach to Addressing Persistent and Dire Health Disparities," April 2018, 2. https://www.nationalpartnership.org/our-work/resources/health-care/maternity/black-womens-maternal-health-issue-brief.pdf.

[78] Chosen states were Arizona, California, Florida, Michigan, New Jersey, New York, and North Carolina. Analyzed indicators included: complicated vaginal delivery, complicated cesarean delivery, obstetric trauma, blood transfusion, other obstetric complications, obstetric wound complications postvaginal delivery, obstetric wound complications postcesarean delivery, puerperal infection, postpartum urinary tract infection, peripartum hysterectomy if patient had PPH, obstetric thrombosis or embolism,

Black birthing people also experience difficulty accessing quality reproductive health care, specifically quality contraceptives and counseling. "For example, in a recent analysis of California women enrolled in Medicaid, Black women were less likely than white or Latina women to receive postpartum contraception, and when they did receive it, they were less likely to receive a highly effective method."[79] Such disparities in contraceptive care also contribute to black birthing people experiencing unintended pregnancies almost double the rate of non-Hispanic white birthing people.[80] They also had the highest rate of unintended pregnancies among all racial and ethnic groups from the nation's previous data report.[81]

Many important factors can inform the complicated performance metrics of majority black-serving hospitals and other healthcare sites providing reproductive care for black people. These can include funding, if the institutions are public hospitals;

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uterine rupture if patients had trial of labor, puerperal cerebrovascular disorders if patient had HDP, in-hospital mortality. *See* Andrea A. Creanga et al., "Performance of racial and ethnic minority-serving hospitals on delivery-related indicators," *AJOG* 211, no. 6 (2014): 647.e7-647.e12.

[79] National Partnership for Women and Families, "Black Women's Maternal Health," 2.

[80] Unintended pregnancies are defined as pregnancies that "occurred when a woman wanted to become pregnant in the future but not at the time she became pregnant ('wanted later') or one that occurred when she did not want to become pregnant then or at any time in the future ('unwanted')." Reporting data on unintended pregnancies in the U.S. is somewhat inconsistent, but the most recent statistics from 2011 reveal there were "98 pregnancies for every 1,000 women aged 15-44…45 unintended pregnancies for every 1,000 women aged 15-44…Unintended pregnancy rates are highest among low-income women, women aged 18-24, cohabiting women and women of color…At 79 per 1,000, the unintended pregnancy rate for non-Hispanic black women in 2011 was more than double that of non-Hispanic white women (33 per 1,000)." *See* "Unintended Pregnancy in the United States," Guttmacher Institute, last modified January 2019, https://www.guttmacher.org/fact-sheet/unintended-pregnancy-united-states.

[81] Lawrence B. Finer and Mia R. Zolna, "Unintended pregnancy in the United States: incidence and disparities, 2006," *Contraception* 84 (2011): 480.

quality of care, if institutions are teaching hospitals; the health of patients presenting to these hospitals; and quality-of-life resources available in the neighborhoods where patients receive care. Regardless of contributing factor, reform is needed to address the quality of obstetric care, and all other forms of healthcare, in the U.S.

Higher rates of unintended pregnancies are also a result of what the Institute for Gender and Culture (ICG) at Black Women's Blueprint has named, "the sexual abuse to maternal mortality pipeline." This pipeline is defined as "the trajectory of individuals engaged in women's health across the spectrum of one's reproductive lifespan in which sexual abuse impacts maternal health and one's physical health more broadly."[82] There are eight steps on the pipeline that examine the ways black women are disproportionately impacted by sexual violence, contributing to mismanaged maternal care. All eight steps will not be reviewed here, but the pipeline begins with the reality of embodied trauma stemming from sexual assault.

Black women disproportionately experience sexual abuse and trafficking, forced sodomy, fondling, groping, assault, and rape. These abuses and traumas often go unaddressed because this demographic has lesser access to mental health services, resulting in them often experiencing further sexual abuse and trauma. As bodily trauma is compounded, "weathering"—defined as "the impact of racism as a more pervasive form of stress requiring a more complicated understanding of the ways in which systems of oppression impact women's health"—exposes the complexities of sociocultural traumas

[82] IGC, "The Sexual Abuse to Maternal Mortality Pipeline," 6.

that cause chronic health conditions, further complicating black birthing people's health during pregnancy.[83] Sociocultural oppressions compounded with unaddressed physical traumas inform black birthing people's avoidance or delay of gynecologic and maternal health care. If gynecologic and obstetric care is pursued, black birthing people experience higher levels of being dismissed by clinicians and minimization of pain and symptoms. Such recurring traumas increase the distance these individuals feel from their clinicians, reducing their trust in pursuing necessary healthcare.[84]

Whether poor, non-man, immigrant, racial and/or ethnic minority, uneducated, or any intersection of these identifiers, the data around health disparities is evidence that the U.S. is failing vulnerable and marginalized communities. And this failing has existed for centuries. Many researchers have worked to uncover the deep impact of health disparities and inequities, as well as proposing additional areas of needed research to find new solutions to address the state of health for the majority of the nation's population. Some of these measures include new clinical and policy practices centering improved quality of life, care, and wellbeing.

Unfortunately, the implementation of new practices is either slow moving and therefore unable to attend to the urgency of declining and poor health, or new practices are ineffective because they remain rooted in dehumanizing systems and frameworks that continue rejecting the personhood and right to health of vulnerable communities. The result is the ineffective capacity of these practices to eliminate health inequities. Because

[83] IGC, "The Sexual Abuse to Maternal Mortality Pipeline," 14.

[84] IGC, "The Sexual Abuse to Maternal Mortality Pipeline," 19-48.

the history and problem of health disparities runs deeper, new solutions require new frameworks to consider differently the ethics of health disparities. Therefore, a different framework is needed, one rooted in the morality of the nation and its ability to pursue repair against harmed and marginalized communities.

Moral Wrong, Moral Damage, and Moral Repair

The first step towards a new framework is recognizing that contemporary health disparities and inequities, informed by a fraught history of racism, discrimination, and marginalization, are morally wrong and morally damaging. Morally wrong acts are those we ought not to perform, either because of social codes of conduct or because of the consequences those actions bring about. Some actions are so wrong they require legal punishment because they are "morally prohibited, morally impermissible, acts one ought not to do, and acts one has a duty to refrain from doing."[85] Other moral wrongs are not legally punishable but are unethical behaviors that cause individual and social harm, leading to moral damage. They, too, should not be done.

Lisa Tessman names that moral damage "occurs when there is a certain sort of a self that one ought to be, but the unconducive conditions of oppression bar one from cultivating this self."[86] As an Aristotelian moral philosopher, Tessman argues that moral damage challenges flourishing, or *eudaimonia*, because virtues are damaged and become

[85] "Ethical Theory," University of Missouri School of Medicine Center for Ethics, last reviewed 2023, https://medicine.missouri.edu/centers-institutes-labs/health-ethics/faq/theory#:~:text=Morally%20wrong%20acts%20are%20activities,are%20activities%20that%20are%20allowed.

[86] Lisa Tessman, *Burdened Virtues: Virtue Ethics for Liberatory Struggles* (Oxford: Oxford University Press, 2005), 4.

vices. If there is interference with virtues that could help communities resist oppression, moral damage becomes complicit in maintaining systemic inequities, health disparities included.

As she works to create necessary revisions to Aristotle's eudaimonistic theory that consider the ability of a wider population to flourish and fight oppression beyond simply a learned and privileged populace, Tessman notes that oppression interferes with flourishing by creating "circumstances external to the oppressed agent (whether that agent be virtuous or not) that limit options so that every way one turns one runs into barriers that make it difficult or impossible to gain or be granted freedom, material resources, political power, and respect or social recognition of personhood—all of which are needed to live well."[87] The facts around health disparities for impacted demographics speak to the heavy load oppression imposes on daily life. From "womb to tomb," particular demographics are riddled with ill health, minimal health access, and poor health outcomes. This weight of oppression further jeopardizes their ability to live how they ought to live under burdensome social circumstances.[88]

Alongside naming the weight of oppression and the need to change social circumstances to help others flourish, Tessman calls for a new form of interdependence that positions societies towards flourishing: "if people are interdependent in such a way that the flourishing of one is tied to the flourishing of all, then for the privileged to flourish, they would have to worry a lot more about the well-being of the

[87] Tessman, *Burdened Virtues*, 26.

[88] Tessman, *Burdened Virtues*, 31.

disadvantaged."[89] Yet, more is needed in the U.S. to begin redressing the centuries of harm brought on society by marginalizing policies and social practices. Margaret Urban Walker provides more with her theory of moral repair.

Posing the question, what ought we to do *now*?, Urban Walker defines moral repair as,

> the task of restoring or stabilizing – and in some cases creating – the basic elements that sustain human beings in a recognizably moral relationship. By "moral relationship" I refer to a kind of relationship or mode of relating rather than to an order governed by a particular scale of values, set of imperatives, or system of role-bound obligations. Such "moralities" are the shared terms that societies set for responsible conduct and properly lived lives. Any such morality (including those streamlined normative ethical systems that philosophers elaborate, were they to be enacted in life) must be embedded in the responses, feelings, and attitudes, as well as the beliefs, of human beings in order to become and remain a functioning moral order in actual time and space. By "moral relationship" in the generic sense I mean a certain disposition of people toward each other and the standards they trust, or at least hope, are shared.[90]

Maintaining focus on relationships and how we engage with one another in our human community, Urban Walker provides a moral framework for victims' just deserts and highlights the importance of attempts to initiate repair of harms caused by wrongdoers. Such a framing also calls upon communities to support reparative steps, all components of which are necessary to address the lasting moral damages caused by health disparities and systemic inequities keeping those disparities in place.

Naming health disparities a moral wrong signals to victims across all identifiably marginalized demographics that dominant communities who are not riddled with these

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[89] Tessman, *Burdened Virtues*, 7.

[90] Margaret Urban Walker, *Moral Repair: Reconstructing Moral Relations after Wrongdoing* (Cambridge: Cambridge University Press, 2006), 23.

disparities and inequities "grasp the fact of the violation, its clear wrongfulness, the culpability of the perpetrator, and the reality of the harm and suffering" experienced by the victims.[91] This naming also requires accountability from the offender, be it from institutions or individuals, that allows affected communities to restore all they have lost, including, "to regain self-respect, to avoid self-blaming, to re-establish moral equilibrium, to trust again, to hope, to live without terror, to feel safe from those who have harmed them, to forgive if they choose."[92] Each of these restorative actions are owed to communities historically and contemporarily overrun with health disparities.

Birthing people whose mortality rates were blamed on their choosing to get pregnant should be free of self and social blame because sexist, classist, and racist health and insurance systems have failed them. Formally incarcerated persons deemed cheap labor for medical experimentation should be supported in achieving moral equilibrium because social systems should be centered for their dehumanizing beliefs, instead of deeming those incarcerated objects only fit for perfecting chemicals and medications for the non-incarcerated populace. Immigrants should be able to live without fear of terror because medical systems should not be built on hunting them down to study their physical anomalies, nor stripping them of their health autonomy and making decisions for them.

More often than not, the U.S. has inflicted a second wound on health-disparate communities by abandoning them and rejecting their complaints, fears, and expressions

[91] Urban Walker, *Moral Repair*, 19.

[92] Urban Walker, *Moral Repair*, 19.

of perceived injustices. Urban Walker names this second wound "normative abandonment," which "violates the morally essential trust that there are recognized, shared rules by which we live and which we can count on to protect and guide us."[93] This abandonment jeopardizes the ability of harmed communities to trust the normative expectations that shape our moral relationships. Exhibiting rightful anger and resentment at systems and policies meant to protect and offer care but consistently failing, health-disparate communities are excluded from moral relationships in which they should be included because their "sense of wrongfulness" surrounding their rights and norms being violated is not receiving proper moral addressal.[94]

Morally wounded and excluded, these communities continue playing by rules set forth in society without the same protections (*e.g.*, paying taxes into federal insurance programs to receive less than satisfactory health care; paying municipal taxes to remain in food deserts while funds better support other zip codes). These realities require a form of repair that moves beyond the status quo and instead aims "at bringing morally diminished or shattered relations closer to morally adequate form."[95] To do this, Urban Walker challenges communities to six tasks to achieve moral repair: (1) holding wrongdoers responsible; (2) addressing the harms imposed on victims; (3) "authoritatively instating or reinstating moral terms and standards within communities where wrong may have caused fear, confusion, cynicism, or despair about the authority

[93] Urban Walker, *Moral Repair*, 20.

[94] Urban Walker, *Moral Repair*, 24.

[95] Urban Walker, *Moral Repair*, 26.

of those standards"; (4) recreating trust among victims that reinforces shared moral standards and normative expectations; (5) nourishing hope; (6) when possible, bringing together wrongdoers and victims.[96] These six steps affirm victims' unconditional participation and inclusion in the community, being fully recognized and protected, and removing their doubt about and mistrust in the normative expectations and moral relationships in which all members should and do participate.

For wrongs such as health disparities due to historic and systemic injustices and marginalization, moral repair will be a long-term project that requires "reforming or replacing some attitudes and understandings that are distorted and injurious, even malignant."[97] These actions include reformed policies, laws, education, and social change to remedy the exploitation and terror inflicted on so many communities in the U.S. Without a start to the process, wounds remain open with the potential of becoming worse, as was contemporarily witnessed during the COVID-19 pandemic. Communities experiencing health inequities for generations were plagued with high mortality rates. For example, a 2021 CDC study of national hospital admission data determined racial and ethnic minorities were disproportionately affected by COVID-19 among infections, hospitalizations, and deaths. Disparities in hospitalizations and care received were highest at the peak of the pandemic (May-July 2020), with racial and ethnic minorities being admitted less than their white counterparts.[98] Social determinants of health across regions

[96] Urban Walker, *Moral Repair*, 28.

[97] Urban Walker, *Moral Repair*, 35.

and zip codes informed much of the disparity data, including types of occupations, housing (in)security, and modes of transportation during the pandemic. Gaps in these determinants of health have been recognized for years and the pandemic hastened the declining health of many demographics already on the brink.

Considering the history and complicated factors of health disparities in the U.S., moral repair must be genuinely pursued. Without sincerity, wrongdoers, witnesses, and beneficiaries of these unjust systems continue compounding the harms done. The deep wounds from health disparities cannot be undone, but "there is still plenty of room for reparative gestures that work on the moral plane to relieve suffering, disillusionment, isolation, and despair."[99] This moral plane includes restoring confidence in a fractured system, and trust and hope in society's responsiveness to inflicted harms. Sustaining health inequities continues to result in collateral moral damage, threatening to "demoralize us, undermining the hope that lies at the living center of the sense of responsibility that makes us capable as moral beings."[100] By restoring hope in systems meant to protect us and foster our wellbeing, society reinstitutes the value of our shared norms and the confidence citizens should have in those norms informing how we are to live with and among one another. We are then able to trust each other's attempts to fulfill

[98] Sebastian Romano and Anna Blackstock, "Trends in Racial and Ethnic Disparities in COVID-19 Hospitalizations, by Region — United States, March–December 2020," *MMWR Morb Mortal Wkly Rep* (2021): 560–565.

[99] Urban Walker, *Moral Repair*, 37.

[100] Urban Walker, *Moral Repair*, 65.

the requirements of our shared moral standards, acting as we should, and demanding compliance and redress when we fail.

Even with institutions, trust in institutions' proper action and compliance with moral standards remain necessary because institutions provide services upon which members of society depend. This trust should be ordinary. In fact, this trust is ordinary for members of dominant social groups who have not been marginalized and put in positions of skepticism toward systems meant to protect. "Lucky are those whose social worlds allow them to operate over the wide range of ordinary encounters from a position of default trust that is broad and deep."[101] For example, not everyone has access to primary care physicians who listen to their health concerns, believe they will be compliant with various health interventions, and offer them all possible treatments. Still those victims of unjust systems receiving subpar services have no choice but to continue relying on the minimal health care they receive to engage in daily life to the best of their abilities.

Repairing health disparities that date back centuries is a daunting task. While efforts have not fully eliminated health disparities, sustained work began approximately forty years ago with the *Report of the Secretary's Task Force on Black and Minority Health* (Heckler Report, 1985). This report "documented persistent health disparities that accounted for 60,000 excess deaths each year and synthesized ways to advance health equity. The Heckler Report led to the creation of the U.S. Department of Health and

[101] Urban Walker, *Moral Repair*, 87.

Human Services Office of Minority Health and influenced federal recognition of and investment in many aspects of health equity."[102] The Heckler Report was later followed by the Institute of Medicine's *Unequal Treatment*, which acknowledged the role systemic racism plays in health disparities. These two research projects changed the trajectory of health disparities research but have not concluded in the elimination of identified disparities. Some inequities have even worsened since this research began.

Alongside research, "executive orders, professional standards, and legislation, are currently being used to focus on eliminating health disparities and achieving health equity."[103] The landmark policy providing expanded health insurance coverage through the 2014 implementation of the Patient Protection and Affordable Care Act led to increased coverage for racial and ethnic minorities. And the COVID-19 pandemic, which made aware to the nation the dire state of health many communities grappled with on a daily basis, resulted in increased federal health policy measures over the past three years. President Biden named health equity a priority for his administration, followed by many federal agencies naming commitments to achieving health equity.[104] These actions show siloed improvement, but they have not resulted in nation-wide moral repair.

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[102] Nambi Ndugga and Samantha Artiga, "Disparities in Health and Health Care: 5 Key Questions and Answers," KFF, last reviewed April 21, 2023, https://www.kff.org/racial-equity-and-health-policy/issue-brief/disparities-in-health-and-health-care-5-key-question-and-answers/.

[103] Mary Hall et al., "Policy Approaches to Advancing Health Equity," *Journal of Public Health Management and Practice* 22, supplement 1 (2016): S57; "Health Disparities Legislation," National Conference of State Legislatures, last modified February 21, 2022, https://www.ncsl.org/health/health-disparities-legislation.

[104] "In its Health Equity Plan, the Department of Health and Human Services (HHS) outlined a series of new strategies, including addressing increased pregnancy and postpartum morbidity and mortality

The majority of citizens today are not primary wrongdoers, but intervention is required as we continue witnessing a system that perpetuates harms to marginalized communities. We must initiate and attempt justice as a measure of proper conduct according to the moral standards to which we all agree and share. We currently live in societies that still elevate "the interests or authority of some arbitrarily over others, or that expose some kinds of people to subordination, exploitation, exclusion, violence, or marginality in important spheres of public life."[105] To replace this system, the

among Black and AIAN women; addressing barriers that individuals with limited English proficiency face in obtaining information, services, and benefits from HHS programs; leveraging grants to incorporate equity consideration into funding opportunities, implementing equity assessments across its major policies and programs; investing in resources to advance civil rights; and expanding contracting opportunities for small, disadvantaged businesses…The Centers for Medicare and Medicaid Services (CMS) released an updated framework to advance health equity, expand health coverage, and improve health outcomes for people covered by Medicare, Medicaid, CHIP, and the Health Insurance Marketplaces…including expanding the collecting, reporting, and analysis of standardized data on demographics and social determinants of health; assessing the causes of disparities within CMS programs and addressing inequities in policies and operations; building capacity of health care organizations and the workforce to reduce disparities; advancing language access, health literacy, and the provision of culturally tailored services; and increasing all forms of accessibility to health services and coverage…

Early in the pandemic, Congress passed the Families First Coronavirus Response Act (FFCRA), which included a temporary requirement that Medicaid programs keep people continuously enrolled during the COVID-19 Public Health Emergency in exchange for enhanced federal funds…Most recently, the Consolidated Appropriations Act of 2023 included a requirement for all states to implement 12 months of continuous coverage for children, supporting their coverage stability…In April 2021, President Biden issued a proclamation to recognize the importance of addressing the high rates of maternal mortality and morbidity among Black people…In June 2022, the Biden Administration released the Blueprint for Addressing the Maternal Health Crisis [outlining] priorities and actions across federal agencies to improve access to coverage and care, expand and enhance data collection and research, grow and diversify the perinatal workforce, strengthen social and economic support, and increase trainings and incentives to support women being active participants in their care before, during and after pregnancy…

In May 2021, the Biden Administration announced that the HHS Office for Civil Rights (OCR) would include gender identity and sexual orientation as it interprets and enforces the ACA's prohibition against sex discrimination (Section 1557), reversing the approach taken by the Trump Administration…In January 2023, the Administration released its Federal Evidence Agenda on LGBTQIA+ Equity, a 'roadmap for federal agencies as they work to create their own data-driven and measurable SOGI Data,' which the Administration views as central to understanding disparities and discrimination facing this community." *See* Nambi Ndugga et al., "Disparities in Health and Health Care."

[105] Urban Walker, *Moral Repair*, 101.

subordinated need community support in favor of moral judgments that reject its demeaning norms. Support from international communities, such as the international human rights movements, can also bolster legitimate expectations for a better life and society.

This wide-ranging support also challenges those accustomed to the power to hurt and ignore others' humanity to recognize that their belief in their own superiority is false. This begins with shifting the moral standard of a person away from "a possibly predictable entity 'to be managed or handled or cured or trained; and perhaps to simply be avoided'."[106] Shifting personhood back to a view of people being ends unto themselves, endowed with dignity and full moral rights, requires that we become accountable to persons because they are participants in our shared common good. Persons who have been systemically marginalized are then freed from being viewed as "entities we need to control for our safety, amusement, or convenience."[107] When we begin viewing members of marginalized communities as full persons, we begin setting right the moral damage society has carried since initiating subpar standards of living for some demographics. We initiate trust in moral relationships and shared values that avoid "crossing certain boundaries out of a sense of responsibility."[108] Setting right health disparities and inequities informed by historical injustices also requires engagement from individuals who may think of these problems as "long ago" and not their responsibility.

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[106] Urban Walker, *Moral Repair*, 104.

[107] Urban Walker, *Moral Repair*, 104.

[108] Urban Walker, *Moral Repair*, 161.

Any resistance to repair (*i.e.*, viewing marginalized communities as "professional victims") requires hard moral actions that avoid reductionism and evasion.

> When one really looks at the complex conditions of acknowledgement, and the multiple concrete tasks of creating or restoring confidence in the shared moral standards, initiating or replenishing trust among responsible actors, and nourishing or igniting hope in both the standards and in ourselves, it is not surprising that moral repair is discouraging work exactly where it is most profoundly needed and required. The worse the wrong, one might say, the more arduous is the work and uncertain the possibility of repair.[109]

Yet, not pursuing repair is a greater moral wrong, leading to further humiliation, disenchantment, and contempt among marginalized communities. The moral damage sustained from historic moral wrongs gets worse with each generation inheriting a system and society that continues failing them. The health inequities experienced by racial and ethnic minorities are due to violent and unrepaired racial injustices that have lasted across generations, compounded with racial injustices that occur contemporarily. These histories require repair not simply to address a specific event, but also for "the restoration of relationships among segments of the U.S. population whose very understanding of themselves as segments, and whose alienation as citizens, has been produced by the history of raced relationships legitimized and enforced by political institutions."[110] Restoring relationships and trust restores moral standards and normative expectations, even in the face of historic inequities that have resulted in debilitated communal health for some populations in the U.S.

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[109] Urban Walker, *Moral Repair*, 205.

[110] Urban Walker, *Moral Repair*, 224.

Conclusion

Health disparities in the U.S. are a social, economic, political, and most importantly, moral wrong of the highest magnitude. Multiple communities throughout U.S. history and contemporarily have been unfairly and unjustly impacted by a system that has valued them less than their personhood requires. By creating a pseudoscience whose primary purpose was to legally dehumanize and disenfranchise the majority of the U.S. population, physicians have been at the root of the unhealth of the nation. This "science" has created a healthcare system protected by policies sustaining appalling health statistics affecting every dimension of life for impacted communities. And the proliferation of the inequities born from this "scientific system" leads to national moral damage.

Moral repair must be pursued to achieve better physical and moral health for all persons. Margaret Urban Walker provided an invaluable framework for articulating and pursing repair, and the various levels of support that can bring about repair. By holding wrongdoers responsible, addressing harms imposed on victims, reinstating moral standards within the community, reestablishing trust, nourishing hope, and bringing wrongdoers and victims together, many specific measures can be taken as forms of moral repair. The next chapter will begin providing concrete steps to achieve moral repair and redress for the harms imposed by systemic health inequities that have plagued health-disparate communities for generations. Two resources will prove critical.

First, given the U.S.'s inability to eliminate health disparities and provide basic care and health in accordance with our shared normative expectations, support from the

international community is required. The United Nations (UN) provides several critical legal documents affirming the rights to health and quality of life owed to all citizens in all supporting nations, of which the U.S. is one. At a communal level, the UN also provides conditions for acknowledging historic and systemic wrongdoings, as well as support for victims in the form of legislation outlining how they should be able to live. The following chapter will explore these measures as a community-level form of moral repair acceptable by all, regardless of religious or philosophical outlook.

Second, from a theological perspective, French Catholic theologian Jacques Maritain provides a view of personhood and humanity helpful in reorienting how we view and engage with one another. His theory of personhood, affirming our individual dignity as the source of our rights to quality life and health, provides theological and philosophical import to our moral standards and relationships. Together, the UN and Maritain will provide a two-tiered approach to moral repair that will be applied to the case of black birthing people.

CHAPTER TWO: Right to Health as Diagnosis and Prescription

"It is my aspiration that health finally will be seen not as a blessing to be wished for, but as a human right to be fought for."

—United Nations Secretary-General Kofi Annan

The previous chapter examined the troubling history of health disparities in the United States (U.S.) and framed them as a moral wrong in need of repair. Following Margaret Urban Walker's six-step reparative framework, this chapter examines the universal declarations, bodies, and conventions that offer resources for the repair necessary to overcome the normative contempt and abandonment experienced by health-disparate communities in the U.S. Primarily performing a landscape analysis of the international community's application of morality and duty in their outlined right to health, this chapter interprets the various iterations of the universal right to health and subsequent protections for specific historically marginalized communities as a path to reducing health disparities in the U.S. This analysis provides space to better understand violations of fundamental human rights, especially the right to health, and opportunities for protecting rights as a form of moral repair. *The human rights framework both provides a path forward to a healthier nation and gives voice to those communities whose health needs have been neglected due to various social power structures.*

As articulated in the first chapter, Margaret Urban Walker provides a definition for moral repair along with steps to achieving said repair for victims, wrongdoers, and the

wider community.[1] In the case of health, health-disparate communities in the U.S. have been victims for generations and dominant, healthier communities have insufficiently grasped the violations to health and inflicted harms experienced by the victimized. The disregard evident in dominant communities and bystanders has led to broken trust between health-disparate victims and the healthcare system, leaving victims morally and relationally abandoned. In the absence of reparative national actions that remain in place regardless of presidential administration, the international community is poised to provide moral and legal resources in the form of human rights instruments to begin much needed steps towards moral repair and the re-establishment of trust.

The tangible effects of international resources can include new and reformed health policies, laws, and education that create social changes directed towards increased trust and safer participation in the health system for health-disparate communities. There is also the opportunity to restore hope in the health system because accountability, redress, and respect of personhood will be the moral norms guiding care. To understand these benefits, an analysis of the human rights framework and its history must first be conducted.

[1] Moral repair is defined as, "the task of restoring or stabilizing – and in some cases creating – the basic elements that sustain human beings in a recognizably moral relationship." The tasks for achieving moral repair are outlined as follows: (1) holding wrongdoers responsible; (2) addressing the harms imposed on victims; (3) "authoritatively instating or reinstating moral terms and standards within communities where wrong may have caused fear, confusion, cynicism, or despair about the authority of those standards"; (4) recreating trust among victims that reinforces shared moral standards and normative expectations; (5) nourishing hope; (6) when possible, bringing together wrongdoers and victims. *See* Margaret Urban Walker, *Moral Repair: Reconstructing Moral Relations after Wrongdoing* (Cambridge: Cambridge University Press, 2006), 23, 28.

Human Rights Framework and the U.S.

Human rights are a combination of positive and negative, "equal and inalienable rights of all members of the human family", regardless of a person's social identifiers.[2] By virtue of being human and bearing inherent dignity, each person's fundamental human rights are meant to be respected and protected at all times. Further, as members of societies, every person "has the right to social security and is entitled to realization, through national effort and international co-operation and in accordance with the organization and resources of each State, of the economic, social and cultural rights indispensable for [their] dignity and the free development of [their] personality."[3] Because human rights concern individuals who make up societies, they are "about how our societies and our institutions should be organized in terms of the basic moral and political framework. …that will form the core of good, or at least decent, human societies."[4]

Human rights are not to be mistaken for a full account of all human political and moral norms. Rather, as a starting framework for how we continue engaging in and building societies, human rights have the power to speak to our evolving moral and social thinking: we *ought* to form and engage in these societies in a way that makes space for

[2] UN General Assembly, "Preamble," *Universal Declaration of Human Rights*, 10 December 1948, 217 A (III), available at: https://www.refworld.org/docid/3ae6b3712c.html

[3] UN General Assembly, "Article 22," *Universal Declaration of Human Rights*, 10 December 1948, 217 A (III), available at: https://www.refworld.org/docid/3ae6b3712c.html

[4] Johan Brännmark, "Respect for Persons in Bioethics: Towards a Human Rights-Based Account," *Hum Rights Rev* 18 (2017): 177.

the recognition of the inherent dignity borne by every human being and affirmed by the preamble of the United Nations' Universal Declaration of Human Rights (UDHR). A human rights framework that begins with inherent dignity also makes space for personhood as a political status informing morality.[5] Personhood will be engaged more thoroughly in the proceeding chapter, but it is important to note in relation to human rights that, "the relevant sense of personhood is about being a member of a society built on human rights and then it is dignity as part of what is involved in that package…that is of primary interest."[6] Dignity, personhood, and rights further provide opportunities for humans to navigate societies based on who they are instead of what they are for, integrating our moral standing into our social, political, and moral participation in shared institutions.[7] As a result, a human rights framework has the power to challenge social systems and institutions in the U.S. that are currently experienced as dehumanizing, impersonal, belittling, and victim-blaming for a significant portion of the population.[8]

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[5] Brännmark, "Respect for Persons in Bioethics," 173.

[6] Brännmark, "Respect for Persons in Bioethics," 183.

[7] In an examination of Christian ethics' response to economic medical rationing for poor and elderly citizens, L. Gregory Jones argues that U.S. culture has yet to answer the question, "what in hell are people for?" Technological advances have focused on extending life, which has now become a primary goal of medicine instead of understanding why we should extend life and when it is appropriate to extend or not extend. Encouraging a Christian ethic of virtue among physicians and patients, Jones concludes that we must always observe life from the perspective of those who suffer. "We cannot rest easily with any systems of medical care which fail to attend to the primary health care needs of the poor and those who are ill. We are, or at least ought to be, people who would rather accept our own death than use up precious resources if preventing our death would mean that others will go without care." *See* L. Gregory Jones, "A Pathology of Medical Ethics: Economic Medical Rationing in a Morally Incoherent Society," in *On Moral Medicine: Theological Perspectives in Medical Ethics,* eds. Stephen E. Lammers and Allen Verhey (Grand Rapids, MI: Wm. B. Eerdmans Publishing Co., 1998), 997-1000.

When examining the development of human rights, there is no historical moment at which human rights were birthed, but the Holocaust played a catalyzing role in the development of the United Nations (UN) and Universal Declaration of Human Rights (UDHR). Prior to the development of the international organization and its seminal charter, there was no established international way to categorize massacring one's citizenry as a legal offense.[9] After witnessing the widescale trauma of the Holocaust, nations gathered in San Francisco in 1945 and created the UN as an international body to help regulate one another.[10] Out of the UN, the UDHR was created as the first legal document naming those fundamental human rights to be protected by domestic and international human rights law, asserting that human rights are inalienable, universal, indivisible and interdependent, equal, and non-discriminatory.[11]

While they possess revolutionary social *potential*, there is little scholarly agreement on the efficacy of international human rights. Because states can protect or violate human rights, some western scholars argue that these norms for how we ought to treat one another as fellow human beings "do not reside solely in the state and instead are

[8] Teresa Maldonaldo, "Sick of Being Poor," in *On Moral Medicine: Theological Perspectives in Medical Ethics*, eds. Stephen E. Lammers and Allen Verhey (Grand Rapids, MI: Wm. B. Eerdmans Publishing Co., 1998), 1002-1004.

[9] Jack Donnelly, *International Human Rights Vol. 3 Dilemmas in World Politics* (Boulder, CO: Westview, 2007), 5.

[10] Zakiya Luna, *Reproductive Rights as Human Rights: Women of Color and the Fight for Reproductive Justice* (New York: NYU Press, 2020), 29.

[11] "What are human rights?" UN Human Rights Office of the High Commission, last modified 2023, https://www.ohchr.org/en/what-are-human-rights.

a relationship practice."[12] Expanding human rights to include the state *and* interpersonal relationships allows greater opportunity for activists to expand human rights discourse to draw attention to the plight of marginalized communities still fighting for their human rights to be fully recognized.

The wider relational view of human rights has been invoked in the U.S. since World War II as black Americans fought for recognition of their civil and human rights locally and federally.[13] Black American consultants and lobbyists worked with the UN on preliminary drafts of the UDHR to draw attention to human rights violations within the U.S.'s borders. Activists not only demanded political rights but also political health promotion in recognition of the human right to health.[14] This activism unfortunately led a U.S. policy advisor to craft Article 2, para. 7 of the charter for UN member states granting power to individual nations to protect domestic interests.[15]

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[12] Luna, *Reproductive Rights as Human Rights*, 4.

[13] For additional reading on Black Americans' lobbying with the UN, *See* Mary McLeod Bethune, *Mary McLeod Bethune: Building a Better World* (Indianapolis: Indiana University Press, 1999); Carol Anderson, *Eyes off the Prize: African Americans, the United Nations, and the Struggle for Human Rights, 1944-1955* (New York: Cambridge University Press, 2003); Thomas F. Jackson, *From Civil Rights to Human Rights: Martin Luther King, Jr., and the Struggle for Economic Justice* (Philadelphia: University of Pennsylvania Press, 2007); W.E.B. Du Bois, "An Appeal to the World: A Statement of the Denial of Human Rights to Minorities in the Case of Citizens of Negro Descent in the United States of American and an Appeal to the United Nation for Redress," in *W.E.B. DuBois International Thought* (Cambridge: Cambridge University Press, 2022).

[14] "Noted civil rights activist Fannie Lou Hamer was often quoted as saying she was 'sick and tired of being sick and tired' and openly discussed her experience of having been forcibly sterilized. Geographer Jenna Loyd points to how disparate groups of Los Angeles-area community members simultaneously fought against militarization while demanding government investment in community health programs. Sociologist Alondra Nelson details how the Black Panthers fought for community-controlled health centers and against racist assumptions of medical authorities. And historian Jennifer Nelson has demonstrated how feminist women's health advocates understood their activism as extending beyond medical care to include intertwined social issues." *See* Luna, *Reproductive Rights as Human Rights*, 13.

The U.S.'s success in including Article 2, para. 7, which greatly limited domestic activists' work to have full human rights recognized, has been termed the "domestication of human rights" by sociologists. Zakiya Luna defines the term as "the discursive process of relating international rhetoric to a domestic problem."[16] Luna argues the U.S. government has engaged in *restrictive domestication* by narrowing the meaning of human rights to suit political needs. Yet activists historically and contemporarily have engaged in *revolutionary domestication* by calling upon the international rhetoric and its relevance within the U.S. The persistent turn towards inclusive, international rhetoric shines important light on the sociopolitical dynamics shaping the positive and negative factors that determine access to and fulfillment of human rights domestically.

The restrictive domestication inherent in Article 2, para. 7 strengthened nations' exceptionalism and hypocrisy, especially in the western hemisphere.[17] Michael Ignatieff goes a step further and names three functions of exceptionalism resulting from the article, with the U.S. engaging equally in all three: self-exemption from signed agreements (exceptionalism); bias towards personal and allies' conduct (double standards); and, a lack of incorporating international human rights laws in domestic courts of law (legal

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[15] Article 2, par. 7 states, "Nothing contained in the present Charter shall authorize the United Nations to intervene in matters which are essentially within the domestic jurisdiction of any state." Luna succinctly argues the impact of this article in advocating nation-state exceptionalism: "Thus, just as another attempt at a global cooperative of nations was being developed, each national interested was being protected, undermining the purpose of a global body…[As such, t]he domestic jurisdiction clause makes it possible for any recognized nation to turn away from its own social problems and focus instead on criticizing other nations. Thus, exceptionalism is embedded in the UDHR for all nations." *See* U.N. Charter, art. 2, para. 7.; Luna, *Reproductive Rights as Human Rights*, 31, 34.

[16] Luna, *Reproductive Rights as Human Rights*, 4.

[17] Luna, *Reproductive Rights as Human Rights*, 34.

isolationism).[18] Even after the signing of the UDHR, black Americans continued to feel the weight of restrictive domestication as their ongoing fight for human rights recognition intersected with the Cold War and McCarthyism.

The more activists sought expansive socioeconomic rights to supplement their political and civil rights, McCarthyites labeled them un-American, forcing them to forgo the inclusive rhetoric altogether and settle for those "first-generation" human rights to political access legally protected in the U.S. (*e.g.,* voting).[19] Another negative result of Cold War sentiments was the defeat of a national insurance proposal by Harry Truman despite Franklin D. Roosevelt years prior arguing for "the right to adequate medical care and the opportunity to achieve and enjoy good health."[20] The efficacy of this strategy has led to ongoing domestic restrictions of human rights, especially the right to health, as the U.S. adopted a framework of discussing human rights and their violations as a foreign

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[18] Michael Ignatieff, *American Exceptionalism and Human Rights* (Princeton, NJ: Princeton University Press, 2009), 4; Luna, *Reproductive Rights as Human Rights*, 34.

[19] Luna distinguishes between first- and second-generation rights. "According to the [UDHR], everyone has the same human rights irrespective of any social statuses. Nevertheless, supporters of human rights point out that some human rights are privileged over others. In many countries, 'Civil and political rights are viewed therefore as inherent, universal and justifiable, while social and economic rights [second-generation rights] are viewed as evolving gradually as a matter of social policy rather than fundamental justice.' This 'first-generation' of human rights are most supported by the US government." Second-generation rights can include "the right to free elementary education." *See* Luna, *Reproductive Rights as Human Rights*, 32, 38; Zakiya Luna, "From Rights to Justice: Women of Color Changing the Face of US Reproductive Rights Organizing," *Societies Without Borders* 4 (2009): 345; Joanna Kerr, "The Context and The Goal" in *Ours by right: Women's rights as human rights* (London: Zed Books, 1993), 5; Zakiya Luna, "Domesticating Human Rights: Possibilities and Ambiguities in the Emerging Reproductive Justice Movement" (PhD diss., University of Michigan, 2011), 4, 18.

[20] Some argue that the explicit absence of a class system, weak labor movements, poor attitudes about the U.S. government, and the structure of the U.S. constitution are all potential factors resulting in the U.S. not supporting a national insurance program. However, the defeat of Truman's proposal fits well within the U.S.'s historic dismissal of incorporating human rights rhetoric and frameworks within domestic laws and policies. *See* Alicia Ely Yamin, "The Right to Health Under International Law and Its Relevance to the United States," *Am J Public Health* 95, no. 7 (2005): 1156.

concept that nondemocratic nations violate while ignoring domestic violations because all citizens are granted civil rights.[21]

The U.S. continues to "win" in all categories of human rights because of the equation of human rights with democratic freedoms and values, an understanding far different from the international framework wherein states have obligations to upholding positive and negative rights of citizens. Luna articulates best the restrictions to human flourishing brought about by such an approach.

> Restrictive domestication offers a tempting view of human rights: that individuals can achieve human rights through exercising an individual right to vote or that a legal guarantee of equality under the law is the most important way to access human rights. People can live under equally horrible conditions while still retaining their civil rights. Thus, a focus on civil rights does not require human flourishing. Further, restrictive domestication does not address what people need in order to exercise these rights on a practical level. It does not, for example, address how reliance on market logics has eroded the right to *have* rights, even for formal citizens.[22]

The past decade's sociological scholarship has further revealed the U.S.'s ongoing policy promotion of civil rights and ignorance of second-generation social and economic rights, posing a critical challenge to various forms of activism seeking to hold the nation accountable for its violations and neglect of human rights, including rights to health.[23]

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[21] Luna, *Reproductive Rights as Human Rights*, 40.

[22] Luna, *Reproductive Rights as Human Rights*, 36.

[23] Analyzing Diana Grace Zoelle's and Carol Anderson's works to provide grounding to the distinctions between civil and human rights, Luna asserts, "the tension between civil rights and more expansive human rights results from the fact that the initial goal of civil rights legislation was, primarily, to protect African Americans and women from active discrimination rather than passive neglect. The important difference between civil rights and human rights is that civil rights do not go as far as human right because civil rights 'are merely adjustments to a systemic structure that is otherwise entirely acceptable,' whereas 'human rights' suggest the necessity of a supportive social structure even if that

This focus on civil rights and ongoing ineffective reforms continues to draw attention away from the systemic changes necessary to revolutionarily change the ways citizens are valued in society while the U.S. remains "uniquely averse to accepting international human rights standards and conforming national laws to meet them."[24] This named aversion dates back to the 1950's as a contingent of Congressional representatives fought to challenge the Supreme Court decision, *Missouri v. Holland*, intending to assert the supremacy of states' rights over international laws and treaties.[25] These actions resulted

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means systemic change. However, this downplays how radical civil rights were to many, as evidenced by the intense violence faced by civil rights-era activists. Further, the continued backlash against codification of basic civil rights shows how radical that subset of human rights remains a century after African Americans began mobilizing around those issues." *See* Luna, *Reproductive Rights as Human Rights*, 37-39; Diana Grace Zoelle, *Globalizing Concern for Women's Human Rights: The Failure of the American Model* (New York: Springer, 2000); Anderson, *Eyes off the Prize*.

[24] Here, Yamin concludes U.S. aversion from the detailed history of U.S. international affairs researched by Louis Henkin. Henkin explores the ways the U.S. constitution supports and hinders international relationships. In the case of adherence to international human rights laws, covenants, and conventions, Henkin concludes, '[i]n part, the United States adheres to human rights conventions because it is concerned to maintain leadership in international affairs by proving that it deserves it, by its behavior at home and by its willingness to join in cooperative international efforts to promote respect for human rights elsewhere. In larger part, the United States is concerned to see minimum standards of constitutionalism, democracy, and human rights observed in other countries in order to safeguard our own standards, to promote conditions that are conducive to U.S. prosperity and to U.S. interests in international peace and security…The United States does not adhere to human rights covenants and conventions in order to distort or circumvent our constitutional system, to legislate larger guarantees of human rights for its own citizens by treaty rather than by act of Congress, or to take additional matters from the states into the federal domain; the United States adheres to such treaties in order to modify the behavior of other governments in ways that further U.S. interests. To have other nations undertake to observe higher standards and to give the United States the right to request and help monitor compliance with those standards, the United States undertakes to apply similar standards in the United States and to recognize the right of other nations to request and observe U.S. compliance." *See* Louis Henkin, *Foreign Affairs and the United States Constitution*, 2nd ed. (Oxford: Oxford Academic, 1996), 475-476; Yamin, "The Right to Health Under International Law," 1157.

[25] "In 1913, Congress enacted a statute to regulate the hunting of migratory birds. Two lower federal courts declared the statute invalid, finding that it was not within any enumerated power of Congress, and the Department of Justice feared that the statute might meet the same fate in the Supreme Court. It was suggested, however, that migratory birds were a subject of concern to other nations as well, for example Canada; and if the United States and Canada agreed to cooperate to protect the birds, Congress could enact the legislation it had previously adopted under its power to do what is 'necessary and proper' to

in the U.S. refusing "to adhere to human rights covenants and conventions [for decades]. When, finally, the United States adhered to several of them, it did so subject to major reservations, understandings, and declarations which, in the view of many, substantially vitiated U.S. adherence."[26] This delayed and reserved adherence perfectly captures the functioning legal isolationism rooted in the U.S.'s exceptionalism regarding international rights.

Despite the nation's previous reservations regarding international rights, laws, and practices, the nation could move towards increased international rights cooperation. Considering the legal reality that international law is binding on the U.S. and Congress, the U.S.

> could accept the jurisdiction of a tribunal such as the Inter-American Court of Human Rights, with jurisdiction over complaints of human rights violations brought by other states or by an international body. It could even, I have little doubt, adhere to an international court or tribunal that could hear complaints against the United States by individuals, including its own citizens or residents.

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implement the treaty. The treaty was made, the statute enacted, and the Supreme Court upheld it. *Missouri v. Holland* involved the validity of the act of Congress, not the validity of the treaty itself, but if 'the treaty is valid there can be no dispute about the validity of the statutes under Article I, para. 8, as necessary and proper means to execute the powers of the Government…the Constitution delegated powers to various branches of the federal government, not only to Congress; the Treaty Power was delegated to the federal treaty-makers, a delegation additional to and independent of the delegations to Congress. Since the Treaty Power was delegated to the federal government, whatever is within its scope is not reserved to the states: the Tenth Amendment is not material. Many matters, then, may appear to be 'reserved to the States' as regards domestic legislation if Congress does not have power to regulate them; but they are not reserved to the states so as to exclude their regulation by international agreement…Eventually, the implications of *Missouri v. Holland* were recognized and understood, but not everywhere welcomed. They were particularly objectionable to those who resisted U.S. adherence to treaties by which the United States might accept common international standards for governmental behavior towards its own citizens, for example international human rights covenants and conventions." While *Missouri v. Holland* clarified that states' rights do not trump international treaties, Congress has yet to utilize its full power to incorporate international human rights laws into the U.S.'s domestic framework. This refusal maintains a morally failed stance that continues to cause moral damage to the nation as a whole. *See* Henkin, *Foreign Affairs and the United States Constitution*, 191-192.

[26] Henkin, *Foreign Affairs and the United States Constitution,* 193.

> Nothing in the Constitution, we have seen, prevents the United States from undertaking international obligations in regard to its own citizens and residents; nothing prevents the United States from submitting its compliance with such obligations to scrutiny and judgment by an international tribunal. There would seem to be no compelling constitutional reasons why the relations between the United States and its citizens could not be subject to both the laws and courts of the United States and to international law administered by international tribunals exercising international judicial power.[27]

To date, the U.S. has not taken this potential stance combining international and domestic law. The U.S.'s indifference to and intentional neglect of incorporating international human rights rhetoric into domestic law and policy can be seen as a facilitative vice—the U.S. upholds itself as a good nation while masking the effects of its "unjust, cruel, callous, dishonest, and so on actions."[28] As a member of the dominant community of developed nations, the U.S. is closely aligned with similarly developed nations who agree with how to promote health and a good life for their citizenry: the pathway is grounded in beliefs about meritocracy and individualism, with success defined "as the attainment of self-interested rather than collective goals."[29] Such beliefs can be seen across the U.S.'s health culture that blames individuals for not attending to their health well enough while simultaneously rejecting the systemic inequities that have led to generations-long disparities impacting identifiable communities. Lisa Tessman further argues that these beliefs in oneself being good, further affirmed by likeminded others, represents a form of epistemic privilege which eventually leads to epistemic isolation. This form of isolation

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[27] Henkin, *Foreign Affairs and the United States Constitution*, 267.

[28] Lisa Tessman, *Burdened Virtues: Virtue Ethics for Liberatory Struggles* (Oxford: Oxford University Press, 2005), 78.

[29] Tessman, *Burdened Virtues*, 79.

allows the U.S. to promote well living for those who can afford it, while others suffer disproportionately within and beyond its borders.

Another way Tessman articulates this behavior is as the *ordinary vices of domination*, which can be seen as a failure to exhibit virtues, especially those of justice, compassion, and generosity.[30] The U.S.'s failure to engage virtuously towards health-disparate groups by enacting and protecting human rights leads to the moral damage of those victimized communities who are left to manage their lives and health as well as possible. They settle for civil rights instead of full human rights. They navigate resource-poor neighborhoods and mistrust of physicians whose profession has enacted generational harm on the bodies of their ancestors and sometimes on their own bodies. Meanwhile, dominant communities internally affirm their own moral goodness, achieve the good life despite domestic and global health suffering, continue engaging in oppressive actions, and are extremely resistant to recognizing disparities in healthcare. The work of moral repair through the instruments of an international human rights framework has the potential to bring about domestic revolutionary change that diminishes the harmful impacts of the U.S.'s oppression, moral harm, historic traumas, and dehumanization.

The first step to this revolutionary domestication of rights in the U.S. is a more accurate understanding of human rights. Instead of considering human rights a list of proposals to which other nations should attend, the U.S. must come to understand human

[30] Tessman, *Burdened Virtues,* 63.

rights as "a set of norms, institutions, and laws with which governments must engage to some degree in order to appear legitimate. This is the case because human rights are contained in a 'model' that experiences 'a considerable amount of consensus' globally."[31] This globally accepted model allows activists and individuals to appeal to global norms and the supporting bodies upholding these norms to pursue domestic accountability for protection of their rights.

While human rights cannot solve all problems considering the social determinants that have created and upheld systemic injustices, they do provide immense potential for citizens demanding necessary resources to access rights, to which cosigning nations have agreed they are entitled.[32] Shifting the view of human rights within the U.S. also provides

[31] Luna, *Reproductive Rights as Human Rights*, 41.

[32] It is important to note several contemporary domestic legal cases in which U.S. citizens have charged the nation with violating their human rights and demanded redress. Interestingly, the majority of ongoing cases involve non-citizens (*e.g.*, immigrants trafficked to the U.S. or unlawfully detained). Those citizens who comprise the majority of human rights violations or imprisoned. There are nonprofits who regularly go before international bodies to present the case of human rights violations, but their advocacy occurs beyond the legal realm. The 1996 *Olmstead v L.C.* case addressed the rights to health and wellbeing for patients with mental disabilities. The Supreme Court voted in favor of the plaintiffs that mental health challenges are disabilities and unjustified isolation of patients with mental disabilities is discrimination. The 1999 *Jessica Gonzalez v. U.S.A.* case went before the Inter-American Commission on Human Rights, resulting in the commission declaring that the U.S. violated Gonzalez's and her children's human rights due to police inaction to protect them from domestic violence. The 2005 *Sabbithi, et al. v. Al Saleh, et al.* case addressed human trafficking conducted by international diplomats on U.S. soil, overriding diplomatic immunity. The 2011 *David, et al. v. Signal International LLC, et al.* and *EEOC v. Signal International, LLC* cases address labor trafficking and discrimination in employment. Several cases addressing human rights violations in the U.S. are ongoing: *Weir v. U.S.* (addressing inhumane conditions and unlawful detainment of Jamaican fishermen detained by the U.S. Coast Guard), *Ashker v. Governor of California* (focusing reformed use of solitary confinement in California detention centers), *Petition on Behalf of Men and Women in the State of New Jersey Prohibited from Voting Pursuant to State Disfranchisement Laws, Policies and Practices begore the IACHR* (centering felon disfranchisement laws), *KC v. Nedelkoff* (a class action lawsuit challenging inhumane practices and abuse in youth detention centers) and *Egbert v. Boule* (centering reform of laws allowing unlawful entry of private property by law enforcement agents). The vast majority of cases in the U.S. addressing human rights do so under "civil rights" and are not brought before the Inter-American Court of Human Rights. *See* "Court Cases: Human Rights," ACLU, last modified September 20, 2022, https://wp.api.aclu.org/court-cases/page/5?issue=human-rights#all_content.

opportunities for marginalized communities, and other health-disparate communities struggling for recognition of their right to health, to collectively "challenge inequality under the rubric of gaining wider human rights that go beyond the limited rights supported by any particular government."[33] The forward movement provided by human rights then allows communities to challenge the public versus private binary the U.S. has been able to uphold by outwardly championing human rights internationally while ignoring those rights domestically.[34]

Using Luna's domestication framework and considering the lack of knowledge many Americans have regarding the purpose and functioning of the UN, this chapter now pivots to delve deeply into the international human rights rhetoric as a source of moral repair, insisting on the relevance of the right to health as a means of overcoming health disparities in the U.S.[35] Engaging the radical and culturally shifting ideas generated from the International Bill of Rights allows the remainder of this chapter to simultaneously name the negative culture of exceptionalism informing the U.S.'s restrictive domestication and challenge the U.S.'s ongoing marginalization of rights-bearing communities. Further, the following analysis upholds the importance of "second-generation rights" that build on the first-generation civil rights already legally granted in the country.

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[33] Luna, *Reproductive Rights as Human Rights*, 66.

[34] Luna, *Reproductive Rights as Human Rights*, 5.

[35] Luna, *Reproductive Rights as Human Rights*, 164.

International Right to Health

WHO's Health

The right to health has been internationally recognized since 1946 with the drafting of the World Health Organization's (WHO) Constitution. The right was later affirmed in 1948 in the UDHR and reiterated in 1966 in the International Covenant on Economic, Social and Cultural Rights (ICESCR). Considering their close proximity in being drafted, the WHO Constitution and UDHR "were the first international instruments to enshrine health as a fundamental right of every human being."[36]

WHO defines health as "a state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity. The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition."[37] Informed by World Warr II and mass destruction of human life, this definition was crafted in a culture that hoped health and respect of persons would maintain peace because cosigning nations would promote good living, social, and economic conditions such that there would be no further cause of war.[38] This unprecedented step named health a positive right inclusive of improved social determinants of health such as proper

[36] "Human Rights" World Health Organization, last modified 2023, https://www.who.int/health-topics/human-rights#tab=tab_1.

[37] World Health Organization (WHO), *Constitution of the World Health Organization: Basic Documents* (Geneva: World Health Organization, 1946).

[38] Marianna Nobile, "The WHO Definition of Health: A Critical Reading," *Medicine and Law: World Association for Medical Law* 33, no. 2 (2014): 34.

nutrition, thriving working conditions, access to clean water, and sanitary living conditions.

Broadening health beyond a focus on disease and infirmity, "[t]he normative scope and content of the right to heath (*i.e.*, the standard for the human right to health) comprises four interrelated elements which require that public health and healthcare facilities, goods, services, and programmes, in addition to the underlying determinants of health, be Available, Accessible, Acceptable and Quality."[39] These elements require implementation from states, "including the guarantee of non-discrimination, and the obligation to take deliberate, concrete and targeted steps towards realizing the right to health for all."[40] WHO's definition also "implies there is some intrinsic relationship between the good of the body and the good of the self" as it moves beyond solely defining health as the absence of disease.[41] This definition further considers the health of societies made up of individuals whose holistic and intersectional health matters.

From definitions to research, WHO has aimed to inform the care health professionals provide and the social constructions of health that continue to reverberate in societies today. Over time, it has increased its activism in protecting the right to health for all human beings. The agency primarily engages in activism by assuming the responsibility of taking the lead on global health matters, shaping research agendas and

[39] "Human Rights."

[40] "Human Rights."

[41] Daniel Callahan, "The WHO Definition of 'Health'," in *On Moral Medicine: Theological Perspectives in Medical Ethics*, eds. Stephen E. Lammers and Allen Verhey (Grand Rapids, MI: Wm. B. Eerdmans Publishing Co., 1998), 253.

health norms, creating and sharing potential health policies, and monitoring global health trends.[42] Therefore, the definition and its implementation strategically impact all social areas of life, influencing "the demands and expectations of health, the health care systems, the policy makers, and many other key aspects of health."[43]

There are several contemporary objectors to the WHO's encompassing definition of health. Fabio Leonardi summarizes six of the most popular objections: (1) "complete well-being" is too extreme of a standard that remains unattainable. For example, older people and people with chronic diseases will never achieve complete health despite being able to live longer due to advances in medical science. Therefore, complete health is always a temporary state never permanently actualized. (2) The definition is impractical and unusable to concrete medical cases "because it is neither operational nor measurable." (3) The definition is so broad that "it conflates scientific assessments with moral and political arguments." (4) The definition leads to increasing medicalization of society and a higher demand for medical services when citizens should potentially look towards other social services. (5) There is an assumption that well-being and health are always linked, diminishing the wide range of human emotions, activities, and needs. (6) The definition's stated forms of well-being always assume a positive correlate, but negative forms of well-being (*e.g.*, risk-taking behavior) can occur where a person

[42] WHO Office of the UN High Commissioner for Human Rights, *The Right to Health: Fact Sheet No. 31* (Geneva: WHO Press, 2008), 29.

[43] Fabio Leonardi, "The Definition of Health: Towards New Perspectives," *International Journal of Health Services* 48, no. 4 (2018): 736.

threatens their physical well-being for psychosocial well-being.[44] These objections cannot be dismissed because they represent valid concerns; however, no scholar to date has been able to propose an internationally accepted definition of health that contributes to social wellbeing. Further, these objections dismiss the role of social medicine, which intentionally seeks to engage all social dimensions of life and social determinants of health in an increasingly interconnected world to improve health across those dimensions.

Despite increasing lifespans and improved access to healthcare technologies in all regions of the world, the fact remains that many communities have never achieved a significant level of basic health since 1946, nor had their rights to health enacted and protected. This fact requires ongoing engagement with the WHO's embracing definition to understand the ways health can be improved among these health-disparate communities. Further, how communities view health impacts their health behaviors and decisions. As such, marginalized communities, specifically those health-disparate communities in the U.S. under examination in this work, deserve an inclusive framing of health that is agreed to by most of the planet in order to guide their health behaviors and reinforce the positive right to health owed to them. As a source of moral repair, the current definition of and right to health outlined by the international community operates as an inspiring and motivating goal, including for health-disparate communities in the U.S.

Articles Supporting WHO's Health

[44] Leonardi, "The Definition of Health," 736-738.

Supplementing the WHO's definition of health and its position as a fundamental right irrespective of challengers, Article 25 of the UDHR enshrined health as one aspect of an adequate standard of life:

> 1. Everyone has the right to a standard of living adequate for the health and well-being of [themselves] and of [their] family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond [their] control.
> 2. Motherhood and childhood are entitled to special care and assistance. All children, whether born in or out of wedlock, shall enjoy the same social protection.[45]

Article 12 of the ICESCR later reiterated the right to health defined by WHO as a human right:

> 1. The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.
> 2. The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for:
>   a) The provision for the reduction of the stillbirth-rate and of infant mortality and for the healthy development of the child;
>   b) The improvement of all aspects of environmental and industrial hygiene;
>   c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases;
>   d) The creation of conditions which would assure to all medical service and medical attention in the event of sickness.[46]

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[45] UN General Assembly, *Universal Declaration of Human Rights*, 10 December 1948, 217 A (III), available at: https://www.refworld.org/docid/3ae6b3712c.html.

[46] It should be noted paragraphs 2 and 3 of Article 10 argue for wellbeing protections for birthing people and children:

> a) Special protection should be accorded to mothers during a reasonable period before and after childbirth. During such period working mothers should be accorded paid leave or leave with adequate social security benefits.
> b) Special measures of protection and assistance should be taken on behalf of all children and young persons without any discrimination for reasons of parentage or other conditions. Children and young persons should be protected from economic and social exploitation. Their

An implicit result of the 1946 definition of health and ensuing rights is the inclusion of individuals' choices alongside the physical manifestations of social determinants of health. This expansion implied the importance of whole-person wellbeing and care as the end result of health. Where we live, how we engage in the world, and how our lived engagement influences the manifestation of conditions and diagnoses matter to our health over the course of our lifetime. The right to health provided a framework that complements solutions to social problems that threaten wellbeing while challenging the reductionist understanding of health in the western hemisphere that prioritizes medicine (individual-focused) and public health (population-focused), neither of which defines what health is.[47] Since 1946, "every State has ratified at least one international human rights treaty recognizing the right to health. Moreover, States have committed themselves to protecting this right through international declarations, domestic legislation and policies, and at international conferences."[48] The U.S. is deeply engaged in this

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> employment in work harmful to their morals or health or dangerous to life or likely to hamper their normal development should be punishable by law. States should also set age limits below which the paid employment of child labour should be prohibited and punishable by law.

See UN General Assembly, *International Covenant on Economic, Social and Cultural Rights*, 16 December 1966, United Nations, Treaty Series, vol. 993, available at: https://www.refworld.org/docid/3ae6b36c0.html

[47] Some scholars disagree with health's role in solving social problems, arguing instead that health should be "the ability to adapt and self-manage in the face of social, physical, and emotional challenges." They argue this definition: (1) takes into account evolving epidemiological issues, (2) reduces the potential of normative expectations being framed within health's goals to exploit health for the sake of political aims, and (3) eliminates the potential ethical problem of resource allocation in working to ensure every citizen reaches complete health per the WHO's 1946 definition, which remains the official definition to date. *See* Machteld Huber et al., "How should we define health," *BMJ* 343 (2011): d4163; Nobile, "The WHO Definition of Health," 35-37; Jonathan M. Mann et al., "Health and Human Rights," in *Health and Human Rights in a Changing World,* ed. Michael A. Grodin, Daniel Tarantola, George J. Anna, and Sofia Grufskin (New York: Routledge, 2013), 16.

[48] WHO, *The Right to Health*, 1.

international culture of health as a human right, providing external affirmations; but it is in dire need of international accountability to bolster its internal actions.

Over the years, the UN has provided clarification to the right to health, articulating those services and norms that fall under the right and the misconceptions that have traditionally created obstacles to actualizing the right. Regarding inclusions, the international right to health includes access to care and facilities alongside "underlying determinants of health" that promote overall wellbeing and participation in society; freedoms from "non-consensual medical treatment"; entitlements to equal and timely access to and opportunities for care, disease control, access to necessary medicines, reproductive care, health education, and participation in local and national health-related decisions without any form of discrimination.[49]

The UN addresses three important misconceptions: "The right to health is NOT the same as the right to be healthy"; "The right to health is NOT only a programmatic goal to be attained in the long term"; and, "A country's difficult financial situation does not absolve it from having to take action to realize the right to health."[50] States are not meant to guarantee citizens' *good* health because good health requires a level of personal responsibility. However, States are meant to guarantee *access to* health because access is intimately connected to underlying determinants that are under States' control and contribute to the "highest attainable standard" of health. These underlying determinants

[49] WHO specifically defines underlying determinants of health as, "the factors and conditions which protect and promote the right to health beyond health services, goods and facilities." *See* WHO, *The Right to Health*, 3-5.

[50] WHO, *The Right to Health*, 5.

also require consistent engagement from States, including immediate and long-term goals.

> In fact, States must make every possible effort, within available resources, to realize the right to health and to take steps in that direction without delay. Notwithstanding resource constraints, some obligations have an immediate effect, such as the undertaking to guarantee the right to health in a non-discriminatory manner, to develop specific legislation and plans of action, or other similar steps towards the full realization of this right, as is the case with any other human right. States also have to ensure a minimum level of access to the essential material components of the right to health, such as the provision of essential drugs and maternal and child health services.[51]

The immediate and long-term nature of actualizing the right to health must occur regardless of the number of resources a State has. Whatever the constraints, States must work towards the right to health because its existence and thriving are interdependent upon all other rights. Therefore, by violating the right to health the U.S. violates all other human rights because "human rights violations have health impacts. [Jonathan Mann proposes] that all rights violations, particularly when severe, widespread, and sustained, engender important health effects, which must be recognized and assessed."[52] Conversely, by promoting the right to health the U.S. promotes all other human rights.

Returning again to Luna's domestication of rights and the sociological conclusion that a human rights framework also requires relationality, an important consequence of the interdependence of rights is the evaluation of health disparities. Through this lens, U.S. health disparities can no longer be understood merely as "questions of quality care,"

[51] WHO, *The Right to Health*, 5.

[52] Mann, "Health and Human Rights," 19.

but instead must be engaged as "fundamental matters of democracy and social justice."[53] As a matter of democracy, actualizing the right to health "implies providing individuals and communities with an authentic voice in decisions defining, determining, and affecting their well-being."[54] This connection between health and democratic values demands both that health resources are distributed equally and equitably across the nation's diverse population, and that research on health-resource allocation take full account of its relation to policies and laws, as well as health impact. Focusing on health impact alone obscures the direct links among laws, policies, and impacts.

Interconnectedness of the Need for Redressal

Considering the ample resources in the U.S., the nation has the ability to revolutionarily actualize the right to health for all citizens, further eliminating the ongoing history and presence of health disparities. The most critical step is to overcome discrimination within the healthcare system. The previously narrated history of U.S. health disparities reveals the ongoing impact of discrimination reverberating through all facets of healthcare, ultimately resulting in the violation of the right to health because of the many structural inequalities with which poor communities, women, and communities of color continue to grapple.

Because these communities have borne "a disproportionate share of health problems," the U.S. must engage the human rights principles of non-discrimination and equality to eliminate discriminatory practices in healthcare and policy as well as

[53] Yamin, "The Right to Health Under International Law," 1156.

[54] Yamin, "The Right to Health Under International Law," 1157.

"recognize and provide for the differences and specific needs of groups that generally face particular health challenges, such as higher mortality rates or vulnerability to diseases."[55] Specific demographics, such as birthing people and people of color, require correspondingly specific health metrics that attend to their physiological needs. Marginalized groups require positive health protections to overcome centuries of medical and social abuse. The clarity of universal human inclusion in the right to health means that "there is no justification for the lack of protection of vulnerable members of society from health-related discrimination, be it in law or in fact. So even if times are hard, vulnerable members of society must be protected."[56] To live up to the obligation to protect vulnerable populations, the UN suggests States should "disaggregate their health laws and policies and tailor them to those most in need of assistance rather than passively allowing seemingly neutral laws and policies to benefit mainly the majority groups."[57] Such an act would greatly benefit marginalized communities in the U.S. considering their care continues to be rooted in health practices and laws carrying the legacy of legal discriminatory practices. Disaggregation goes further by decentering the always-affirmed personhood of dominant communities and making space for the historically rejected personhood of marginalized communities and their health needs.

Women

[55] WHO, *The Right to Health*, 7.

[56] WHO, *The Right to Health*, 8.

[57] WHO, *The Right to Health*, 11.

Women, for example, can experience the same diagnoses as men but the experience of those diagnoses differs.[58] It is important to consider several underlying determinants of health that compound the differing diagnostic experience. In the U.S., women across nearly all races and ethnicities live in higher rates of poverty than men, with approximately ten million women living in deep poverty.[59] Sexism and racism have social and institutional effects that "limit the employment opportunities available to women, availability of caregiving supports, [and] access to public social assistance programs…leading to higher rates of poverty among women, particularly women of color, compared to men."[60]

[58] Alyson McGregor describes this phenomenon through the example of coronary artery disease. "Coronary artery disease is the leading cause of death in both men and women. Due to the typical patient with heart disease being male, the diagnostic workup has been focused on large coronary artery disease obstruction. Recent evidence has demonstrated that symptoms of angina in women may represent microvascular disease, a diffuse narrowing and abnormal vasomotor regulation of the smaller arteries. Safdar et al support the need for novel sex-specific diagnostic algorithms that detect both coronary artery disease and microvascular disease, as current standard testing in emergency departments does not include screening for or detection of microvascular disease as a potential cause of chest pain. We cannot expect to improve the gap in mortality between the sexes, with women having poorer postinfarction outcomes and higher mortality than men, without a greater understanding of alternate forms of disease." *See* Alyson J. McGregor, "The Impact Sex Differences Research Can Have on Women's Health," *Clinical Therapeutics* 38, no. 2 (2016): 238; Jean C. McSweeny et al., "Women's Early Warning Symptoms of Acute Myocardial Infarction," *Circulation* 108 (2003): 2619-2623; Basmah Safdar et al., "Microvascular Dysfunction as Opposed to Conduit Artery Disease Explains Sex-specific Chest Pain in Low to Moderate Risk Emergency Department Patients," *Clin Ther* 38, no. 2 (2016): 240-253.

[59] Black women, Latinas, and American Indian or Alaska Native women represent disproportionate statistics of women in poverty. "While Latinas represent 18.1 percent of all women in the U.S. population, they constitute 27.1 percent of women in poverty. Similarly, Black women represent 22.3 percent of women in poverty but make up only 12.8 percent of all women in the U.S. population." *See* Robin Bleiweis et al., "Fact Sheet: The Basic Facts About Women in poverty," Center for American Progress, last modified August 3, 2020, https://www.americanprogress.org/article/basic-facts-women-poverty/

[60] Bleiweis, "Fact Sheet."

Women on average earn less wages than men, "are less likely to have the savings and wealth necessary to weather financial shocks and provide for themselves and their families throughout their lifetimes," and are often segregated into low-wage jobs due to undervaluing traditional women's labor as low-skilled.[61] Gender stereotypes aside, the U.S. provides inadequate public supports such as child care, unemployment insurance, and other support resources for people with disabilities and victims of domestic violence, a significant portion of which are women. Such underlying determinants can have adverse effects on women's health and health decision-making, resulting in them facing particular issues and forms of discrimination within and beyond healthcare systems. Working toward the immediate and long-term elimination of discrimination and bettering the provision of social supports that help women achieve the highest attainable standard of health are integral to the U.S. fulfilling health as a human right.

According to Article 12 of the Convention on the Elimination of all Forms of Discrimination against Women (CEDAW),

1. States Parties shall take all appropriate measures to eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, access to health care services, including those related to family planning.
2. Notwithstanding the provisions of paragraph I of this article, States Parties shall ensure to women appropriate services in connection with pregnancy, confinement and the post-natal period, granting free services where necessary, as well as adequate nutrition during pregnancy and lactation.[62]

[61] Bleiweis, "Fact Sheet."

[62] UN General Assembly, *Convention on the Elimination of All Forms of Discrimination Against Women*, 18 December 1979, United Nations, Treaty Series, vol. 1249, p. 13, available at: https://www.refworld.org/docid/3ae6b3970.html

Not only does CEDAW grant equal value between men's and women's lives, a consequence of Article 12's focus on women's health is that "every woman has the right to a safe pregnancy, delivery and post-natal outcome, and access to emergency obstetric care should she develop complications."[63] Protecting women's right to health also requires protecting other fundamental rights promoting equality because women must have equal and protected access to employment, as well as equal pay for equal work. Women must have equal access to education and information, especially health information considering the different ways women experience diagnoses than men.

Because of the U.S.'s protection of first-generation civil rights, women do have their rights to political participation protected; however, the political arena must better permit and respect women's full rights to health access. The recent Supreme Court decision overturning *Roe v. Wade* and *Casey v. Planned Parenthood* signals that the connection between women's physical and psychological health reflects "the poor health of women's rights in the body politic and in influential community institutions, whether political, economic, religious, or health care."[64] This reflection requires attention to all rights that help health-disparate communities experience improved access to health care, including reproductive and gender-affirming care. The intersection of women's care also reveals the complexity of the U.S.'s needed shift from merely a commitment to human

[63] Helen de Pinho, "On the 'Rights' Track: The Importance of a Rights-Based Approach to Reducing Maternal Deaths," in *Health and Human Rights in a Changing World,* ed. Michael A. Grodin, Daniel Tarantola, George J. Anna, and Sofia Grufskin (New York: Routledge, 2013), 437.

[64] *Dobbs v. Jackson Women's Health Organization* 597 U.S. (2022); Rebecca J. Cook, "Gender, Health and Human Rights," in *Health and Human Rights in a Changing World,* ed. Michael A. Grodin, Daniel Tarantola, George J. Anna, and Sofia Grufskin (New York: Routledge, 2013), 348.

rights to the revolutionary enactment of policy and culture changes that help achieve health as a human right.

In the case of reproductive health, "[it] is particularly harder because it is often the states that are responsible for violating women's rights in general."[65] In the U.S., reproductive health violations are most apparent as seen through the nation's maternal mortality statistics, which will be explored in more detail in the fourth chapter. By adopting a human rights framework over the current neo-liberal medical approach that has been in effect for several decades, the U.S. will stop viewing health and its delivery as a commodity exchanged in the capitalist market and begin understanding "the dynamics of power at work in structuring health outcomes, in this instance maternal health, and make visible the connections between poverty, discrimination, inequality and health."[66] Through engagement with the multiple stakeholders involved in health care delivery (*e.g.*, non-governmental agencies, research centers, local communities), the U.S. can intentionally identify and eliminate the power structures that have historically threatened communities' right to health. If elimination is not possible, the U.S. must rearrange the power structures to ensure equitable care to those historically marginalized communities, "offering a counter to the decades of systematic undermining of health services."[67] A necessary step to achieving a redistribution of power is the adoption of the

[65] Sara E. Davies, "Reproductive Health as a Human Right: A Matter of Access or Provision?," in *Health and Human Rights in a Changing World,* ed. Michael A. Grodin, Daniel Tarantola, George J. Anna, and Sofia Grufskin (New York: Routledge, 2013), 394.

[66] de Pinho "On the 'Rights' Track," 437.

[67] de Pinho "On the 'Rights' Track," 437.

human rights values of transparency, nondiscrimination, accountability, and equity. These guiding values influence health policies that attend to formal mechanisms of accountability and have the capacity to address human rights violations to health.

To promote accountability in the face of poor reproductive, maternal, and sexual health delivery, just as the U.S. collects data on reproductive health indicators through the Centers for Disease Control and Prevention (CDC), the UN High Commissioner for Human Rights (OHCHR) collects similar data on a global scale to gauge nations' performance, which ensures transparency in helping women achieve their highest attainable standard of health.[68] The UN's reproductive health data-gathering model considers process and outcomes, and "focuses on implementation of relevant human rights treaties (structure), coverage of reproductive needs and maternal care (process), and infant/perinatal/maternal mortality rate (outcome)," featured in the below table.[69] This framework is a critical step towards an equitable health system that does not discriminate against any woman pursuing health services and the fulfillment of their fundamental rights.

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[68] Davies, "Reproductive Health as a Human Right," 402.

[69] Several countries have successfully adopted this rights-based framework to enhance relationships between the government, local communities, and health partners, resulting in drastic improvements in the areas of maternal, reproductive, and sexual health. Malawi implemented an integrated health plan—Road Map to Reduce Maternal Mortality—focused on increasing access to basic obstetric care, improved health worker training and health care infrastructure, enhanced drug and supply procurement, and a stronger referral system for various levels of care. Malawi, Mozambique, and Tanzania strengthened trainings for non-physician clinicians in rural communities in the delivery of emergency obstetric care, decreasing maternal deaths in remote regions of the countries. Sri Lanka and Mozambique adopted the processes of the sexual and reproductive health instrument, improving their international metrics in data reporting to the OHCHR. *See* Davies, "Reproductive Health as a Human Right," 402; de Pinho "On the 'Rights' Track," 438; OHCHR and World Health Organization (WHO), *Human rights, health and poverty reduction strategies: Health and Human Rights Publication Series*, (Geneva, Switzerland: OHCHR, 2008), 5.

Table 25.1 Sexual and reproductive health (OHCHR 2008: 25)[70]

Structural	• International human rights treaties, relevant to the right to enjoyment of the highest attainable standard of physical and mental health (right to health), ratified by the State. • Date of entry into force and coverage of the right to health in the Constitution or other forms of superior law. • Date of entry into force and coverage of domestic laws for implementing the right to health, including a law prohibiting female genital mutilation. • Number of registered and/or active nongovernmental organizations (per 100,000 persons) involved in the promotion and protection of the right to health. • Estimated proportions of births, deaths, and marriages recorded through vital registration system. • Time frame and coverage of national policy on sexual and reproductive health. • Time frame and coverage of national policy on abortion and fetal sex determination.
Process	• Proportion of received complaints on the right to health investigated and adjudicated by the national human rights institution, human rights ombudsperson, or other mechanism and the proportion of these responded to effectively by the government. • Net official development assistance (ODA) for the promotion of health sector received or provided as a proportion of public expenditure on health or Gross National Income.* • Proportion of births attended by skilled health personnel. * • Antenatal care coverage (at least one visit and at least four visits). * • Increase in proportion of women of reproductive age using, or whose partner is using, contraception (COR). * • Unmet need for family planning. * • Medical terminations of pregnancy as a proportion of live births. • Proportion of reported cases of genital mutilation, rape, and other violence restricting women's sexual and reproductive freedom responded to effectively by the government.
Outcome	• Proportion of live births with low birth weight. • Perinatal mortality rate. • Maternal mortality ratio. *

[70] OHCHR and World Health Organization (WHO), *Human rights, health and poverty reduction strategies*, 5.

International instruments like the sexual and reproductive health framework not only allow women to achieve health access inclusive of sexual and reproductive care, but the instrument aids health systems in strengthening their health delivery access in the forms of treatment and health data. This is an essential step to ensure the right to health is realized in tangible ways through health services. These systemic evolutions demonstrate to U.S. citizens and international partners that the U.S. "is conducting its own evaluations to ensure public health services are being delivered and directed according to greatest public need."[71] Thus, nondiscriminatory access to and provision of care is established as the right to health becomes progressively realized for marginalized communities through "a comprehensive national health plan, a published national list of essential medicines, a national workforce strategy, or government expenditure on health per person above the minimum required."[72]

Communities of Color

Chapter one thoroughly addressed the discrimination and generational health disparities and inequities faced by racial and ethnic communities in the U.S. dating back prior to the nation's inception. The ongoing prevalence of these disparities for the past six decades has been a moral and legal violation of the right to health of U.S. communities of

[71] Davies, "Reproductive Health as a Human Right," 403.

[72] Davies, "Reproductive Health as a Human Right," 403; Gillian Backman et al., "Health systems and the right to health: An assessment of 194 countries," *The Lancet* 372 (2008): 2077.

color because the U.S. is a cosigner to the International Convention on the Elimination of all Forms of Racial Discrimination (CERD).[73]

Per Article 5, section e,[74]

[73] On December 16, 2009, the U.S. Subcommittee on Human Rights and the Law convened to discuss the state of human rights implementation in the U.S. That meeting was "the first ever congressional hearing on U.S. compliance with our human rights treaty obligations." Having played a critical role in the development of international rights instruments and Congress's passage of legislation to implement the international treaties, the committee celebrated important wins but also acknowledged losses. Congress has not, then nor now, "held a single hearing on U.S. compliance with human rights treaties that we have ratified." While the U.S. has submitted obligatory periodic reports to the UN since the mid-1990's, the nation has often "been tardy in submitting its reports, and it certainly has not provided detailed information." The U.S.'s recent turn towards submitting reports and taking very slow steps towards compliance with international treaties has sustained an atmosphere in which rights violations have occurred without redress for decades. Because Congress has not held hearings to attend to CERD violations, despite UN concerns and recommendations, citizens have disproportionately carried the burden of pursuing accountability domestically.

The 2009 meeting discussed all international treaties that should be upheld in the U.S. In relation to CERD, numerous concerns were raised including health. The "CERD Working Group on Health and Environmental Health submitted a shadow report entitled *Unequal Health Outcomes in the United States* (January 2008), which outlined the racial and ethnic disparities in U.S. health care and highlighted the fact that such disparities in health outcomes 'are caused not only by structural inequities in our health care systems, but also by a wide range of social and environmental determinants of health.' The report found that many government policies continue to create and perpetuate health disparities and have failed to address the problems both through the health care system and through environmental justice. Key problems in government policy exist in the areas of monitoring and enforcement of racial disparities; failure to protect racial and ethnic minorities from disproportionate environmental burdens; ongoing government policies that restrict health care access; including the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 and the Deficit Reduction Act of 2005; unequal access to sexual and reproductive rights for women of color; and genetic discrimination."

Recommendations to become compliant with CERD included increasing insurance coverage and reducing obstacles to achieving adequate health (*e.g.*, providing equitable distribution of health resources, improving public health services heavily accessed by minorities, collecting better data on health disparities "disaggregated by age, gender, race, ethnic or national origin") for racial and ethnic minorities; "strengthening civil rights agencies' investigative capacities in the area of racial or ethnic disparities in health and applying Title VI to those parts of Medicare not currently covered"; and, addressing environmental "factors that affect the health and well-being of underserved communities and communities of color." *See* "The law of the land: U.S. implementation of human rights treaties: hearing before the Subcommittee on Human Rights and the Law of the Committee on the Judiciary," United States Senate, One Hundred Eleventh Congress, first session, December 16, 2009, (2010): [i]-484.

[74] Article 2 of CERD states, "1. States Parties condemn racial discrimination and undertake to pursue by all appropriate means and without delay a policy of eliminating racial discrimination in all its forms and promoting understanding among all races, and, to this end: (a) Each State Party undertakes to engage in no act or practice of racial discrimination against persons, groups of persons or institutions and to

In compliance with the fundamental obligations laid down in article 2 of this Convention, States Parties undertake to prohibit and to eliminate racial discrimination in all its forms and to guarantee the right of everyone, without distinction as to race, colour, or national or ethnic origin, to equality before the law, notably in the enjoyment of the following rights:

(a) The right to equal treatment before the tribunals and all other organs administering justice;

(b) The right to security of person and protection by the State against violence or bodily harm, whether inflicted by government officials or by any individual group or institution;

(c) Political rights, in particular the right to participate in elections-to vote and to stand for election-on the basis of universal and equal suffrage, to take part in the Government as well as in the conduct of public affairs at any level and to have equal access to public service;

(e) Economic, social and cultural rights, in particular:

(i) The rights to work, to free choice of employment, to just and favourable conditions of work, to protection against unemployment, to equal pay for equal work, to just and favourable remuneration;

(ii) The right to form and join trade unions;

(iii) The right to housing;

(iv) The right to public health, medical care, social security and social services;

(v) The right to education and training

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ensure that all public authorities and public institutions, national and local, shall act in conformity with this obligation;

(b) Each State Party undertakes not to sponsor, defend or support racial discrimination by any persons or organizations;

(c) Each State Party shall take effective measures to review governmental, national and local policies, and to amend, rescind or nullify any laws and regulations which have the effect of creating or perpetuating racial discrimination wherever it exists;

(d) Each State Party shall prohibit and bring to an end, by all appropriate means, including legislation as required by circumstances, racial discrimination by any persons, group or organization;

(e) Each State Party undertakes to encourage, where appropriate, integrationist multiracial organizations and movements and other means of eliminating barriers between races, and to discourage anything which tends to strengthen racial division.

2. States Parties shall, when the circumstances so warrant, take, in the social, economic, cultural and other fields, special and concrete measures to ensure the adequate development and protection of certain racial groups or individuals belonging to them, for the purpose of guaranteeing them the full and equal enjoyment of human rights and fundamental freedoms. These measures shall in no case entail as a consequence the maintenance of unequal or separate rights for different racial groups after the objectives for which they were taken have been achieved." *See* UN General Assembly, *International Convention on the Elimination of All Forms of Racial Discrimination*, 21 December 1965, United Nations, Treaty Series, vol. 660, p. 195, available at: https://www.refworld.org/docid/3ae6b3940.html

Through signing CERD, the U.S. has agreed to address racial and ethnic discrimination and completely eradicate its presence. This responsibility is held at all levels of government, but "the ultimate accountability for state and local law and policy resides with the federal government under international law. Thus, when state or local governments fail to eliminate health disparities, the federal government cannot divest itself of final responsibility."[75] Racial discrimination in healthcare is another prime example of the interconnection of all fundamental human rights. Because discrimination can be seen across multiple underlying determinants of health, racial discrimination and health disparities must be examined as a social justice issue resulting in racial and ethnic minorities experiencing violations of multiple human rights.

Since 1994, UN Special Rapporteurs have called the U.S. to fulfill its responsibility to address "sociological inertia, structural obstacles and individual resistance hindering the emergence of a truly integrated society based on the equal dignity of the American nation."[76] The Special Rapporteurs further argued that, "when persons from ethnic minorities aspire to equal treatment, they are not asking for favours, but seeking to enjoy the rights guaranteed by the United States Constitution in their daily lives."[77] Without fulfilling this responsibility and upholding discriminatory cultures, the

[75] Yamin, "The Right to Health Under International Law," 1158.

[76] Yamin, "The Right to Health Under International Law," 1159.

[77] Yamin, "The Right to Health Under International Law," 1159; *Implementation of the Programme of Action for the Second Decade to Combat Racism and Racial Discrimination, Report of Mr. Maurice Glele-Ahanhanzo, Special Rapporteur on Contemporary Forms of Racism, Racial Discrimination, Xenophobia and Related Intolerance on His Mission to the United States of America from 9 to 22 October 1994* (Geneva, Switzerland: United Nations, 2005); *Interim Report of Paul Hunt, Special Rapporteur of the Commission on Human Rights* (New York, NY: United Nations, 2003).

U.S. will continue grappling with negative consequences impacting the health of the nation. The nation will also continue implicitly maintaining poor health outcomes among communities historically burdened by the government's inaction and regulatory failure and will fail to live into a fully moral, inclusive, and accountable identity that it demands from other nations.

There are several ways the U.S. has avoided accountability by CERD, including the nation's delayed ratification of the treaty almost thirty years after signing it, 1994 and 1966 respectively. Once the treaty was ratified in 1994, the U.S. made several reservations, understandings, and declarations. The nation "would not accept any obligation under ICERD to restrict U.S. freedom of speech, expression, and association. The United States further asserted that, to the extent ICERD seeks to regulate private conduct in a stricter manner than what already exists under U.S. law, the United States would not be obliged to take any such measures."[78] These caveats "reflect a posture that U.S. law prevails over multilateral, negotiated international human rights treaties, even if the treaty in question provides broader protections against racial discrimination."[79] This posture is reflected in the U.S.'s final reservation, "which provides that the treaty is non-self-executing [preventing] litigants from bringing independent ICERD claims into U.S.

[78] Maya K. Watson, "The United States' Hollow Commitment to Eradicating Global Racial Discrimination," *Human Rights Magazine* 44, no. 4 (2020): 19. https://www.americanbar.org/groups/crsj/publications/human_rights_magazine_home/black-to-the-future-part-ii/the-united-states--hollow-commitment-to-eradicating-global-racia/.

[79] Watson, "The United States' Hollow Commitment to Eradicating Global Racial Discrimination," 19.

courts. U.S. citizens cannot bring a claim into a U.S. court solely alleging that ICERD provisions have been violated, unless that claim also implicates a U.S. law."[80]

This reservation is detrimental to marginalized communities pursuing accountability, especially health-disparate communities doubly marginalized by systemic racism and poor health. Whereas self-executing treaties are weighed similarly to domestic law, and therefore enforceable across the U.S. judicial system, non-self-executing treaties cannot be enforced domestically. Many requests have been made to the U.S. to grant ICERD legal effectiveness, especially given the more inclusive way ICERD defines racial discrimination, but no such legislation has been enacted.[81] The U.S. has argued "its laws already provide comprehensive protections against discriminatory conduct. The United States further explained that racial discrimination can be addressed both by U.S.

[80] Watson, "The United States' Hollow Commitment to Eradicating Global Racial Discrimination, 19.

[81] "ICERD permits individuals to file a complaint against a State Party after local remedies have been exhausted, if the State recognizes the competence of the ICERD Committee to hear the case. Individual complaints are optional, and States must agree to submit themselves to such claims. The Russian Federation, South Africa, France, Brazil, Germany, and Hungary all permit the Committee to hear individual complaints. The United States has not agreed to do so. The United States argues that U.S. law already provides adequate opportunities to remedy racial discrimination. But U.S. laws do not go as far as ICERD mandates. Permitting the ICERD Committee to hear individual complaints will provide marginalized individuals with opportunities to voice how unaddressed racial and ethnic discrimination has affected them. As ICERD requires that local remedies be exhausted first, U.S. judicial means and administrative agencies must still be the routes of first resort. The ICERD complaint mechanism will only be used where U.S. racial discrimination laws fall short. To fully embrace ICERD, the United States should recognize the Committee's competence to hear individual complaints." *See* Watson, "The United States' Hollow Commitment to Eradicating Global Racial Discrimination," 20.

constitutional and statutory law, including the Equal Protection Clause and the Civil Rights Act of 1964."[82]

Another way the U.S. has avoided ongoing accountability is the infrequent sharing of data on discrimination. Periodically, the U.S. is meant to send a report to a UN monitoring body that assesses the country's progress towards the elimination of all forms of racial discrimination. The UN remains concerned with the persistent disparities experienced by marginalized communities in the U.S. and continues to encourage the nation to implement positive and negative measures to better protect the right to health for racial and ethnic minorities.[83] CERD's acknowledgement of ongoing, solvable obstacles to the right to health in the U.S. underlines the necessity of national accountability on the international stage. Without international accountability, the health system will continue to neglect the human rights-based need for "governmental accountability for redress, as well as for improved collection, analysis, and dissemination of appropriately disaggregated data that permits the detection of disparities and potential

[82] ICERD's definition of racial discrimination, "does not require proof of discriminatory intent; if a policy's impact is disparate, then it is discrimination under ICERD. Unlike ICERD, U.S. law, generally, requires that racial discrimination claims prove discriminatory intent. Disparate impact often will not suffice. Consequently, the burden of proof for legal claims of discrimination in the United States is difficult to satisfy, making remedies for racial discrimination rare. Given that ICERD offers broader protections against racial discrimination, the U.S. government should enact legislation to fully implement the treaty domestically." *See* Watson, "The United States' Hollow Commitment to Eradicating Global Racial Discrimination," 20.

[83] Because the U.S. does not report to the Committee on Racial Discrimination regularly, UN comments are infrequent. But themes remain consistent since 2001 given the ongoing prevalence of health disparities based on domestic data. *See* United Nations, "Concluding observations of the Committee on the Elimination of Racial Discrimination: United States of America," *CERD 59th Session,* A/56/18, paras. 380-407, 2001.

discrimination."[84] A practical step towards achieving accountability can include the expansion of domestic health departments that report health disparities data to local civil rights departments, who in turn annually submit data to the Civil Rights Division of the Department of Justice to ensure regular and accurate reporting to the UN.

Poor Communities

Article 25 of the UDHR follows rights outlined for workers and universalizes the idea that there is a base line of socioeconomic wellbeing under which no person should fall. Food, clothing, housing, social services, and medical care are all social determinants of health to be promoted by States to ensure adequate health and wellbeing for their citizenry. Yet, these rights remain inaccessible for a significant portion of the U.S. population. For example, healthcare remains expensive for many U.S. citizens, including those receiving insurance coverage from employers (due to economic fluctuations). The COVID-19 pandemic shed a stark light on the disparities faced by economically fragile communities.

Throughout the COVID-19 pandemic, approximately ten million Americans lost employer-sponsored health insurance due to vocational layoffs.[85] Many of these people limited their pursuit of necessary medical services as a consequence of limited or

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[84] Yamin, "The Right to Health Under International Law," 1159.

[85] "The Importance of Universal Health Care in Improving Our Nation's Response to Pandemics and Health Disparities," Universal Health Care, last modified October 24, 2020, https://www.apha.org/policies-and-advocacy/public-health-policy-statements/policy-database/2021/01/14/the-importance-of-universal-health-care-in-improving-response-to-pandemics-and-health-disparities.

nonexistence insurance coverage. Although the U.S.'s neoliberal society attempts to diminish its reality, poverty remains a prime obstacle to health and wellbeing. As of 2021, the official poverty rate in the U.S. was 11.6% or 37.9 million people.[86] Almost half of this population is in deep poverty, "living in a household with a total cash income below 50 percent of its poverty threshold."[87] For these communities, every international obligation the U.S. steps back from places more burden on local communities to fill the gap in the absence of international accountability.

Opportunities for Moral Repair Using a Rights Framework

Keeping in mind the health research of WHO, the obligations of the U.S. as a cosigning state to the International Bill of Rights, and the adoption of a human rights framework rooted in personhood, there are large and small opportunities available to begin the long process of moral repair for health-disparate communities. Further, the U.S.'s participation in upholding universal fundamental rights around the world binds the nation to the progressive realization of the right to health for all its citizens using domestically available resources, as well as "those available from the international community through international cooperation and assistance as outlined in article 2 (1)."[88] The UDHR, ICESCR, CEDAW, and CERD are additional international

[86] "What Is 'Deep Poverty'?," Center for Poverty and Inequality Research, last modified December 14, 2022, https://poverty.ucdavis.edu/faq/what-deep-poverty.

[87] "What Is 'Deep Poverty'?"

[88] Article 2 (1) refers to the ICESCR, "Each State Party to the present Covenant undertakes to take steps, individually and through international assistance and co-operation, especially economic and technical, to the maximum of its available resources, with a view to achieving progressively the full realization of the rights recognized in the present Covenant by all appropriate means, including particularly

instruments providing structure and guidance on the treatment of citizens and the actualization of their human rights. Returning to Zakiya Luna's restrictive vs. revolutionary domestication of rights framework, by shifting from restrictive to revolutionary domestication, the U.S. can appropriately utilize international resources to promote second generation human rights that accompany granted civil rights and attend more directly to institutions and structures to provide improved, equal, and non-discriminatory determinants of health.

On a moral and philosophical level, by adopting and engaging a human rights framework, the U.S. recognizes the inherent dignity and personhood of all citizens. The government's adoption of a dignity-affirming culture is a logical step towards reshaping health policy given, "provision of health care has in most developed countries become more and more a central concern of our political institutions, with governments playing a significant role in regulating and facilitating the provision of health care, in many countries even largely organizing it."[89] Social interactions, laws, and policies informed by the recognition of human dignity would critically change the trust that marginalized communities have in the systems meant to protect them. Health-disparate communities could begin seeking consistent care from healthcare institutions knowing their personhood was valued and their rights protected based on the important social changes

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the adoption of legislative measures." *See* WHO, *The Right to Health*, 23; UN General Assembly, *International Covenant on Economic, Social and Cultural Rights*, 16 December 1966, United Nations, Treaty Series, vol. 993, p. 3, available at: https://www.refworld.org/docid/3ae6b36c0.html.

[89] Brännmark, "Respect for Persons in Bioethics," 172.

previously taken to center dignity as exemplified in the WHO Constitution, UDHR, and subsequent international instruments.

Beginning with dignity would also shift the practices of third-party and non-governmental agencies who are increasingly assuming the responsibilities of local governments. In healthcare for example, "biomedical research institutions, health insurance companies, health management organisations, the pharmaceutical industry, and care providers" have minimal oversight and poor monitoring.[90] As these agencies continue serving alongside government-sponsored hospitals to expand healthcare infrastructure, the U.S. must maintain ethical requirements rooted in dignity and human rights that frame their actions, research, and health involvement with communities and individuals.

Currently in the U.S., few to no "objective measures are available of the commitment and capacity of governments to ensure that actions taken by the private sector and other players, including civil society, are informed by and comply with human rights."[91] The UN provides methodologies for capturing this data that respects dignity and the right to health. Because human rights can enhance the work of health practitioners, health educators, and policy creators, the nation needs to take seriously the use of UN-approved methodologies and tailor them to the diversity of the U.S. to gain important data on the efficacy of health strategies rooted in human rights. This data could

[90] Sofia Grufskin et al., "History, Principles and Practice of Health and Human Rights," in *Health and Human Rights in a Changing World,* ed. Michael A. Grodin, Daniel Tarantola, George J. Anna, and Sofia Grufskin (New York: Routledge, 2013), 38.

[91] Grufskin, "History, Principles and Practice of Health and Human Rights," 38.

then inform research agendas to refine monitoring and evaluating tools to better understand the relationship between health and human rights domestically. The agenda can further identify health norms and violations that impact health inequities and disparities across communities. For those existing methods and indicators that exist in the U.S. but are underutilized, they must be refined by international tools to better understand how successful clinical and public health interventions are for communities and their human rights. If interventions need to be altered, refined tools will allow us "to develop an evidence base that shows the value of attention to rights for health as well as the negative effects on health of both grievous and subtle human rights violations."[92]

This need becomes increasingly imperative as health practices shift based on cultural norms and constraints. Sofia Grufskin and her coauthors importantly assert that even if the U.S. commits to "respect for human rights, health workers need to be educated about how to incorporate human rights principles into their work, and this should be done equally at schools of medicine, schools of public health, and nursing schools."[93] By adopting the revolutionary domestication of human rights articulated by Zakiya Luna, wider educational initiatives can be undertaken to educate professionals and the larger populace on their dignity-informed rights, how those rights are meant to be protected, the instruments and processes available to protect fundamental rights, and the ways the U.S. can better participate globally to enhance domestic and international collaboration.

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[92] Paul Hunt and Gunilla Backman, "Health Systems and the Right to the Highest Attainable Standard of Health*," in *Health and Human Rights in a Changing World,* ed. Michael A. Grodin, Daniel Tarantola, George J. Anna, and Sofia Grufskin (New York: Routledge, 2013), 73.

[93] Grufskin, "History, Principles and Practice of Health and Human Rights," 38.

Upon affirming human dignity, the U.S. must provide clarity on the normative obligations to protect citizens' rights. Once obligations are clarified, then violations can be understood, and reparative actions can be taken, all occurring in an iterative relationship that considers the process to achieve the right to health and all outcomes as the right is increasingly actualized. Even if the widespread belief is correct that communities experiencing poor health have made intentional choices leading to these negative health outcomes (and in fact this is a highly complex question), "just as society provides defense counsel to criminal defendants, who arguably may have exercised poor choices, so too would the state have an obligation to ensure access to health facilities, goods, and services", all of which are normative protections under the right to health.[94] Understanding norms and violations, processes and protections expands the function of health in the U.S. beyond the basic functioning of the health system to *how* the health system functions, with the ideal being towards transparency, equality, respect for cultures, and nondiscrimination.[95]

A healthcare system that represents the aforementioned ideals can practically be composed of "an appropriate mix of primary (community-based), secondary (district-based), and tertiary (specialized) facilities and services, providing a continuum of prevention and care."[96] Health workers will also have the knowledge necessary to know

[94] Yamin, "The Right to Health Under International Law," 1157.

[95] Hunt and Backman, "Health Systems and the Right to the Highest Attainable Standard of Health*," 64.

[96] Hunt and Backman, "Health Systems and the Right to the Highest Attainable Standard of Health*," 67.

how and when to transfer patients to different levels of care and communities will have the necessary resources to maintain good quality facilities. The interconnectedness of rights and underlying determinants of health also requires coordination between departments that are directly and indirectly linked to health, "such as health, environment, water, sanitation, education, food, shelter, finance, and transport", all informed by effectively functioning policy and delivery.[97]

Alongside clarity on norms and violations, the U.S. should adopt "a national strategy to ensure to all the enjoyment of the right to health, based on human rights principles which define the objectives of that strategy. Setting indicators and benchmarks will be decisive in the formulation and implementation of such a strategy."[98] The UN has developed a methodological framework to measure disaggregated indicators that capture various dimensions of the right to health. Such a methodology helps to,

> assess the steps taken by a State in meeting its obligations—from acceptance of international human rights standards (structural indicators) to efforts being made by the State to meet the obligations that flow from these standards (process indicators), on to the results of those efforts from the perspective of the population (outcome indicators). Indicators that illustrate the right to the highest attainable standard of health are, for instance, the number of international human rights treaties relevant to the right to health that the State has ratified (structural indicator), the proportion of births attended by skilled health personnel (process indicator) and maternal mortality ratio (outcome indicator). It is also crucial that indicators be disaggregated by relevant population group and possible ground of discrimination.[99]

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[97] Hunt and Backman, "Health Systems and the Right to the Highest Attainable Standard of Health*," 68.

[98] WHO, *The Right to Health*, 24.

[99] WHO, *The Right to Health*, 24-25.

While the ICESCR alludes to the difficulties in maintaining the right to health, cosigning nations are still bound to a minimum obligation to providing the minimum amount of essential access to health. This minimum obligation is rooted in the philosophical obligations to: respect the right and not interfere in citizens accessing health services, protect citizens and their right from private sector interference, and fulfill the right through domestic legislative and administrative measures.[100]

An important opportunity for the U.S. is the effective implementation of universal health care as outlined in and adopted by the 2019 UN General Assembly resolution. The U.S. is a member state that signed this resolution which implies universal coverage grants health and health care access to all people,

> without discrimination, to nationally determined sets of the needed promotive, preventive, curative, rehabilitative and palliative essential health services, and essential, safe, affordable, effective and quality medicines and vaccines, while ensuring that the use of these services does not expose the users to financial hardship, with a special emphasis on the poor, vulnerable and marginalized segments of the population.[101]

The current U.S. healthcare system does not meet these metrics considering the large numbers of individuals remaining uninsured with limited access to health facilities and affordable services across the nation. Universal health care directly addresses these gaps by providing a more cohesive health system prepared to respond to national and local

[100] WHO, *The Right to Health,* 25-27.

[101] "The Importance of Universal Health Care in Improving Our Nation's Response to Pandemics and Health Disparities."; UN General Assembly, Resolution adopted by the General Assembly on 10 October 2019—political declaration of the high-level meeting on universal health coverage, last modified 30 September 2020. https://www.un.org/pga/73/wp-content/uploads/sites/53/2019/07/FINAL-draft-UHC-Political-Declaration.pdf.

health crises and routine care. One example of this is long-term disability insurance as part of a national insurance program that protects one of several vulnerable and health-disparate demographics, the disabled.[102]

Conclusion

Moral repair requires actions, cultural shifts, and accountability. As a member of the global community committed, at least on paper, to upholding the inherent dignity of all citizens and the fundamental rights that accompany that dignity, the United States has an enormous amount of work to do to recognize human rights, most specifically the right to health, for all citizens. The United Nations has the instruments to hold the U.S. accountable for its violations of human rights and several levels of international authority have commented on the prevalence of marginalization, social inequities, and rights violations experienced by minority communities in the U.S. These statements effectively name the U.S.'s wrong actions and the harms imposed onto victims, but the U.S. must take the next step and implement laws, policies, and organizations that adopt new moral frameworks that provide clarity on rights violations and the nation's failure to address its own wrongdoing.

Regarding health, health departments reporting to civil rights organizations, universal health coverage, dignity-centered care, and adoption of UN instruments in domestic data collection and policy are but a few actions that the nation can take to reestablish harmed communities' trust in the health system and wider government meant

[102] "The Importance of Universal Health Care in Improving Our Nation's Response to Pandemics and Health Disparities."

to offer protection and promotion of their right to health. These actions further nourish a sense of hope in the betterment of the nation because of systems that promote transparency, equality, and nondiscrimination as citizens rightfully pursue access to the services protected under their right to health.

It has been the task of this chapter to articulate some practical benefits of a human rights framework in the U.S., despite the domestic obstacles posed to bifurcating first generation human rights from second generation human rights. Through a human rights framework, health care systems and supporting social and political structures require re-shifting and redistributions of power to effectively overcome the generations-long governmental failures to select communities who have borne the brunt of disparities, inequities, and poor health outcomes. These changes are possible and provide opportunities for the U.S. to actualize in its own nation the very standards to which it holds the rest of the world. There are also opportunities to alter the moral fabric of the country by promoting the forms of personhood and human dignity that ground the international declarations and treaties analyzed in this chapter. The next chapter will perform a thorough analysis of the benefits of recognizing personhood and inherent dignity, which, together with international instruments evolving from a human rights framework, can provide enhanced health and wellbeing for all health-disparate communities.

CHAPTER THREE: Analysis-in-Depth Using the Christian Theological Category of Maritainian Personalism

"There is a certain grandeur and nobility in administering to another's need out of one's fullness and plenty."

--Howard Thurman

Following an articulation of health disparities as a moral wrong, the previous chapter examined the instruments provided by the United Nations (UN) and some ways they can be incorporated into U.S. domestic laws and policies as a form of moral repair. These instruments can help the nation move beyond normative abandonment towards a level of health that prioritizes the needs of marginalized communities and simultaneously does not ignore dominant communities. While the international instruments provide a framework for policies directly aimed at reducing health disparities through the protection of rights to health and adequate health care, philosophical questions remain regarding human nature, the virtues that should accompany recognition of our nature, and how those virtues inform our rights. This chapter takes seriously these questions and closely analyzes a theological framework that pushes humanity to consider how "our deepest convictions about what is good or authentic human life ground our moral choices."[1] A vocational result of this chapter is the provision of personhood as a reclaimed tool for bioethicists, clinicians, and policy experts that more faithfully

[1] Edmund D. Pellegrino, "Humanism and Bioethics: The Prophetic Voice of Jacques Maritain (1882-1973)," in *The Vocation of the Catholic Philosopher: From Maritain to John Paull II,* ed. John P. Hittinger (Washington, D.C.: Catholic University of America Press, 2014), 207.

addresses the sacrality of human nature within sociopolitical contexts, most specifically those contexts centering health.

As mentioned in the introduction, numerous personalist frameworks can be chosen to articulate the importance of personhood as a tool attending to human nature. This chapter centers Jacques Maritain's Thomist-informed philosophy that defines a theory of personhood in which persons bear dignity because they are created by God, thus entitling them to rights and a good life. Because persons are direct creations of God, neglecting human rights, including the right to health, moves beyond moral wrong. Neglect escalates to a deep violation that presents an urgency to pursue repair. To articulate the urgency of moral repair for historically marginalized communities whose rights have been neglected, thereby implying their personhood has been neglected, this chapter performs a thorough analysis of the significance of personhood across various camps of thinkers, its shortcomings, and the benefits of Maritain's conception as a way forward.

The Significance of Personhood

"Persons" and "personhood" have been integral to western philosophy for years, yet there is minimal consensus or clarity on what the terms mean or how they should inform actions and beliefs. Personalists also have differing values and goals when engaging the concept, some of which conflict.[2] The result is that "there remains such

[2] Some scholars seek to propose criteria for or clarify previously presented criteria of personhood. Others seek to discuss the literature on personhood to determine an appropriate formulation likely to solve moral problems. Despite their best efforts, the discussions often reveal personal biases toward a particular iteration of personhood. Those moral problems inviting solutions from personhood, also known as

intractable and wide disagreement over the meaning of 'person,' about the criteria for its correct application, and about the true conditions for its proper use in practice," leaving the term prescriptive and value-laden for many.[3] To further complicate the concept, most theories fall within two broad camps: functionalist and inherent.[4] A functionalist conception generally requires persons to have a capacity for thoughts and concludes that not all humans are persons. An inherent conception generally agrees that all humans are persons, and they have duties to one another because of their potential for moral agency.[5] Regardless of the community to which scholars subscribe, both functionalist and inherent personalists use their community's characteristics to define relationships between personhood, human rights, and human dignity.

A Contemporary History of Personhood's Use in Ethics

Since the early 1960's, personhood and accompanying criteria to define persons have been incorporated in medical ethics arguments to determine to whom full moral rights are entitled. Often invoked as a form of protest, "persons" language was also used to challenge the "depersonalization" of medicine. Fearing that technology would reduce

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boundary cases, often center the moral status of fetuses, support for or denunciation of the right to abortion, and proper care to be given patients with cognitive impairments. *See* Ruth Macklin, "Personhood in the Bioethics Literature," *Milbank Memorial Fund Quarterly/Health and Society* 61, no. 1 (1983): 36.

[3] Macklin, "Personhood in the Bioethics Literature," 40.

[4] Philosophers, theologians, and bioethicists all have different ways of defining these two camps (*e.g.*, maximalist vs. minimalist, conservative vs. liberal, reductive vs. personalist/moral), but this work will use functionalist and inherent throughout because they capture most accurately the goals of this project to honor the inherent personhood of communities facing health disparities, most specifically black birthing people.

[5] Mary Anne Warren, "Personhood and Moral Rights," in *Moral Status: Obligations to Persons and Other Living Things* (Oxford: Clarendon Press, 1997), 90.

medicine solely to diagnosis and curative measures, hospital chaplains argued for care towards the *whole* person.[6] Others used "person" to protest the allocation of medical resources in the form of dialysis treatments. "In 1962 the Admissions and Policies Committee of the Seattle Artificial Kidney Center at Swedish Hospital made decisions about who would have access to the recently developed, but clearly effective, dialysis machine—made decisions, that is, about who would live and who would die—on the basis of *ad hoc* comparisons of the social worth of those who needed it."[7] Journalists protested the committee for "reducing the worth of persons to their value on some utilitarian calculus."[8]

As persons language became more widespread in healthcare settings some philosophers began crafting criteria to establish who was included and excluded. Functionalist, Joseph Fletcher, influenced by Michael Tooley, initially identified twenty "indicators of humanhood," divided into positive and negative criteria.[9] Upon objections

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[6] Richard Cabot and Russell Dicks, *The Art of Ministering to the Sick* (New York: Macmillan, 1936).

[7] Stephen Lammers and Allen Verhey, ''Respect for Persons and Their Agency," in *On Moral Medicine: Theological Perspectives in Medical Ethics* (Grand Rapids, MI: William B. Eerdmans Publishing Company, 1998), 373.

[8] Lammers et al., ''Respect for Persons and Their Agency," 373.

[9] Fletcher's positive characteristics included: minimal intelligence (IQ above 20), self-awareness, self-control, a sense of time, a sense of futurity, a sense of the past, capability for others, communication, control of existence, curiosity, change and changeability, balance of rationality and feeling, idiosyncrasy, and neo-cortical function. The negative criteria included: being non-artificial, not essentially parental, not essentially sexual, not bundles of rights, and not essentially worshippers. In his article turned book, "Abortion and Infanticide," Michael Tooley distinguished between human beings and persons. Persons were to be treated as pure moral concepts with a serious moral right to life. Tooley used examples of killing over murder to make his distinction between general rights and a moral right to life, concluding that fetuses are human beings but not persons; therefore, they have no moral right to life. Further, the terms person and

that his standards were too high, he reduced his concept of humanhood to four criteria: self-consciousness, relationality, ability to experience happiness, and neocortical functioning.[10] Mary Anne Warren also established criteria and first used the term in a bioethical analysis of the legal status of persons in 1973.[11] In pursuit of an answer to the status of fetuses, she questioned, "[h]ow are we to define the moral community, the set of beings with full and equal moral rights, such that we can decide whether a human fetus is a member of this community or not? What sort of entity, exactly, has the inalienable rights to life, liberty, and the pursuit of happiness?"[12] She concluded that fetuses were humans but not persons; therefore, fetuses were not entitled to full moral rights.

Conversely, inherent personalist, John Noonan held to only one criterion of personhood, being conceived by human parents. Noonan argued that lists of criteria rested on "feeling", which is,

> notoriously an unsure guide to the humanity of others. Many groups of humans have had difficulty in feeling that persons of another tongue, color, religion, sex,

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human should not be used interchangeably. He asserted, "[a]n organism possesses a serious right to life only if it possesses the concept of a self as a continuing subject of experiences and other mental states, and believes that it is itself such a continuing entity." *See* Joseph Fletcher, "Indicators of humanhood: A tentative profile of man," *Hastings Center Rep.* 2 (1972): 1-4; Michael Tooley, "Abortion and Infanticide," *Philosophy and Public Affairs* 2, no. 1 (1972): 37-64.

[10] Joseph Fletcher, "Four indicators of humanhood—The enquiry matures," *Hastings Center Rep* 4 (1974): 4-7.

[11] Warren stated, "I will argue that a fetus, whatever its stage of development, satisfies none of the basic criteria of personhood, and is not even enough *like* a person to be accorded even some of the same rights on the basis of this resemblance. Nor, as we will see, is a fetus's *potential* personhood a threat to the morality of abortion, since, whatever the rights of potential people may be, they are invariably overridden in any conflict with the moral rights of actual people." Warren went on to include five key "traits" of personhood: consciousness, reasoning, self-motivated activity, the capacity to communicate, and the presence of self-awareness. *See* Mary Anne Warren, "On the Moral and Legal Status of Abortion," *The Monist* 57, no. 1 (1973): 43-61.

[12] Warren, "On the Moral and Legal Status of Abortion," 52.

> are as human as they…Yet experience shows that sight is even more untrustworthy than feeling in determining humanity. By sight, color became an appropriate index for saying who was a [human], and the evil of racial discrimination was given foundation. Nor can touch provide the test; a being confined by sickness, "out of touch" with others, does not thereby seem to lose [their] humanity…Any attempt to limit humanity to exclude some group runs the risk of furnishing authority and precedent for excluding other groups in the name of the consciousness or perception of the controlling group in society.[13]

Abortion remains a live example of the ways feelings can dictate criteria for personhood and moral rights.[14] Chapter one also provided many historic examples of the abuses brought on communities when their personhood is subjected to feelings and pseudoscientific beliefs (*e.g.*, the enslaved women purchased by J. Marion Sims, the Canadian fur trapper routinely captured for medical experiments, individuals imprisoned throughout the carceral system, and black birthing people's disproportionate mortality rates). Until inherent dignity becomes the universal foundation of personhood, all communities remain subject to harm if they fall beyond contemporary criteria.

Functionalist Personhood

Although functionalists require specific criteria to determine personhood, they bring forth important considerations. Functionalists argue that "the moral status of person is attributed to the subject capable of a moral life."[15] They differ on the full range of capacities necessary to live a moral life, but they agree minimally that some form of

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[13] John Noonan, "Abortion: From 'An Almost Absolute Value in History'," in *Moral Problems in Medicine*, ed. Samuel Gorovitz, Andrew L. Jameton, Ruth Macklin, Kohn M. O'Connor, Eugen V. Perrin, Beverly Page St. Clair, and Susan Sherwin (Englewood Cliffs, NJ: Prentice-Hall, 1976), 293-294.

[14] Bloomberg Law, "Beyond Abortion: The Fight over Fetal Personhood is Here," filmed January 12, 2023 at The National Library of Medicine, Washington, D. C., video, 6:19, https://youtu.be/J-9Evt6j8SQ.

[15] Antonio G. Spagnolo, "Personhood: order and border of bioethics," *J Med Pers* 10 (2012): 99.

consciousness is required. Additionally, various thinkers posit sentience, relationality, or rationality are necessary for an individual to be considered a person.[16] This view implicitly concludes that personhood is uncertain until a being's actions are compared with the actions of those considered to be persons.[17] And because not all potential capacities to live a moral life exist across the entire human life span, functionalist personalism can exclude some humans and include some nonhuman animals.

Some functionalists try to take a moderate approach, arguing that "personhood strengthens and then fades as various attributes develop and later deteriorate."[18] Common examples denoting this spectrum are fetuses at the beginning of life and patients with dementia at the end of life. The moderate position still requires some quantifiable measure of personhood that can ebb and flow throughout the life course. Conversely, moderate functionalists also agree with inherent personalists that there are sacred characteristics of the person. Those characteristics are simply strongest at the height of rationality and have the potential to diminish.

Functionalists are part of a lineage beginning with Immanuel Kant who argued that "personhood consists in rational moral agency. His theory is that being a moral agent is (1) a necessary condition for any moral status; and (2) a necessary and sufficient

[16] Warren, "Personhood and Moral Rights," 94.

[17] Donal P. O'Mathuna, "Personhood in bioethics and biomedical research," *Research Practitioner* 7, no. 5 (2006): 2-3.

[18] O'Mathuna, "Personhood in bioethics and biomedical research," 7.

condition for full moral status."[19] Full moral status deems persons morally responsible for their actions because they possess an internal moral law allowing them to self-reflect on moral actions to determine their rightness of wrongness, as well as first-order desires.[20]

John Locke built on the self-reflection criterion and considered persons to be "thinking intelligent being[s], that ha[ve] reason and reflection, and can consider [themselves] as [themselves], the same thinking thing[s] in different times and places; which [they do] only by that consciousness which is inseparable from thinking, and, as it seems to me, essential to it."[21] According to this reasoning, a Lockean person is a moral agent. Because they are capable of reason and reflection, they are capable of laws and duties.[22] They can also be held morally responsible for their actions in different times and places. Some scholars, like Warren, would argue that Locke was mildly functionalist, but his focus on psychological capacities shaped the future trajectory of functional personalism.

A major challenge of the functionalist model is the high standard of personhood that potentially excludes humans, specifically cognitively impaired individuals. Any cognitive or psychological property chosen to define functional personhood will inevitably be lacking in some human beings and potentially present in some nonhuman

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[19] Warren, "Personhood and Moral Rights," 90.

[20] O'Mathuna, "Personhood in bioethics," 1; Immanuel Kant, *Critique of Practical Reason,* trans. Lewis White Beck (New York: The Bobs-Merrill Company, 1956), 161-162.

[21] John Locke, *An Essay Concerning Humane Understanding in Four Books* (London: Eliz. Holt, 1690), 1.25.11.

[22] Warren, "Personhood and Moral Rights," 95.

beings. Tom Beauchamp and James Childress put forth the example of primates. They "often possess humanlike properties that some humans lack, such as intellectual quickness, the capacity to feel pain, and the ability to enter into meaningful social relationships."[23] Those humans lacking functional cognitive properties may include infants, senile persons, persons with severe brain injuries and mental disability, each exemplifying that biological humans can be considered "animals" if ever they lack functioning, challenging the very category of "human being." For these vulnerable humans, "[i]f animals can be treated as mere means to human ends, then comparable 'marginal' cases of human capacity can also be treated as mere means to human ends."[24]

This tension leads inherent personalists to question whether excluded humans have a right to life and "whether people with poor quality of life should or should not considered *[sic]* full persons."[25] Functionalists respond that excluded humans' wellbeing is contingent upon the kindness of those with full personhood. They further assert that excluded communities may not qualify as persons but, "we may still have good reasons for not killing them—for example, because people value them or because a policy allowing them to be killed would be harmful to society."[26]

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[23] Tom Beauchamp and James Childress, "Moral Status," in *Principles of Biomedical Ethics 7th edition*, (New York: Oxford University Press, 2013), 68.

[24] Beauchamp and Childress, *Principles*, 70.

[25] Spagnolo, "Personhood," 100.

[26] Lewis Vaughn, "Abortion," in *Bioethics: Principles, Issues, and Cases* (New York: Oxford University Press, 2010), 260-261.

Challenging the functionalist model, this work agrees with Antonio Spagnolo that "the main flaw of this approach is the failure to admit that the functions described as descriptive of the person are present to some degree in all human beings and are inseparable from the ontological subject. The ability to perform a function is not an abstract attribute that is either present or absent."[27] It is impossible to grade degrees of personhood according to objective standards, making functionalist personalism inadequate for this work. Functionalism also diminishes the unique qualities individuals bring to their communities.

Inherent Personhood

Inherent personalism contrasts functionalism in its belief that all human beings, from the moment of fertilization to the moment of irreversible death, are persons. As "the individual substance of rational nature," with the ability, or at least the potential, to use intellect and will to engage in community, self-reflect, and self-determine, persons are "a unitotality of body and spirit."[28] Many inherent personalists agree with Laura Palazzani that,

> [p]ersonhood belongs to the ontological order: the possession of a substantial personal status cannot be acquired or diminished gradually, but is a radical condition: one is not more or less person, but either a person or not a person. The absence of properties or functions does not nullify the existence of the ontological reference, which remains such by nature, since ontologically speaking it pre-exists [their] own qualities.[29]

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[27] Spagnolo, "Personhood," 100.

[28] James M. Jacobs, "The Metaphysical Nature of Personhood," *HeyJ* 59 (2018): 707; Spagnolo, "Personhood," 100.

[29] Laura Palazzani, *Introduction to the philosophy of biolaw* (Rome: Studium, 2009).

Because there is no clear, nor agreed upon line between persons and nonpersons, any demarcation would be arbitrary. Inherent personalists conclude then that the only sufficient demarcation is conception because "a full complement of genetic information is present to propel development of a completely formed, mature human."[30] Many in this camp, like Eva Feder Kittay, further challenge the functionalist focus on rationality, questioning why other capacities cannot be considered for a moral life, "such as giving care and responding appropriately to care, empathy, and fellow feeling; a sense of what is harmonious and loving; and a capacity for kindness and an appreciation for those who are kind."[31] These exemplary characteristics promote goodness as well as reduce harm.

Naming personhood as an inherent feature of being human results in "all humans [possessing] 'equal and intrinsic dignity by virtue of what (*i.e.,* the kind of entity) they are, not in virtue of any accidental characteristics, which can come and go, and which are present in human beings in varying degrees."[32] Interestingly, many inherent personalists, like Ludger Honnefelder, also ground their argument that all humans "[possess] equal and intrinsic dignity" in Kant, which requires that all humans be treated as moral subjects.[33] Therefore, all human beings, as moral subjects, deserve protections and special rights. Elsewhere, Honnefelder builds on Kant in that,

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[30] Vaughn, *Bioethics*, 259.

[31] Eva Feder Kittay, "At the Margins of Personhood," *Ethics* 116, no. 1 (Oct 2005): 122.

[32] O'Mathuna, "Personhood in bioethics," 6; Robert P. George and Patrick Lee, "Acorns and embryos," *New Atlantis* 7 (2004/2005).

[33] Ludger Honnefelder, "The Concept of a Person in Moral Philosophy," in *Sanctity of Life and Human Dignity,* ed. Karl Bayertz (Dordrecht: Kluwer Academic Publishers, 1996), 144.

> all living beings that we refer to by means of the sortal predicate "human being" have an intrinsic or unconditional value which bars them from being evaluated in comparison to other goods. This means that all morality is based on a fundamental practical judgement stating that a human, as a living being equipped with the natural capacities of reason and free will is an intrinsic or unconditional good, and that humans have this value simply for being humans, that is, regardless of all other properties except for the property of being human; in other words, for being referred to by means of the sortal predicate "human."[34]

Just as with functionalist personalism, there are challenges and tensions with inherent personalism, namely speciesism. Some functionalists argue that "if we assume that an entity is a person just because it happens to belong to our favored biological classification", then inherent personalists are practicing a form of racism.[35] To avoid trappings of speciesism and potential racism, inherent personalists must provide answers to questions such as, how do we determine that someone is a human being?; how do we determine that a nonhuman animal is not a human being?; and, if genetics is the answer to the determination, how are those humans with different numbers of chromosomes to be classified and treated?

Kittay proposes a model challenging claims of speciesism and racism, while taking seriously sortal groups. She argues that "pernicious nationalism" and racism assume that desirable traits are exclusive to the privileged group and undesirable traits are exclusive to the despised group.[36]

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[34] Ludger Honnefelder, "Bioethics and the Normative Concept of Human Selfhood," *Studia Ecologiae et Bioethicae* 1 (2003): 211.

[35] Vaughn, *Bioethics*, 260.

[36] Kittay uses the examples of U.S. enslavement and Naziism to further elaborate this point: "Whites in slave-owning states, including such enlightened figures as Thomas Jefferson, speak of the

> The idea that giving moral properties to humans is analogous to pernicious nationalism or to racism is erroneous in that it assumes that the evils of nationalism (or racism) are based solely on the principle of giving priority to one's own group—or that their signature is the sortal "group membership," and it is this that has the undesirable moral consequences, in the absence of any compelling moral reasons to give priority to "one's own." I want to suggest instead that what makes racism and pernicious nationalism moral evils is the special way they depend on "property sortals."[37]

Because racism and nationalism use pseudoscience to qualify undesirable traits in an effort to exclude undesired humans, racial purity is pursued to ensure "prized and devalued properties can[not] migrate across groups, thereby [tightening] the identification of group membership with distinctive properties."[38] While not disavowing group membership, Kittay instead argues that family membership should be the moral guide: "I propose that membership in a group of moral peers based solely on species membership has as its appropriate moral analogue family membership, not racism, and not pernicious nationalism. As humans we are indeed a family."[39]

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inferior mental capabilities of blacks, of the superior sensibility of whites, of the unattractiveness of the African physique, and of the artistic merits present in whites but absent in blacks. This racism is based not merely on group membership but also on the possession of certain properties by one group, whites, and their absence or their antithesis in the other group, blacks…[w]hat is pernicious, and what has the most destructive consequences, occurs when a group defines itself as the sole possessor of a set of properties, properties which, in turn, define it and which give members of the group, as the possessors of those properties, the authority to appropriate goods, power, and other privileges." *See* Kittay, "At the Margins of Personhood," 119, 121.

[37] Kittay, "At the Margins of Personhood," 119.

[38] Kittay uses the example of Sethe from Toni Morrison's, *Beloved*, to note the pseudoscientific verity of racism. "Sethe's schoolteacher measures her skull in an effort to validate the correlation between race, skull size, and cognitive capacities, [Sethe learns her enslaved status] is not to be justified merely by the fact that she belongs to a different race. Sethe sees herself reduced to measurably intrinsic properties, sorted by these properties the way animals are, and she feels shamed and humiliated in a special way." *See* Kittay, "At the Margins of Personhood," 119-120.

Criticisms of Personhood

Just as it has conflicting support, personhood also has critics. Not all scholars agree that personhood is a useful and effective concept upon which to frame social advancements and ethical actions in the form of policy, legislation, and professional practice. The lack of agreement in ethical debates regarding who is a person with full moral rights has led some scholars to call for the "end of personhood."[40] Others persist in using personhood but argue for additional specificity about its philosophical import.[41] Yet others argue for broadening the community of interlocutors, reviving the efficacy of personhood by engaging communities whose personhood has been threatened through arbitrary lines of marginalization that have historically and negatively impacted minoritized groups.[42] Several positions representing these personalist reservations will be briefly explored before turning to Maritain's personhood and its strengths in combatting these limitations.

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[39] "Family membership is conditional on birth lines, marriage, and (under particular conditions) adoption, not on having certain intrinsic properties. But except where it is misused, as in nepotism in employment where intrinsic properties matter, family membership is not a pernicious relationship. Families (or adequate substitutes) are critical when we are dependent, as in early childhood, during acute or chronic illness, with serious chronic conditions including disability, and in frail old age. At these times, we are generally best served by close personal ties. Families are called on in times or moral crisis for the support of family love and loyalty." *See* Kittay, "At the Margins of Personhood," 124.

[40] Jennifer Blumenthal-Barby, *"*The End of Personhood*," The American Journal of Bioethics* (published online ahead of print, January 12, 2023): 1-10, https://doi.org/10.1080/15265161.2022.2160515.

[41] Francis J. Beckwith, "Taking Abortion Seriously: A Philosophical Critique of the New Anti-Abortion Rhetorical Shift," *Ethics & Medicine: An International Journal of Bioethics* 17, no. 3 (Fall 2001): 155-166.

[42] Jennifer Elyse James, "Black Feminist Bioethics: Centering Community to Ask Better Questions," in *A Critical Moment in Bioethics: Reckoning with Anti-Black Racism through Intergenerational Dialogue,* ed. Faith E. Fletched et al., special report *Hastings Center Report* 52, no. 2 (2022): S21-S23.

For scholars wishing to do away with personhood, they argue that the more we define its characteristics and apply them to all dimensions of life, the more we increase the effects of depersonalization.[43] Consequently, personhood becomes "superfluous, confusing and without pragmatic use, it leads to simplifications and can be easily used as a cover-up concept."[44] Including personhood in every dimension of life—"[f]rom juridical language, which deems it the only thing able to give form to the otherwise ineffective imperative of human rights, to politics, that has long substituted it for the insufficiently universal concept of the citizen"—makes the term an ethical honorific devoid of depth and description.[45]

The depersonalization and emptiness of personhood also impacts rights. Having rights implies a level of exclusion: if there are communities defined by their enjoyment of rights, then there are communities who are excluded from these rights lest the rights become reduced to facts which, do not require legislative protections. This tension between protected and excluded communities dates back to Gaius, and later Justin, who established a hierarchy of persons within the Roman empire, from free, landowning male citizens to slaves. Free, landowning male citizens were considered full persons with their

[43] Robert Esposito names this the "paradox of the person." Calling on the 2006 *Time* cover of a monitor with a reflective mirror naming "you" the person of the year, Esposito argues that the cover and personhood place people in a potentially infinite position that renders all singular features invisible. "It is as if lending everyone the same 'mask' ends up making of it the valueless sign of a pure repetition…The more you want to impress the personal seal of subjectivity, the more you seem to produce the contrary result of subjection to a reifying apparatus." *See* Robert Esposito, "The Person and Human Life," in *Theory After Theory,* ed. Jane Elliott and Derek Altridge (Taylor and Francis Group, 2011), 205-206.

[44] Bert Gordijn, "The Troublesome Concept of the Person," *Theoretical Medicine and Bioethics* 20, no. 4 (1999): 356.

[45] Esposito, "The Person and Human Life," 206.

own ethical status. Others were merely left to the devices of laws and external powers, similar to the contemporary functionalist argument that nonpersons be protected by the kindness and laws of persons. All individuals who were not free, landowning men held a conditional personhood that could (d)evolve as their sociopolitical status (d)evolved.[46]

In ancient Roman society, conditional persons were always *subject to* external powers rather than *subjects of* these powers. This dialectical relationship embodies the passive and active connotation of subjection, "that, inside every living being, the person is the subject destined to subject the part of [themselves] not endowed with rational characteristics, which means the corporeal, the animal."[47] This rationale is further developed in Rene Descartes' subjection of the body to the mind, producing,

> from yet another angle, the same effect of separation and of dominance that we have already individuated in the theological and juridical logic of the person. At that point, not even the passage initiated by Locke and brought to completion by Hume, of the concept of the person from the sphere of substance to that of function, will be able to change things. Personal identity continues to reside in the mind, in the memory, or in a simple, subjective antirepresentation, and its qualitative difference from the very body in which it is installed is increasingly accentuated.[48]

Because some positions of personhood are defined by a separation between embodiment and rationality, as developed by Descartes, scholars argue that the concept becomes a moot point because it does not unify "spirit and flesh, reason and body, right and life, into

[46] Esposito, "The Person and Human Life," 208-10.

[47] Esposito, "The Person and Human Life," 210.

[48] Esposito, "The Person and Human Life," 210.

a single block of meaning."[49] Thomas Hobbes further asserted the complexity of this separation in the distinction between natural people—representing themselves in word and deed—and artificial people—representing the words and deeds of others (*e.g.*, corporations, buildings). Based on these two categories, representation is all that matters, completely eliminating the need for the human body in many instances.[50] A challenging conclusion arises in that things can become persons and persons can become things, disrupting the sacrality of personhood previously established by both personalist positions.

Finally, critics of personhood argue that it is deeply subjected to its sociopolitical and historico-cultural moment, resulting in the concept's meaning constantly shifting despite the consistencies of human nature. This criticism underscores a reality that personhood must maintain a sort of vagueness to remain committed to "a human individual comprised of a rather open-textured set of mental traits."[51] Friedrich Nietzsche and Simone Weil saw these limitations and argued for an impersonal understanding of human nature. Nietzsche argued against personhood because the mind is critical to an embodied being which cannot exist outside of its body. Separating the two is impossible, therefore, personhood cannot work as a viable moral category for human beings.

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[49] Esposito, "The Person and Human Life," 212.

[50] Thomas Hobbes, *Leviathan*, trans. Rod Hay (Hamilton, ON: McMaster University, 1999), 36-38.

[51] Tom Beauchamp, "The Failure of Theories of Personhood," *Kennedy Institute of Ethics Journal* 9, no. 4 (1999): 318.

Nietzsche sought a return to the body because embodiment and politics were inextricably linked, an understanding that plays a role in health and health policy today. Conversely, Simone Weil argued that rights and the person were only related because of their distance from human nature. Rights could not be protected by a justice system built on the exclusion of some over others. She argued that,

> far from being [their] person, what is sacred in a human being, is the impersonal in [them]…I see a passerby on the street. [They have] long arms, blue eyes, and a mind whose thoughts I do not know, but perhaps they are commonplace…If it were the human personality in [them] that was sacred for me, I could easily put out [their] eyes. As a blind [person they] would be exactly as much a human personality as [they were] before. I should not have touched the person in [them] at all. I should have destroyed nothing but [their] eyes.[52]

By challenging the link between rights and personality, Weil raises a critical concern that personhood does not necessarily include protections for our embodiment, which is an essential part of our human nature. Her challenge demands an understanding of human beings that encompasses embodiment and personality and the protection of both according to human rights.

Critics disagree with the personalist focus on who or what a person is because this focus has erroneously centered personhood as the driving force of our obligations to one another. This disagreement becomes most visible in bioethics——"[a] field that is engaged and embedded in a social and practical world; a field that seeks to offer guidance and direction…to real people…struggling with moral dilemmas"—when attempting to

[52] Simone Weil, *Simone Weil: An* Anthology, ed. Sian Miles (New York: Grove Press, 2000) 50-51, 54.

apply the concept to real world situations. Personhood language and arguments often elicit confusion, offense, or conflict, evidencing its need for evolution or retirement.[53]

Jennifer Blumenthal-Barby proposes welfare subjectivity (centered on beings whose existence can be improved or diminished) and recognition respect (centered on what we owe to all beings) as alternatives to personhood. This new framework can move the conversation beyond human adults and their cognitive capacities and the idea "that having the property of 'personhood' is necessary and sufficient for having full moral rights (or 'serious' rights), where rights govern how seriously we ought to take the interests (*e.g.*, interest in life) of the being in question."[54] If welfare subjectivity and recognition respect become the determining factors for how seriously we ought to take the interests of another, then personhood determines specific properties that can be used in normative analysis.[55]

The criticisms raised against personhood are essential to understanding the concept's shortcomings. Many other categories can be incorporated in society to help better the lives of marginalized communities. However, personhood—specifically the theory cultivated by Jacques Maritain—maintains much efficacy, especially for those health-disparate communities who have historically resided at the margins of society.

Maritainian Personhood

Natural Law and Human Rights

[53] Blumenthal-Barby, "The End of Personhood," 5.

[54] Blumenthal-Barby, "The End of Personhood," 2, 6.

[55] Beauchamp, "The Failure of Theories of Personhood," 313.

Jacques Maritain, considered to be one of the most influential twentieth-century philosophers, contemporized Thomist natural law to bridge science and philosophy; reestablish divine law in contemporary society; and, give attention to persons, their wellbeing, and the rights owed to them.[56] His understanding of natural law informed a theory of fundamental human rights that "tells us both what our proper claims are and why we rightly claim them for ourselves and for others."[57] Maintaining a balance between people's rights and their obligations, Maritain acknowledged that communal goods are owed to persons as members of a community because "what is due to particular persons and what is owed by particular persons derives from the person's social nature and role in society."[58] These social duties serve the common good, understood as "the set of social conditions necessary for fostering the proper good of each person and the

[56] For example, Maritain adopted Aquinas's hierarchy of natural inclinations informing human nature's pursuits of basic and complex needs (*e.g.*, shelter and companionship). He also adopted Aquinas's logic informing the hierarchy, that human inclinations stem from human reason, which is informed by divine reason. Maritain's philosophy actively worked to maintain the connection between human reason and divine reason because "it is man's substantive and facultative inclinations that reveal the law," whose contents and authority come from God's eternal law. We come to understand and reflect on our natural ways of being and proper actions because we are ruled by this eternal law, which is created by God and governs all of God's creation. *See* Brooke W. Smith, *Jacques Maritain: Antimodern or Ultramodern? An Historical Analysis of His Critics, His Thought, and His Life* (New York: Elsevier, 1976), 9, 129-35; Denis A. Scrandis, "Maritain's Theory of Natural Law," *National Catholic Bioethics Quarterly* 15, no. 4 (2015): 650; Jacques Maritain, *Natural Law: Reflections on Theory and Practice*, ed. William Sweet (South Bend, IN: St. Augustine's Press, 2001), 40.

[57] Denis A. Scrandis, "Jacques Maritain on the Rights of Man and the Common Good," *National Catholic Bioethics Quarterly* 17, no. 4 (2017): 615.

[58] Maritain explicitly recognized that Thomas Aquinas never developed a theory of human rights, but he does use Aquinas's implied understanding of protections stemming from social duties to begin establishing his theory of human rights rooted in society and the common good. *See* Deborah Wallace, "Jacques Maritain and Alasdair MacIntyre: The Person, the Common Good and Human Rights," in *The Failure of Modernism: The Cartesian Legacy and Contemporary Pluralism,* ed. Brendan Sweetman (Washington, D.C.: Catholic University of America Press, 1999), 130.

overall flourishing of the society."[59] In this case, a person's end is considered before rights are extended to them.

Maritain further argued for "'[p]rimordial rights' [that] exist on account of our eternal end in God and our initial membership in a family but prior to our incorporation into civil society. These primary, fundamental rights take precedence over duties to the common good, for they are not granted by society but are recognized as integral to human dignity."[60] As ends unto ourselves, humanity's value is directly built into our ontology; therefore, there is a right to exist. Correlatively, there is a duty from others not to interfere with our right to exist.

In her analysis of Jacques Maritain's philosophy and articulation of rights, Deborah Wallace argues that, "Maritain developed a rights theory whereby rights fall into three different classes: first, primordial rights derive *directly* and *necessarily* from natural law; secondly, rights of the law of nations derive *necessarily* from the natural law given certain conditions; and thirdly, rights of positive law are *contingently* derived from the natural law."[61] Taken together, these rights transcend temporality and allow people to pursue their absolute purpose to be treated as an end unto themselves. Persons are

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[59] Wallace, "Jacques Maritain and Alasdair MacIntyre," 130.

[60] It will be argued in greater detail later that one of the many strengths of Maritainian personalism is the multitiered approach to ensuring all humans have social entitlements to fundamental rights. Because fundamental rights are not granted by society but natural and eternal law, even babies and other vulnerable groups who cannot contribute to the common good are entitled to primordial rights. This is the strength of his departure from Aquinas, ensuring that rights are to be extended over the entire lifespan by recognition of one's role in all spaces including family units, society, and work. *See* Jacques Maritain, *The Rights of Man and Natural Law* (London: Geoffrey Bles, 1944), 65, 81-82; Wallace, "Jacques Maritain and Alasdair MacIntyre," 131.

[61] Wallace, "Jacques Maritain and Alasdair MacIntyre," 130-131.

allowed to follow their consciences, which are in direct relationship with God's eternal law. This relationship establishes the correlative link between rights and moral obligations.

Individuals have "[t]he right to existence and life.—The right to personal liberty or to conduct one's own life as master of oneself and of one's acts, responsible for them before God and the law of the community…The right to keep one's body whole…Finally, the right of every human being to be treated as a person, not as a thing."[62] Civic persons have rights to active participation in political life, especially the right to vote; the formation of government and political parties; and equal access to employment. And workers have the right to choose work; unionization; just wages; and relief and proper social benefits. These examples are indicative of Maritain's understanding of rights as "primarily positive entitlements for fostering the common good and human fulfillment."[63] These entitlements, grounded in natural law, allowed Maritain to establish "an objective [and bare minimum moral] standard by which to govern the exercise of rights and to judge between competing rights and claims."[64]

Yet, Wallace levies an important criticism against Maritain and his tense strictures between family and society, and those between rights for individual betterment and participation in the common good. Maritain inadvertently reflects a Lockean view of humanity that he so despised, treating individuals as,

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[62] Maritain, *The Rights of Man*, 60-62.

[63] Wallace, "Jacques Maritain and Alasdair MacIntyre," 132.

[64] Wallace, "Jacques Maritain and Alasdair MacIntyre," 132.

> abstract existence prior to membership in society…[T]he danger in this distinction is the suggestion that one's social bonds to family are natural whereas one's connection to the wider society is constructed or artificial. The very notion that primordial rights exist in the "primordial society" or "the family," prior to the larger political community, which can limit rights, seems to set up a false separation between one's social nature and one's political ties to the wider society.[65]

Using Alasdair MacIntyre's critique of Maritain's theory of human rights, Wallace argues against Maritain's insistence that primordial rights exist simply because of our humanity, not necessarily because of our social relationships. Interestingly, this will remain a point of tension with Maritain's theory of personhood because persons require communion in society to be recognized as persons.[66] Maritain's positing that primordial rights are extended by virtue of humanity is also conflicted by "his acknowledgement that all rights are subject to limitations if special needs arise in the body politic."[67] He attempts to assuage this tension by creating a distinction between possessing and exercising rights, but the distinction is thin if one rejects his multidimensional understanding of persons being informed by natural and eternal law, always working toward the common good of earthly society and the eternal good of divine society. This multidimensional

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[65] Jacques Maritain, *Man and the State* (Chicago: University of Chicago Press, 1951), 101; Wallace, "Jacques Maritain and Alasdair MacIntyre," 131.

[66] Of course, absent a society it does not matter if anyone recognizes your personhood because you have no one from whom to claim rights, nor one to deprive you of rights. Yet, per Maritain's philosophy, a person absent society (*e.g.*, in isolation on a deserted island) remains a person, but there is no need to discuss the common good of society. If the deserted person were to come in contact with another person, then the common good exists between the two. However, for the purposes of policy addressing health disparities in the U.S., the case of the deserted person and the common good is beyond the scope of this work.

[67] Wallace, "Jacques Maritain and Alasdair MacIntyre," 136.

understanding of persons must be explored to comprehend Maritain's link between persons, society, and rights.

Ontological Anthropology

As with every other dimension of his philosophy, Thomas Aquinas influenced Maritain's ontological anthropology, which, he named an integral humanism grounded in the incarnation. "The creature should be respected in [their] connection with God because [they are] totally dependent upon [God]; a humanism indeed but a theocentric humanism rooted in what is radical in [humans]; integral humanism, the humanism of the Incarnation."[68] Aquinas believed there are two metaphysical distinctions of the whole person: individuality—informed by the body's materiality—and personhood—informed by reason, intellect, and will.[69] He highlighted the intellect and considered it the defining characteristic between human animals and nonhuman animals because we "alone are directed by God to [our] actions for the sake, not only of the species, but also of the individual."[70] Intellectual creatures are also capable of supreme goodness, are made in God's image, and our souls grasp God's essence to enter into "society" with God.[71]

[68] It should be noted this term, "ontological anthropology," is its own discipline of study apart from Maritain's integral humanism, but the source of study does anachronistically capture his desire to bridge Thomist anthropology, metaphysics, and biology. *See* Jacques Maritain, *True Humanism* (New York: Charles Scribner's Sons, 1950), 65.

[69] Jacques Maritain, *The Person and the Common Good* (New York: Charles Scribner's Sons, 1947), 3.

[70] Thomas Aquinas, *Summa Theologica*, III, 112.

[71] Aquinas, *Summa Theologica*, I, 93, 2.

Maritain built on this idea of the rational soul, arguing that, in the absence of materiality and mortality, the soul allows humans to,

> [exist] physically but, through knowledge and love, ha[ve] a more than merely material or brutish existence: [they have] a reason-infused, cognitively enriched, and nobler existence. [Their] knowledge can grasp the universe of beings—all of its natural forms—and through love, [they] can give [themselves] to others, who are, as it were, other selves to [them]. This person has a value…greater than the entire, merely material universe, which is not capable of knowing and loving the person in return.[72]

This person with value greater than the whole universe is comprised of two metaphysical aspects, the individual and the person. Persons are the most noble and perfect in all of creation as they reflect God's perfection being made in God's image.[73] As perfect creatures reflecting God's perfection, persons are required to love themselves because they love God.[74] By arguing for perfection, Maritain sought to positively engage the relationship between material (individual) and spiritual (person) being.

Regarding the individual, Maritain argued that only individual realities exist outside of the mind; therefore, individuality is directly opposed to universality. The individual constitutes "that concrete state of unity and indivision, required by existence, in virtue of which every actually or possibly existing nature can posit itself in existence as distinct from other beings."[75] He uses the examples of angels and God as intelligible individuals who differ in their essences from one another and from material nature. As

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[72] Scrandis, "Jacques Maritain on the Rights of Man and the Common Good," 616.

[73] Aquinas, *Summa Theologica*, I, 29, 3

[74] Maritain, *The Person*, 22-3.

[75] Maritain, *The Person*, 24.

material beings in existence, material individuals are informed by a soul that makes the individual "carnal and spiritual…Soul and matter are the two substantial co-principles of the same being, of one and the same reality, called [hu]man."[76] The relationship between the soul and the material body gives the person a mysterious distinction from every other person, and every other form of matter.

Maritain sums up this relationship as "narrowness of the ego, forever threatened and forever eager *to grasp for itself* [emphasis Maritain's]."[77] Grasping for oneself is an ongoing act because our materiality is prone to dispersion, leaving beings "fragments of a species, a part of the universe, a unique point in the immense web of cosmic, ethnical, historical forces and influences—and bound by their laws."[78] Although our materiality is shaped by the physical world, this shaping does not control our personhood, which "signifies interiority to self."[79] This interiority allows a person to be a "master of itself" through the communication of knowledge and love with others, bearing absolute dignity as the image of God.[80] Most importantly, personhood naturally inclines toward a socially communicative body. People require "membership in a society in virtue of both [our]

[76] Maritain, *The Person*, 26.

[77] Maritain, *The Person*, 27.

[78] Maritain, *The Person*, 28.

[79] Maritain, *The Person*, 31.

[80] Maritain, *The Person*, 31-32.

dignity and [our] needs" because there is always a desire to share what we know and who we are through knowledge and love.[81]

Contributing to some critics' frustrations with the concept, Maritain does spend time articulating who and what a person is, but his theory is stronger than their objections because persons are obligated to one another, not because of any sortal characteristic they possess as individual material beings, but as God's image bearers. Honoring personhood, as understood in contemporary constructions, is not the driving force of obligations to the other. Instead, our human nature, informed by a natural law that establishes us as ends unto ourselves, determines our obligations to each other. Persons are therefore equal to one another, with rights from *and* to one another informed by a specific metaphysical property of material individuality and divine-informed personality. Divine personality also challenges the constraints of functionalist personhood because all human beings are capable of a moral life. There is no scale of personhood, nor any arbitrary line determining when one is or is not a person because, per Maritain, all humans operate according to God's eternal law with the purpose of always moving towards God regardless of theological or philosophical belief.

It could be argued that this conclusion is insufficient because it requires trusting in the moral capabilities of persons regardless of their behavior in society, but the conclusion remains true for inherent personalists who include all humans and their potential for morality in the category of persons. Maritainian personalism does include

[81] Maritain, *The Person*, 37.

functionalist capacities to live a moral life, but these capacities are not the limiting factor. They should instead be seen as abilities that derive from our personhood, endowed by God, that help us engage in communion with one another.

As mentioned earlier through the words of Deborah Wallace, Maritainian personhood is a bare minimum moral standard that does not include so many characteristics that it becomes depersonalized. Grounded in a rich Catholic humanism, this personhood avoids critics' argument of being vapid or without descriptive merit. Based on Maritainian personalism, rights should be viewed as facts of humanity that do not require legislative protections since no one is excluded from the category of persons, thus ensuring all people enjoy rights.[82] But because history has yet to witness a society that treats persons with full respect such that fundamental rights are a fact of society for everyone, Maritainian personalism remains a fitting category open to evolution as societies move closer to achieving fuller respect of persons. As with Aquinas, Maritain believed his moral philosophy should evolve with each sociocultural shift, always guaranteeing the unique needs of a community to attain bare minimum standards of respect, dignity, and accompanying rights, while also striving towards a fuller expansion of those standards.

Returning to Maritain's idea of persons, a person—comprised of individuality and personality—cannot be whole unless they are members of a society working toward the

[82] The distinction between rights and facts, and who enjoys rights at the expense of those who are excluded is a reference to Esposito's analysis of Roman history. Persons gain their status as persons (*i.e.*, free, land-owning male citizens) because of the exclusion of nonpersons and conditional persons (*i.e.*, everyone else). *See* Esposito, "The Person and Human Life," 205-206.

fullness of life. Maritain argues that societies are naturally required by humans and brought about through reason. Therefore, societies are human creations that allow persons to be identified as "a political animal, which means that the person craves political life, communal life, not only with regard to the family community, but with regard to the civil community."[83] It then follows that persons cannot reach their highest potential unless they receive the necessary communicative good from society.[84]

By examining Maritain's approach to each element of the problem of human nature—human nature rooted in natural law; human nature comprised of the metaphysical aspects of individuality and personality; and, the whole person requiring individuality, personality, and society—his concept of the whole person provides a rebuttal to Wallace's earlier critique. Whether familial or social, our bonds are crucial to our personhood and human dignity, entitling us to primordial rights. Persons need socially communicative bodies to communicate who we are, whether in or beyond the home. Family and external society are but two examples of communion that allow persons to achieve the fullness of life through expressing themselves and being recognized by others through the protection of their entitlements to fundamental rights.

Another distinguishing element of Maritain's personalism is his assertion that societies are formed by "human persons, who, moved by the generosity of spirit, [share] life's resources and needs through works of reason and free will."[85] The generosity of

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[83] Maritain, *The Rights of Man*, 7-8.

[84] Maritain, *The Rights of Man*, 38.

[85] Scrandis, "Jacques Maritain on the Rights of Man and the Common Good," 617.

human persons creates multiple levels of society, each with their own goals and goods that protect rights and contribute to humans reaching their ultimate end, God. These societal goods are the culmination of the good of the communal body and the return of that good flowing back into society, which, begin at the basic, material level (*e.g.*, education, judicial systems, public safety, and access to public buildings).[86]

Moving beyond material needs, society also provides "intellectual, moral, and spiritual goods, all of which elevate and liberate, since they optimize the life of the spirit."[87] These upper level goods allow persons to pursue work aligned with reason and virtue: "[humans are] a political animal because [they are] a rational animal, because reason requires development through character training, education and the cooperation of other [humans], and because society is thus indispensable to the accomplishment of human dignity."[88] Persons are thus the social unit of societies and societies are indispensable to each accomplishing their ends. These ends include the absolute end of society as the common good that flows back towards persons to allow them to continue evolving. Through this logic Maritain establishes a direct correlation between the person and the common good. The two imply one another and actively participate in an iterative process to achieve the good of the social community of persons.

[86] Scrandis, "Jacques Maritain on the Rights of Man and the Common Good," 617.

[87] Scrandis, "Jacques Maritain on the Rights of Man and the Common Good," 617.

[88] Maritain, *The Person*, 38-39.

Maritain is quick to distinguish between the common good of the whole and the collection of goods of individual persons, naming such thinking an error because a society's common good,

> [i]s neither the mere collection of private goods, nor the proper good of a whole which, like the species with respect to its individuals or the hive with respect to its bees, relates the parts to itself alone and sacrifices them to itself. It is the good human life of the multitude, of a multitude of persons; it is their communion in good living. It is therefore common to both *the whole and the parts* into which it flows back and which, in turn, it must benefit from it [emphasis Maritain's].[89]

Participating in the common good allows persons to increase in their capacity to live good, free, autonomous lives, which can only happen if societies guarantee persons' fundamental rights to ensure they can live such lives.[90] From this philosophy, the common good does not solely comprise the advantages necessary for each individual to live a good life but is a good unto itself.

Maritain argues that if society's common good were solely to be the sum of individual goods, society would devolve into anarchy because "the entire duty of society [would consist] in seeing that the freedom of each one be respected, thereby enabling the strong to freely oppress the weak."[91] Differing wholly from preconceptual anarchy, the common good is a moral fixture of society focused on the existence and wellbeing of persons, more so the "just and morally good existence of the community."[92] History has

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[89] Maritain, *The Person*, 41.

[90] Maritain, *The Rights of Man*, 9; Maritain, *The Person*, 41.

[91] Maritain, *The Rights of Man*, 8.

yet to witness the full achievement of the common good in any society, but the end of the common good remains "to procure the good of the multitude in such a way that the concrete person gains the greatest possible measure, compatible with the good of the whole, of real independence from the servitudes of nature."[93] Carefully explaining each dimension of the whole person allowed Maritain to articulate the urgency of protecting persons and the common good. And true to his Catholic faith, that urgency did not end on earth.

Maritain ultimately wanted society to understand that persons as wholes reflect their supreme analogue, God. Therefore, society is a whole composed of wholes. Society then becomes a reflection of the divine society above (angels) while also being connected to material society below (nonhuman animals). Angels are pure persons with a pure common good lacking material individuality, and nonhuman animals are pure material individuals with material needs lacking personality and a common good.[94] Human societies exist between the angels and nonhuman animals as "a society of persons who are material individuals, hence isolated each within itself but nonetheless requiring communion with one another as far as possible here below in anticipation of that perfect communion with one another and God in life eternal."[95] Although humans are the lowest

[92] A major strength of Maritainian personalism is his balance between utility and anarchy while avoiding both. By holding the individual and society as equally important, despite the potential that their goods may conflict if an individual chooses opposite the common good, Maritain reinforces persons' capacity to live moral lives and choose the common and eternal good. *See* Maritain, *The Person*, 43.

[93] Maritain, *The Person*, 44.

[94] Maritain, *The Person*, 48-49.

[95] Maritain, *The Person*, 49.

level of persons because of material individuality, they are still persons requiring a greater whole to achieve their perfections and meet their needs due to material deficiencies. Conversely, with God as humanity's ultimate end, humans are elevated higher than all other material beings because their souls are worth more than all materiality.[96] The common good then becomes subordinated to the eternal good, just as natural law is subordinate to the eternal law.

The common good's subordination to the eternal good also serves as an example for persons in cases where they must subordinate themselves to the good of society. This subordination creates a paradox between individual and social human flourishing. Because persons and society exist around and within one another, "[humans] finds [themselves] subordinating [themselves] to the group, and the group attains its goal only by serving [humans] and by realizing that [humans have] secrets which escape the group and a vocation which the group does not encompass."[97] This reality creates tension because persons are naturally part of society; yet, they are also independent because they are masters of themselves. In such instances, persons lose themselves temporally to society for its wellbeing, "in the most real and complete fashion. Yet the person is not defeated. The [society] still serves it because the soul of [humans] is immortal and because the sacrifice gives grace one more chance."[98]

[96] Maritain, *The Person*, 50-52.

[97] Maritain, *The Rights of Man*, 13.

[98] Maritain, *The Person*, 56.

Possessing an immortal soul allows human persons to own their existence without demand from society, which can promote the common good and society's ability to engage in the common good for generations. The opposite is also possible, that in owning their existence, human persons can work against the common good, squandering opportunities and destroying lives. Both possibilities hold true because social life exists between two opposite ends: the freedom of persons and the enslavement of persons considered only by their material individuality.[99] Maritain articulated this tension two ways, as "collective moral transgression into which a people may fall, and the collective moral recovery to which they may be bound in conscience."[100] When persons choose to work against the common good, squandering opportunities and destroying life,

> [t]he true question concerns a people's awareness or lack of awareness of the evil by which they allowed themselves to be contaminated, and of which the members of a community (even those who remained personally immune, even those who fought against that evil) recognize or do not recognize that the community was guilty. It is not good for a people to humiliate itself before others. But it is not good for a people to settle into stiff-necked pride. There is a way of beating the breast and accepting abjection which destroys the dignity of a nation. But there is also a way of refusing to beat the breast, while deceiving one's conscience and nurturing hatred, which destroys this dignity just as unmercifully. Is there no way out of this dilemma? Is there not a way of acknowledging, with sorrow and strength of soul, the faults of the community to which one belongs, and of desiring at all cost that the community atone for them and free itself of them -- a way which, for a people determined to rehabilitate itself morally, is at the same time an evidence and a safeguard of its dignity?[101]

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[99] Maritain, *The Person*, 67.

[100] Jacques Maritain, "The Possibilities for Co-Operation in a Divided World," in *The Range of Reason* (South Bend, IN: University of Notre Dame Press, 2005), 176-177.

[101] Maritain, "The Possibilities for Co-Operation in a Divided World," 176.

There are moral implications to choosing against the common good, leaving society reeling from its complicity in the destruction of life. Maritain witnessed this moral crisis throughout World War II. While health disparities are incomparable to war, their prevalence suggests communal complicity in devaluing the personhood of each group of people suffering from debilitating, yet preventable conditions. National health disparity landscape analyses, previously analyzed in the first chapter, have revealed declining health trends among U.S. citizens and clinical actions and policies that have not been framed to address persons and the promotion of their human dignity.

The crisis becomes even more glaring among birthing people. The WHO's 2023, *Trends in maternal mortality 2000-2020* provided data that the U.S. is one of eight countries, most importantly the only developed country, that experienced worsening maternal mortality rates, and one of twenty-four countries that experienced COVID-19 as a contributing factor to at least ten percent of maternal deaths in 2020.[102] Birthing people are being mistreated by being reduced to their material individuality, despite constantly striving towards being treated as whole persons, demanding the justice of society and its political leaders to impose new actions that engage them as moral agents to whom appeals to reason and free will can be made.[103]

Maritain named these marginalized communities, "prophetic shock-minorities… leavening agents that awaken the people to a higher will," challenging society to

[102] *Trends in maternal mortality 2000 to 2020: estimates by WHO, UNICEF, UNFPA, World Bank Group and UNDESA/Population Division* (Geneva: World Health Organization, 2023).

[103] Maritain, *The Person*, 68-69.

recognize their personhood over their material utility.[104] In the next chapter, black birthing people and their advocates for improved birthing practices and policies will be analyzed as prophetic shock minorities working to recenter their personhood as they combat critical mortality and morbidity statistics. But first, an analysis of how Maritain's personalism helps us pursue moral repair in the face of the moral wrong of health disparities must be conducted.

Maritainian Personhood in Conversation with Health-Disparate Communities

Maritain's personalism provides important insights to the ideals to which we should aspire in our treatment of one another as members of society working towards our common good. By attending to the material needs of our individuality and the intellectual and spiritual needs of our personality, Maritainian personalism places our wellbeing in community as whole persons deserving of a life towards ultimate fulfillment because we are endowed with a dignity reflective of God. Therefore, his view of human beings, rooted in dignity with entitlements to fundamental rights by virtue of human nature, can directly impact the ways we care for communities experiencing overbearing loads of disparity across the U.S. Maritain proves that our ideas of human nature show up socially and politically, and clinical and policy encounters are not excluded from our ideas of humanity and the common good.

Moreover, Maritainian personalism empowers international rights rhetoric grounded in morals rights. While international instruments are evidence that all cosigning

[104] John Dunaway, *Jacques Maritain* (Boston: Twayne Publishers, 1978), 83.

nations agree to human rights and their protection, they do not define what it means to be human. As such, every society that has signed on to the UDHR and its supporting conventions must decide to whom human rights should be extended and for whom they should be protected. Maritain's personalism names that all humans are persons; therefore, the exclusion of any community is a moral wrong. In the case of health-disparate groups in the U.S., because they are largely demographically identifiable along lines of race and ethnicity, U.S. society has morally failed them and the protection of their rights. These communities have been wrongly excluded from the category of person because society has not contributed to their individual good, nor supported them in contributing to the common good.

Society's lack of recognizing their personhood has also resulted in health-disparate groups being barred from the very social goods in which they are entitled (*e.g.*, accessible insurance, accessible health facilities and clinicians who take seriously their concerns, affordable medication). Direct action to restore these demographically identifiable groups to whole persons, whose individuality, personality, and participation in the common good of society are protected, requires the devotion of all resources to those falling below the statistical healthy norm. To continue devoting resources to dominant groups, whose personhood is fully respected, without helping those below the norm results in a misallocation of society's resources and violates the common good.

Other personhood theories, especially those developed along utilitarian lines, can be used to argue that health disparities are bad, but they do not provide sufficient conviction to demand restorative actions through the reallocation of resources based on

our shared humanity and equal personhood. Maritain's personalism demands action through its balance of the individual and society. Both are held as absolute, inherent goods. Further, society's good is subordinate to a person's spiritual good. To respect both as absolute goods, actions must be taken to ensure persons have what is required to live good lives working towards their ends. Good health is a requirement to live a good life and society is subject to providing that good, especially a society that spends the most on healthcare of any developed nation.

Thus, moral repair begins with the U.S. taking responsibility for allowing demographically identifiable, health-disparate groups to remain below the statistical norm of health. The U.S. has not protected all of its citizens, nor has the nation treated health-disparate groups as wholes comprising the whole of the nation. "When America can admit this…it will admit that what it calls a series of crises are not that at all, but rather part of a pattern of cause and effect. America will see the interconnectedness of the privileged and the underclass, the sinner and the saint, as it were."[105] Not to do this is a violation of personhood.

In clinical settings, when we consider the good of health-disparate groups, how physicians view humans is a conduit for "whether [healthcare] sustains and deepens [their] flourishing as [humans], or whether it makes [them] ultimately a victim of [their] own inventiveness."[106] To avoid victimization to inventiveness, respect for persons

[105] Maria K. Mootry, "Confronting Racialized Bioethics: New Contract on Black America," *Western Journal of Black Studies*, 24, no. 1 (2000): 5.

[106] Pellegrino, "Humanism and Bioethics," 216.

should be a primary informant of health, care, and policy. Personhood requires that we act to protect the weakest and most vulnerable members of society, and our moral actions,

> can thus be measured in respect of the person's being and dignity...[P]ersonalist principles [guiding care and policy] include a set of duties which derive from respect of the person. These include respect of the individual's autonomy, the safeguard of confidentiality within a collective and potentially de-personifying framework, the effort to guarantee equity and equal opportunities for everyone in the allocation of health-care resources.[107]

Respect for persons also requires self-reflective moments from clinicians and policy makers as they consider the ways society and biomedicine have failed communities riddled with health disparities, the ways research and healthcare must be transformed to meet the needs of marginalized communities, and how to center lived experiences and facilitate dialogue between marginalized communities, clinicians, and policy makers in the hope of restoring trust in the healthcare system.[108]

When we engage health-disparate communities facing mounting inequities as persons according to Maritain's model, we can no longer continue engaging in a healthcare and health policy system "designed to meet the needs of a certain idealized notion of patient. Other forms of patienthood, including or refusing an intervention" must be welcomed because persons are masters of themselves and are members of a society that should engage in an iterative process of the common good to increasingly better all

[107] Carlo Petrini and Sabina Gainotti, "A personalist approach to public-health ethics," *Bulletin of the World Health Organization* (2008): 626.

[108] James, "Black Feminist Bioethics," S21.

persons and the whole of society.[109] Trusting and cultivating the freedom and dignity of persons shifts health policy and praxis from putting undue burden on unhealthy communities. Instead, the health system better engages with these communities to improve their health and aid their ability to live free, autonomous lives contributing to the common good and receiving its good back in their lives.

Conclusion

Many theories of personhood abound, and many scholars argue for the retirement of the phrase and its use in ethical decision making. Yet, Jacques Maritain's personalism, rooted in a deep Thomist tradition of natural law, remains a fertile concept to address many social injustices, especially health disparities in the U.S. His theory aligns well with the rights framework of the UDHR and supporting conventions without contradicting them. It also reframes the moral wrongs of health disparities by invoking an ontological Christian personalism. Thus, Maritainian personalism becomes an effective and necessary inclusion to policies due to its ability to highlight systemic violations of human dignity inherent in health inequities. Maritain's ontological vision of human dignity strengthens the necessity and urgency of moral repair rooted in the restoration of personhood for marginalized communities, and this has the potential to spark greater change than a rights framework alone, which we will see in the proceeding case study that addresses black maternal mortality.

[109] James, "Black Feminist Bioethics," S22.

CHAPTER FOUR: The Case of Black Maternal Mortality

"I think we're blessed when we get to wake up and we get a whole new day to do something different. So, I feel like every day is like a celebration for me."

—Tori Bowie

In the previous three chapters we explored the dire state of health disparities across marginalized demographics in the U.S. and how these disparities represent moral wrong, and examined a two-tiered framework of moral repair that can be enacted through the incorporation of international instruments enshrining human rights and Maritainian personalism grounding human nature. Putting the options for moral repair to the test, this chapter develops disproportionately high mortality among black birthing people in the U.S. as a detailed case study. As a public health crisis with deep and troubling roots in U.S. history, maternal mortality among black birthing people is representative of the complexity of disparities and intersectionality of identities that exacerbate these disparities throughout the U.S.

By examining how duty to a reclaimed notion of personhood and international rights rhetoric can inform federal policies impacting healthcare practitioners treating black birthing people, this case study delves deeply into the current conditions creating and sustaining this disparity from conception to delivery and beyond. Framing maternal mortality in terms of moral wrong then allows for the application of the right to health and supporting United Nations rights-oriented rhetoric as a first-level approach to moral repair, followed by the invocation of Maritainian personalism as a policy-relevant means of restoring and reclaiming personhood and equitable health for black birthing people

through specific proposed policy measures aligned with existing Congressional recommendations.

The Faces of Maternity and Mortality

The health of black birthing people, especially black women is abysmal. Even as I begin writing this chapter *NBC News* has released an article addressing the conditions under which three-time Olympic gold medalist, Frentorish "Tori" Bowie died. Based on an autopsy performed after her April 2023 death, she was found to be eight months pregnant and suffered childbirth-related complications of eclampsia and respiratory distress.[1] The "fastest woman in the world" could not represent her way out of being a maternal mortality statistic. Stories like Tori's have become media headlines over the past eight years since the first in-depth health journalistic exploration of maternal mortality as a silent endemic most negatively affecting black and Indigenous women in the U.S.[2] As media coverage expanded on the crisis, various levels of government

[1] Eclampsia is defined as, "seizures occurring in pregnancy or after pregnancy that are linked to high blood pressure." The condition evolves from preeclampsia if a birthing person experiences a seizure, which can lead to a coma then death. A mix of risk factors exist for preeclampsia/eclampsia—preexisting hypertension, diabetes, renal disease; being at the extremes of maternal age; multiple gestations; delivering for the first time; and race. *See* "Dictionary," American College of Obstetrics, last modified 2023, https://www.acog.org/womens-health/dictionary; Chantal de Silva, "Olympic sprinter Tori Bowie died from childbirth complications, autopsy finds," *NBC News*, June 13, 2023, https://www.nbcnews.com/news/us-news/olympic-sprinter-tori-bowie-died-childbirth-complications-autopsy-rcna88995; Kathryn R. Fingar, et al. *Delivery Hospitalizations Involving Preeclampsia and Eclampsia, 2005–2014. HCUP Statistical Brief #222* (Rockville, MD: Agency for Healthcare Research and Quality, 2017).

[2] *See* Beyonce Knowles Carter, "Beyoncé in Her Own Words: Her Life, Her Body, Her Heritage," *Vogue*, August 6, 2018, https://www.vogue.com/article/beyonce-september-issue-2018; Elizabeth Chuck, "The U.S. finally has better maternal mortality data. Black mothers still fare the worst," *NBC News*, January 29, 2020, https://www.nbcnews.com/health/womens-health/u-s-finally-has-better-maternal-mortality-data-black-mothers-n1125896; April Dembosy, "Health department medical detectives find 84% of U.S. maternal deaths are preventable," *NPR*, October 21, 2022, https://www.npr.org/sections/health-

provided different responses and remedies.[3] However, these efforts did not positively impact maternal mortality, but rather reflected "inaction and confusion at the state and federal levels [saying] a lot about gridlock and bureaucratic disorganization, but also, who and what we value in our society."[4]

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shots/2022/10/21/1129115162/maternal-mortality-childbirth-deaths-prevention; Adrianna Gallardo, "How We Collected Nearly 5,000 Stories of Maternal Harm," *ProPublica,* March 20, 2018, https://www.propublica.org/article/how-we-collected-nearly-5-000-stories-of-maternal-harm; Gaby Galvin, "The U.S. Has a Maternal Mortality Rate Again. Here's Why That Matters," *U.S. News*, January 30, 2020, https://www.usnews.com/news/healthiest-communities/articles/2020-01-30/why-the-new-us-maternal-mortality-rate-is-important; Erica L. Green, "I Don't Want to Die: Fight Maternal Mortality among Black Women," *The New York Times,* January 18, 2023, https://www.nytimes.com/2023/01/18/us/doula-black-women.html; Daniel Kwateng-Clark, "Serena Williams' Birthing Experience Highlights the Danger of Black and Postpartum," *Essence,* October 24, 2020, https://www.essence.com/news/serena-williams-birthing-experience-vogue-magazine/; Nina Martin, "The Last Person You'd Expect to Die in Childbirth," *NPR,* May 12, 2017, https://www.npr.org/2017/05/12/527806002/focus-on-infants-during-childbirth-leaves-u-s-moms-in-danger; Nina Martin, "Lost Mothers: The New U.S. Maternal Mortality Rate Fails to Capture Many Deaths," *ProPublica*, February 13, 2020, https://www.propublica.org/article/the-new-us-maternal-mortality-rate-fails-to-capture-many-deaths; Sarah Toy, "U.S. Maternal Mortality Hits Highest Level Since 1965," *Wall Street Journal,* March 16, 2023, https://www.wsj.com/articles/u-s-maternal-mortality-hits-highest-level-since-1965-f9829776; Linda Villarosa, "Why America's Black Mothers and Babies Are in a Life-or-Death Crisis," *The New York Times,* April 11, 2018, LexisNexis Academic.

[3] "In 2018, the federal government passed the Preventing Maternal Deaths Act, which provided federal grants to states that actively investigate maternal deaths; fifty-seven members of Congress joined the newly formed Black Maternal Health Caucus; and Illinois senator Dick Durbin and representative Robin Kelly introduced the Mothers and Offspring Mortality and Morbidity Awareness Act (MOMMA Act), which would 'improve access to culturally-competent care' and extend Medicaid coverage to a full year postpartum. And a few days before Mother's Day in 2019, Senator Cory Booker and Representative Ayanna Pressley introduced a bill called the Maximizing Outcomes for Moms through Medicaid Improvement and Enhancement of Services Act (MOMMIES Act), which extended Medicaid coverage—which was required to last sixty days following birth, though some states had longer periods of coverage—for postpartum women to a year after giving birth and explicitly supported 'services that are proven to positively impact maternal health outcomes for black women,' including doulas and midwives." New York, Minnesota, and Oregon all announced expanded Medicaid coverage as a measure to address black maternal mortality in 2018 and San Francisco partnered with local non-profits to help expand doula access for black pregnant people. Baltimore began a program to train residents to become doulas and Washington D.C. formed a commission to address the worrying maternal mortality rates in various geographic areas of the city that far exceeded the already dire national average. *See* Jennifer C. Nash, *Birthing Black Mothers* (Durham, NC: Duke University Press, 2021), 11.

[4] Nash, *Birthing Black Mothers*, 11.

To understand how black birthing people have been undervalued in U.S. society and remain unsuccessful in educating, parenting, politicizing, and working their way out of maternal mortality disparities, I would like to tell the stories of two births. One is a complicated birth that led to death. The other is a complicated birth that avoided death. To tell these stories, I will craft semifictional narratives that help readers understand the fullness of what is at stake in pregnancies, deliveries, and birth outcomes. I am inspired by two figures, Amber Isaac Rose and T'Nika, whose lived experiences are sketched in various places, but I will fill in details relevant to how complexity arises and is managed. For example, I narrate specific symptoms of pregnancy-related complications, reasons informing desired care and fears, and social determinants of health that are obstacles to adequate health care, all of which fill the gaps of birthing encounters experienced by innumerable birthing people. By integrating narrative elements from many other birthing experiences, historically and contemporarily narrated, the reader will be well prepared in having a more complete understanding of what goes wrong and right in complicated birthing cases.

Ebony[5]

[5] Ebony is inspired by real-life Amber Rose Isaac. Although I started studying maternal mortality years prior to Ms. Isaac's death, she stays with me because she died in New York at the height of the COVID-19 pandemic. As I struggled to breathe and finish my fourth semester in my PhD program, I regularly checked Twitter for advice on managing the still unknown symptoms of the virus. My search for answers to strengthen my own health overlapped with Ms. Isaac's struggles to save her life and that of her son's. Since coming across her first tweet hours after she began sounding off social media alarms, I have followed her delivery, death, and partner's ongoing journey to join others of us in the fight to end this senseless pandemic of black maternal mortality. *See* Alexandra Villareal, "New York mother dies after raising alarm on hospital neglect," *The Guardian*, May 2, 2020, https://www.theguardian.com/us-news/2020/may/02/amber-rose-isaac-new-york-childbirth-death; Claudia Irizarry Aponte, "'Every Day I Wake Up Fighting For Her:' A Year After the Childbirth Death of Amber Rose Isaac, What's Changed?,"

Ebony was a vibrant, Dominican/African American, twenty-seven-year-old, first-time pregnant person. The only child of her parents born and raised in Brooklyn, Ebony remained in New York and attended Queens College where she studied psychology and neuroscience. Upon graduation, Ebony became an early childhood educator in Harlem with dreams of bringing an arts therapy program to low-income families in the Bronx and Harlem. Her lifelong goal was to expand the program into a school with grounded academic guidance and financially supported extracurricular activities for underserved communities. She came a step closer to this dream when she met her partner, Brian, a financial consultant who was immediately drawn to her natural leadership skills and gentle attention. He too shared the vision of giving back to underprivileged communities through education and vocational opportunities. He supported her plan to return to graduate school to complete a master's in education.

Just as Ebony was entering her second year in her graduate program, she and Brian learned they were pregnant and immediately began shifting their lifestyle to accommodate a healthy pregnancy and a house full of children and unconditional love. The couple began researching studies and purchasing books, soon learning that the older and more educated a black woman is, the worse her maternal mortality and preterm birth

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The City, April 20, 2021, https://www.thecity.nyc/health/2021/4/20/22394884/year-after-childbirth-death-of-amber-rose-isaac-whats-changed; "Our Beloved Roses," *Save A Rose Foundation*, last modified 2022, https://www.savearosefoundation.org/our-beloved-roses

rates become in the U.S.[6] Ebony and Brian did not let the statistics deter them from their happiness.

They began shifting their diets to remove as many processed foods as possible and focus on consuming more vegetables, fatty fish, fruits, whole grains, low-fat dairy, and lean proteins. They scoured state insurance databases to find the highest rated obstetricians and hospitals within their insurance network. They talked with Ebony's mother to get recommendations for best practitioners at the hospital she worked at as a nurse for two decades. After receiving a free consultation with one of her mother's colleagues, Ebony and Brian began drafting a birth plan with hopes of avoiding a cesarean section, instead giving birth naturally with as few drugs possible. Ebony exercised regularly and went as far as arriving half an hour early to every prenatal appointment to ensure she was not viewed as non-compliant.

Ebony's was a model pregnancy for the first five months. She had minimal pain and swelling, her morning sickness only lasted a few days, and she felt lots of energy as she and the fetus grew. The ease of her pregnancy began changing the closer she

[6] In a 2017 study, Tracy Manuck researched the connection between blackness and preterm births. Manuck identified education and socioeconomic status as possible markers for preterm birth and low birthweight and cited a study examining college graduates across races and ethnicities. The results found that even "after controlling for any variables that they could identify between the graduates, Black female college graduates had a higher risk of delivering preterm (1.28) or having a low-birthweight baby (1.75)." Even among foreign-born and domestic-born black women, foreign-born black women have lower statistical outcomes of preterm birth or low-birthweight because of their reduced exposure to U.S. discrimination. *See* Monique Rainford, *Pregnant While Black: Advancing Justice for Maternal Health in America* (Minneapolis, MN: Broadleaf Books, 2023), 49; Tracy A. Manuck, "Racial and Ethnic Differences in Preterm Birth: A Complex, Multifactorial Problem," *Seminars in Perinatology* 48, no. 8 (2017): 511-518; Gene A. McGrady et al., "Preterm Delivery and Low Birth Weight Among First-Born Infants of Black and White College Graduates," *American Journal of Epidemiology* 136, no. 3 (1992): 266-276; Irma T. Elo et al., "Variations in Birth Outcomes by Mother's Country of Birth Among Non-Hispanic Black Women in the United States," *Maternal and Child Health Journal* 18, no. 10 (2014): 2371-2381.

approached the six-month mark. She found the energy she once had begun fading quickly. Working with the children became a daily struggle as exhaustion and a persistent headache crept up more quickly with each passing day. Because her symptoms came and went, she did not feel the need to be overly concerned. She opted to inform her care team the next time she went in for labs.

After an appointment to have bloodwork evaluated, Ebony noticed her platelet count was quite low given the healthy range noted in her medical records. She researched the significance of platelets and learned they are essential to blood clotting. Her low levels could evolve into HELLP syndrome if left untreated.[7] She paired the low platelet count with the ebb-and-flow symptoms she was recently experiencing, then looked at previous results and noticed her platelet count had been declining for months. She immediately scheduled a telehealth appointment to bring this to the attention of her obstetrician and determine a proper course of action. Not receiving a satisfactory plan of care, Ebony and Brian began researching home births and connected with a black midwife who was also a certified doula. The midwife was immediately concerned about Ebony's lab results, including her platelet count, potential anemia, chronic fatigue, and headaches. She suggested the two plan for bedrest and sadly rejected them as clients because Ebony's pregnancy was too high risk considering the factors. She urged the

[7] HELLP syndrome—hemolysis, elevated liver enzymes, and low platelets—is a severe form of preeclampsia that can develop after the twentieth week of pregnancy. It "involves new onset of high blood pressure and protein in the urine. However, women can have preeclampsia even without protein in the urine if they have other abnormalities usually detected by blood tests or if they have a headache that does not go away with medication or is not explained by other factors." *See* Rainford, *Pregnant While Black*, 65; "HELPP Syndrome," March of Dimes, last modified 2023, https://www.marchofdimes.org/find-support/topics/planning-baby/hellp-syndrome

couple to find another clinician who would be more attentive to the already alarming numbers.

Given the limitations of their insurance network, other obstetricians receiving new patients were out of network. Ebony and Brian decided to persevere with their current provider with the plan to pay particular attention to her platelet count the next time bloodwork would be performed and consult with the midwife once more. At the following seven-month labs appointment, the couple attended together and asked the obstetrician to immediately walk through the results with them in hopes of establishing a new care plan given the increasing risk of the pregnancy. The obstetrician agreed and realized the severity of Ebony's circumstance. She had indeed developed HELLP syndrome. They rapidly scheduled an emergency cesarean section approximately six weeks ahead of her due date. She was rushed to the emergency wing where she had to deliver alone via a birthing route she worked very hard to avoid.

The emergency care team successfully delivered Brian and Ebony's child, a healthy baby girl, but Ebony did not survive the C-section. Brian and the rest of Ebony's family were later informed that her blood was like water and would not clot. Her heart stopped as her daughter was being removed from her uterus. The surgeons attempted a last-ditch effort to remove her uterus while massaging her heart to both stop the bleeding and keep her heart pumping. Ebony tragically died seconds after her daughter was born, weeks prior to her graduation from her M.Ed. program, and a lifetime away from the house full of children's chaos and her loving partner. Her partner and child were left with a gaping hole and a $7,000 hospital claim because Ebony's emergency C-section did not

receive prior authorization. They would spend months fighting the insurance company to prove the medical necessity of all services received and years fighting the hospital to acknowledge the preventability of Ebony's death.

Ebony died from the number one condition impacting black birthing people in the U.S.—high blood pressure disorders during pregnancy. For people like Ebony who have died from blood-pressure related conditions during pregnancy, it is not "that they did not try to get the attention they needed in a timely manner rather it was a failure of the clinicians and/or the healthcare system to give them the timely care that they required."[8] How differently could her pregnancy and delivery have transpired? Ahadi represents a different experience of pregnancy and maternal care that could be provided and is provided to a minority of birthing people in the U.S. considering the statistics and narratives that exist around pregnancy, delivery, and postpartum care.

Ahadi[9]

Twenty-eight-year-old Ahadi resided on the other side of the country in Portland, Oregon. She was the archetypal oldest of four children who always prioritized her siblings' wellbeing as they moved around the country for her parents' different vocational assignments. Eventually her family returned to the Pacific Northwest and settled in an

[8] Rainford, *Pregnant While Black*, 67.

[9] Ahadi is inspired by real life T'Nika, a birthing person profiled in a collection of journalist anecdotes to understand the different experiences of pregnancy and birth that can occur across the U.S. T'Nika was chosen because she lived. She did not experience an easy pregnancy, but she had great resources in place and a care team that prioritized her wellbeing. It is unfortunate that T'Nika's experience is still a minority experience for birthing people in the U.S., but it speaks to the different opportunities for moral repair and how those actions can be successful in the future. *See* Rebecca Grant, *Birth: Three Mothers, Nine Months, and Pregnancy in America* (New York: Simon & Schuster, 2023).

ethnically diverse community to provide balance to the majority white regional population. Because of her parents' commitment to diversity, close family ties, education, and activism, Ahadi always felt a strong sense of pride in her African American culture and the lived experiences of black communities across the country. The commitments of Ahadi's parents also inspired her to become a nurse in a labor and delivery department as a part of the state's changing medical culture focused on creating safe spaces for marginalized birthing people to have healthy and affirming pregnancies and deliveries.

Her journey to become a nurse was extremely challenging but she always felt supported by her husband, Darren, whom she met and began dating in middle school. The lifelong history the two had always gave her the confidence she needed to face the seemingly insurmountable task. As Ahadi gained more nursing experience and participated in more deliveries, she began mapping what she wanted for her future pregnancies. She and Darren began actively trying to get pregnant in the hopes of having their first child before they turned thirty. Several months later they hovered over a positive pregnancy test. Unbeknownst to her, Ahadi would share a due date with Ebony.

Ahadi always dreamed of giving birth at a birthing center just as her mom had done for all her children and years of working in hospitals cemented her dream into a practical decision. Although health culture was positively changing in her state faster than the rest of the country, she and Darren were not willing to compromise on their birthing plan. They wanted an attentive environment with staff who had a long history of working together. They were both adamant about Ahadi avoiding a caesarean section and deeply desired that she be cared for by a care team that respected their decisions. Most

importantly, Ahadi and Darren wanted to be cared for by a staff that welcomed many different ways of giving birth, including the ways in which they were trained in their clinical programs.

After a month of intense research, they found the perfect birth center staffed with seven midwives, each of whom had an apprentice. Two midwives of Ahadi and Darren's choice would be their primary care contacts throughout the pregnancy. Between Ahadi's private insurance through the hospital and Darren's private insurance through his tech firm, their care would be covered sixty percent and they would only need to come out of pocket $3,000, money they considered to be a minor investment for a healthy journey and living mom and child at the end.

Unlike Ebony, Ahadi's pregnancy was challenging through its entirety. Every issue she resolved birthed a new set of debilitating symptoms. From constipation that rendered her nearly immobile to severe headaches, weight loss, urinary tract infections, swelling limbs, intense hormonal itching, and ligament pain, Ahadi was taking pain relievers around the clock. She also stayed in near constant communication with the midwives at her birthing center each time a new ailment occurred. Darren was afraid she would worry their care team too much, but the staff was always compassionate as they listened deeply and took seriously every symptom. Their care team knew the challenges and fears of pregnancy, and they always provided several courses of action, from least to most medicalized. Ahadi and Darren had their pick of treatments, and something always worked successfully.

Ahadi was ill-prepared for the symptoms she did experience and overly prepared for those she did not. At every appointment she was waiting to hear that her blood pressure was too high, and she had developed preeclampsia. Her blood pressure remained normal throughout her pregnancy as she actively worked to keep her home and work stressors to a minimum. Near the beginning of her second trimester, she applied for a better paying nurse practitioner position at another hospital. Upon receiving her offer, she and Darren had to reconfigure their insurance coverage and apply for new parental leave benefits. Ahadi's job worked with her to provide six weeks of short-term disability and sixty-five percent of her new salary over that time. Darren was guaranteed five weeks of parental leave and permanent remote status.

As Ahadi and Darren's due date arrived, Ahadi began experiencing intense pain and Braxton-Hicks cramps, those pesky false labor pains that replicate the feelings of labor. She went to the birth center for an appointment and tips on pain management. There she learned labor had begun, a state she would remain in for thirty-eight hours. She walked for miles and took water baths throughout the day. Her hope was to avoid an epidural because she wanted to give a natural birth, but the pain became unbearable. Her midwives advised her to go to her local hospital for better pain management, a decision that made her hesitant because she did not want to face colleagues who may not understand her desire to be cared for at a birthing center.

The pain soon outweighed the hesitation and she found herself in her old labor and delivery unit. Before receiving pain medication, clinicians performed an ultrasound and found that her daughter's head was tilted into her pelvis, the primary source of the

pain and delayed labor. Their best solution was her least favored, a C-section. She and Darren were faced with a hospital birth by a clinician they did not research nor choose, a decision that was the exact opposite of everything they planned. As her cramps intensified, Ahadi agreed to the C-section.

One hour later she was holding a healthy baby girl that weighed six pounds, four ounces. The pain from her incision exhausted her but she fought to take in the moment with her expanded family. Ahadi and Darren planned for her to be home no more than three days after their daughter was born, but Ahadi's stitches kept coming undone leaving her incision susceptible to infection. Her old unit would be home for three weeks as multiple doctors and nurses examined her body day and night. They were eventually able to find a successful solution, allowing Ahadi to return home and have her remaining follow up appointments with the birthing center. While her hospital stay was undesirable, it opened her eyes to the ongoing reforms needed in post-partum care, giving her new motivation upon her return to work.

The Problematic Data of Maternity and Mortality

Statistics

The experiences of our case study characters occur annually throughout the country for thousands of birthing people. As detailed as Ebony and Ahadi's narratives are, there are far more systemic nuances that color the care birthing people receive and their health outcomes. A March 2023 report issued by the National Center for Health Statistics shared updated data on maternal mortality rates in the country.

> In 2021, 1,205 women died of maternal causes in the United States compared with 861 in 2020 and 754 in 2019. The maternal mortality rate for 2021 was 32.9 deaths per 100,000 live births, compared with a rate of 23.8 in 2020 and 20.1 in 2019.
>
> In 2021, the maternal mortality rate for non-Hispanic Black (subsequently, Black) women was 69.9 deaths per 100,000 live births, 2.6 times the rate for non-Hispanic White (subsequently, White) women (26.6). Rates for Black women were significantly higher than rates for White and Hispanic women. The increases from 2020 to 2021 for all race and Hispanic-origin groups were significant.
>
> Rates increased with maternal age. Rates in 2021 were 20.4 deaths per 100,000 live births for women under age 25, 31.3 for those aged 25-39, and 138.5 for those aged 40 and over. The rate for women aged 40 and over was 6.8 times higher than the rate for women under age 25. Differences in the rates between groups were statistically significant. The increases in the rates between 2020 and 2021 for each of these age groups was statistically significant.[10]

Regardless of race and ethnicity, the U.S.'s maternal mortality rates in 2021 were approximately ten times higher than those of other high-income nations. Nations such as Norway and Australia report two to three deaths per 100,000 live births.[11] The West Bank and Gaza Strip, which have experienced catastrophes on global scales, have lower maternal mortality ratios than the United States.

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[10] "Consistent with previous reports, the number of maternal deaths does not include all deaths occurring to pregnant or recently pregnant women, but only deaths with the underlying cause of death assigned to *International Statistical Classification of Diseases, 10th Revision* code numbers A34, O00-O95, and O98-O99. Maternal mortality rates are per 100,000 live births, based on data from the National Vital Statistics System natality file. Maternal mortality rates fluctuate from year to year because of the relatively small number of these events and possibly due to issues with the reporting of maternal deaths on death certificates. Efforts to improve quality are ongoing, and these data will continue to be evaluated for possible errors. Data are shown for only the three largest race and Hispanic-origin groups for which statistically reliable rates can be calculated." *See* Donna L. Hoyert, "Maternal mortality rates in the United States, 2021," *NCHS Health E-Stats* (2023): doi:10.15620/cdc:124678.

[11] "Country Comparisons-Maternal mortality ratio," CIA World Factbook, last modified 2023, https://www.cia.gov/the-world-factbook/field/maternal-mortality-ratio/country-comparison

It must be noted that accurately reporting and identifying maternal deaths remains a challenge in the U.S. Currently, official statistics are captured through death certificates, which are completed by clinicians and shared with states. "To promote standardization, the National Center for Health Statistics (NCHS) periodically organizes a national consensus process that makes recommendations to states on the content of birth and death certificates."[12] Prior to the implementation of this consensus process, states used different reporting methods, resulting in differing statistics. To better standardize state reporting, a pregnancy checkbox was added to death certificates and physicians were encouraged to check the box if they were aware of a pregnancy during the time of death. Implementation has varied by state, but all states have added the box as of 2017.[13] This checkbox further resulted in a substantial increase in identified maternal deaths, "capturing twice the rate of maternal deaths through death certificates."[14] Because states slowly implemented the checkbox on death certificates, accurately assessing maternal mortality trends remains challenging. There is still no conclusive answer regarding whether deaths have increased due to more accurate reporting or due to increased deaths. In the absence of a conclusive answer and a centralized data-collection

[12] "Detailed Evaluation of Changes in Data Collection Methods," NCHS, last reviewed November 21, 2019, https://www.cdc.gov/nchs/maternal-mortality/evaluation.htm.

[13] "Detailed Evaluation of Changes in Data Collection Methods"; Donna L. Hoyert et al., "Evaluation of the Pregnancy Status Checkbox on the Identification of Maternal Deaths," *National Vital Statistics Reports* 69, no. 1 (2020): 1-23; Lauren M. Rossen et al., "The Impact of the Pregnancy Checkbox and Misclassification on Maternal Mortality Trends in the United States, 1999-2017," *National Center for Health Statistics* 3, no. 44 (2020): 1-49; Donna L. Hoyert et al., "Maternal Mortality in the United States: Changes in Coding, Publication, and Data Release, 2018," *National Vital Statistics Reports* 69, no. 2 (2020): 1-16.

[14] "Detailed Evaluation of Changes in Data Collection Methods."

system with consistent reporting, the U.S. still relies on data from different agencies to better understand the nuances of maternal deaths.

Upon analyzing federal data from the Centers for Disease Control and Prevention (CDC), approximately twenty-two percent of maternal deaths occur during pregnancy, twenty-five percent occur between the day of delivery and one week after delivery, twenty-three percent of deaths occur between seven and forty-two days postpartum, and thirty percent of deaths occur between forty-three days and one year postpartum.[15]

> The 6 most frequent underlying causes of pregnancy-related death — mental health conditions (22.7%), hemorrhage (13.7%), cardiac and coronary conditions (12.8%), infection (9.2%), thrombotic embolism (8.7%), and cardiomyopathy (8.5%) — accounted for over 75% of pregnancy-related deaths…Leading underlying cause of death varied by race and ethnicity. Cardiac and coronary conditions were the leading underlying cause of pregnancy-related deaths among non-Hispanic Black persons; mental health conditions were the leading underlying cause of death among Hispanic and non-Hispanic White persons; and hemorrhage was the leading underlying cause of death among non-Hispanic Asian persons. The leading causes of pregnancy-related death among non-Hispanic American Indian or Alaska Native (AIAN) and non-Hispanic Native Hawaiian and other Pacific Islander (NHOPI) persons were not ranked because of small population size.[16]

Maternal mortality review committees determined that eighty-four percent of deaths surveyed were preventable. Further, "[t]he most common factors identified as contributing to the death were patient/family factors (*e.g.*, lack of knowledge on warning

[15] Susanna Trost et al., "Pregnancy-Related Deaths: Data from Maternal Mortality Review Committees in 36 US States, 2017-2019," Centers for Disease Control and Prevention, US Department of Health and Human Services, last modified September 19, 2022, https://www.cdc.gov/reproductivehealth/maternal-mortality/erase-mm/data-mmrc.html.

[16] Trost et al., "Pregnancy-Related Deaths."

signs and need to seek care) followed by provider (*e.g.*, misdiagnosis and ineffective treatments) and systems of care factors (*e.g*., lack of coordination between providers)."[17]

The growth in maternal deaths captured by accurate reporting did not occur overnight but has been informed by steadily increasing trends across maternal care for decades. Between 1993 and 2014 hypertensive disorders (*e.g.*, preeclampsia) in pregnancy increased approximately seventy-two percent and preeclampsia specifically become sixty percent more common and severe in black birthing people than all other racial and ethnic groups.[18] Birthing people at higher risk of developing preeclampsia are also more likely to experience cesarean sections—with black birthing people more often existing at the dangerous intersection of preeclampsia, c-section, and death, "placental abruption, disseminated intravascular coagulation, cerebral hemorrhage, pulmonary edema, and renal failure."[19] In surveys conducted in the past decade by the Healthcare Cost and Utilization Project (HCUP), preeclampsia is most common among birthing people in the poorest areas whose payer is Medicaid and their birthing outcomes often result in adverse outcomes for the infant.[20] Despite the worsening statistics, there is yet to

[17] "Building U.S. Capacity to Review and Prevent Maternal Deaths," Report from nine maternal mortality review committees, last modified 2018, http://reviewtoaction.org/Report_from_Nine_MMRCs.

[18] Fingar et al., *Delivery Hospitalizations Involving Preeclampsia,* 1.

[19] Fingar et al., *Delivery Hospitalizations Involving Preeclampsia,* 1.

[20] It is important to note, HCUP data does not imply Medicaid causes preeclampsia and worsening infant health outcomes. Yet, more research is needed to understand the impacts of environmental racism and poverty as they coalesce in poor zip codes across the nation. These impacts can reveal opportunities for improved community services, additional health payer options, and better staffed healthcare facilities in these areas. *See* Fingar et al., *Delivery Hospitalizations Involving Preeclampsia,* 9.

exist any formalized population-level data-gathering on hypertensive disorders in pregnancy, their prevalence, nor coexisting complications that exacerbate the conditions.

Severe maternal morbidity is also increasingly plaguing poor birthing people of color whose payer is Medicaid, most often black people who accounted for sixty-six percent of the impacted population.[21] Specifically in 2015, black birthing people were hospitalized at a rate of 240.7 per 10,000 hospitalizations. This rate is forty-nine percent higher than hospitalizations of Hispanic birthing people, seventy-four percent higher than those among Asian and Pacific Islander peoples, and 112% higher than those among white people. In-hospital death statistics were far starker. Black birthing people died at a rate of 10.9 deaths per 10,000 hospitalizations, 123% higher than Hispanic communities and 193% higher than white communities.[22] Most concerning was the decrease in severe maternal morbidity disparities among all racial and ethnic groups excluding black birthing people.

The impact of severe maternal morbidity has led to negative changes in the overall health of birthing people and increases in maternal mortality. From 2006 to 2015 researchers noted a forty-five percent increase in pregnancy hospitalizations due to severe maternal morbidity with eighty percent of those hospitalizations requiring blood

[21] Clinicians define severe maternal morbidity as, "unexpected outcomes of labor and delivery that result in significant short- or long-term consequences to a woman's health. Often called *near- misses,* deliveries involving severe maternal morbidity generally include life-threatening conditions, such as acute myocardial infarction, pulmonary embolism, or sepsis." *See* Kathryn Fingar et al., *Trends and Disparities in Delivery Hospitalizations Involving Severe Maternal Morbidity, 2006–2015. HCUP Statistical Brief #243* (Rockville, MD: Agency for Healthcare Research and Quality, 2018), 1.

[22] Fingar et al., *Trends and Disparities in Delivery Hospitalizations*, 1-2.

transfusions.[23] For every birthing person who dies, 100 birthing people experience severe maternal morbidity.

Care

Personal, clinical education, policy, and systemic failures all contribute to these statistics, but recently more attention is being given to clinical, policy, and systemic factors as authority figures move away from blaming pregnant people for their demise. According to Dr. Audra Meadows, "[t]he health care system that a birthing person is entering matters, the timing that they're entering into that health care system, the health care they receive before becoming pregnant, and then their treatment during their pregnancy and delivery matter as well."[24] Most critical concerning timing is the postpartum period in which forty to sixty percent of maternal deaths occur.

The current maternal care system does not create space for consistent check-ups for birthing people in the postpartum period leaving many patients to present to emergency departments where their symptoms are missed and ineffective treatments are offered, as opposed to presenting to obstetricians who are well versed in their medical history.[25] Missing symptoms is not relegated to emergency departments. Other specialized clinicians also regularly miss symptoms of distress and poor health during

[23] Fingar et al., *Trends and Disparities in Delivery Hospitalizations Involving*, 3.

[24] Jennifer Abbasi, "US Maternal Mortality Is Unacceptably High, Unequal, and Getting Worse—What Can Be Done About It?," *JAMA* (2023): doi:10.1001/jama.2023.11328

[25] Roosa Tikkanen et al., *Maternal Mortality and Maternity Care in the United States Compared to 10 Other Developed Countries* (New York: Commonwealth Fund, 2020).

pregnancy, as well as opportunities to provide earlier interventions to avoid preventable maternal death.[26]

The same clinicians have also been educated and practice in a healthcare system rooted in a racialized science that continues to use racially informed tools. One such tool in obstetrics and gynecology is the Vaginal Birth After Cesarean (VBAC) calculator, "which estimates success rates for vaginal birth among women with a previous cesarean delivery and uses races/ethnicity as a correction factor."[27] Initially this tool was designed to calculate the likelihood of a healthy vaginal birth considering the risk factors associated with pregnancy and previous cesarean sections. A component of the calculator is a race-based correction for black and Hispanic women that systemically assigns lower chances of successful vaginal births for these communities compared to white women, a race factor similar in nature to the eGFR factor mentioned in the first chapter. Taking account of age, body mass index, prior delivery methods, and race and ethnicity, patients can have identical answers for all categories excluding race and get different success predictions.

Returning to one of our case study patients, if Ahadi experiences a second pregnancy after her first C-section, she could be offered a trial of labor after cesarean section (TOLAC) to avoid an additional physically taxing surgery, another potential site

[26] Ching-Yu Cheng et al., "Postpartum Maternal Health Care in the United States: A Critical Review," *J Perinat Educ* 15, no. 3 (2006): 34-42; Christine Morton et al., "Translating Maternal Mortality Review Into Quality Improvement Opportunities in Response to Pregnancy-Related Deaths in California," *Journal of Obstetric, Gynecologic and Neonatal Nursing*, 48, no. 3 (2019): 252-262.

[27] Darshali A. Vyas et al., "Challenging the Use of Race in the Vaginal Birth after Cesarean Section Calculator," *Women's Health Issues* 29, no. 3 (2019): P201.

of infection and postpartum hemorrhage, and a healthier recovery if a future pregnancy after child number two is an option. If Ahadi decides to have her early appointments with an obstetrician in a hospital who uses the VBAC tool, she could present with the same BMI at the same age having previously had one cesarean section as a white patient and receive a lower VBAC score because she is black.[28] While many different variables were considered, all having clear biologic reasonings for their inclusion into the calculation, race and ethnicity remained in the absence of a biological supported mechanism.[29] If the VBAC score solely relied on the social construction of race to account for the negative health outcomes that appear epidemiologically, the tool could positively determine care of black and Hispanic birthing people. However, if the tool is a proxy for implicit stereotypes and biases that cause harm to individuals seeking vaginal births, VBAC calculators contribute to morally wrong inequities in maternal care.[30] Positively or

[28] VBAC researchers have found that the race factors, meant to be "correction factors 'subtract' from the overall likelihood of successful VBAC, so that women identified as African American or Hispanic are systematically assigned a lower chance of successful VBAC than white women. In effect, women of identical age and BMI will be predicted to have significantly different chances of successful VBAC based solely on their race/ethnicity. For example, a 30-year-old woman with a BMI of 35 and one prior cesarean for arrest of labor is assigned a 46% chance of successful VBAC if she is identified as white and a 31% chance if she is identified as African American or Hispanic. Evidence suggests providers are influenced by concerns over liability and perceived risk when counseling patients about a trial of labor after cesarean section; they may thus be less likely to offer a trial of labor to women with low VBAC scores. Given the demonstrated benefits of VBAC, if the algorithm dissuades clinicians from offering a trial of labor to these groups of women, then race-based correction in the VBAC calculator may exacerbate racial disparities." *See* Vyas et al., "Challenging the Use of Race," P201.

[29] Vyas et al., "Challenging the Use of Race," P202.

[30] Since 2020, a new VBAC calculator that excludes race has slowly been introduced to physicians. "It is unclear whether the original calculator itself contributed to poorer outcomes for patients of color, or that the updated version will change care for the better. The tool doesn't offer a binary, yes-or-no directive…[but clinicians found it] important not to have a socially constructed variable—race, ethnicity—in a predictive model because of the potential adverse consequences." *See* Katie Palmer, "Changing the equation: Researchers remove race from a calculator for childbirth," STAT, last modified

negatively, the inclusion of race continues to function as a proxy for stereotypes and biases that determine care for racial minority birthing people.

Ahadi and Ebony succumbing to undesired cesarean sections represents another pillar of the gruesome edifice of maternal death. Currently, "one in three people who give birth in America have a C-section, a rate that is roughly twice that of Europe's. In 1965, the national cesarean birth rate was 4.5 percent, and it has increased sevenfold since then, with a dramatic uptick over the past few decades."[31] WHO asserts that ten to twenty percent of births occurring via cesarean section is a healthy benchmark. Percentages beyond that range indicate the procedures are unnecessarily performed and percentages under that range indicate a necessary procedure is not extended to patients in need.[32]

While cesarean sections are more time-efficient, they are often performed because healthcare institutions can bill more for the surgery than physiological birth; therefore, many hospitals with high rates of cesareans prioritize maximizing resources and profitability.[33] Because cesarean sections can lead to hemorrhaging and blood clots,

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June 3, 2021, https://www.statnews.com/2021/06/03/vbac-calculator-birth-cesarean/; Sharon Begley, "Racial bias skews algorithms widely used to guide care from heart surgery to birth, study finds," STAT, last modified June 17, 2020, https://www.statnews.com/2020/06/17/racial-bias-skews-algorithms-widely-used-to-guide-patient-care/.

[31] Grant, *Birth*, 116

[32] WHO et al., *WHO Statement on Caesarean Section Rates* (Geneva: WHO Human Reproduction Programme, 2015).

[33] "[T]here's evidence to show that differences in cesarean rates hinge on the profit orientation of the hospitals or higher reimbursement rates for cesarean births. In one study out of UCLA, researchers found that 'hospitals with higher profits per cesarean procedure were associated with an increased probability of delivering newborns through cesarean births.' Following payment reform in California, the state saw a 20 percent reduction in low-risk cesarean rates." *See* Grant, *Birth*, 122-123; Rie Sakai-Bizmark et al., "Evaluation of Hospital Cesarean Delivery—Related Profits and Rates in the United States," *JAMA Netw Open* 4, no. 3 (2021): e212-235.

causing severe complications for otherwise healthy birthing people, they should not be used solely for time efficiency and profit maximization. Their effects can be lasting, even endangering the lives of children born via C-section. "[S]ystematic reviews have found that babies born via cesarean face an increased risk of breathing problems and chronic diseases such as asthma, Crohn's disease, type 1 diabetes, and allergies."[34] For birthing people who have subsequent children after their first cesarean, eighty-seven percent will deliver the second child via cesarean as well, increasing chances of maternal complications and death from childbirth.[35]

Beyond racialized tools, missed symptoms, and needless procedures, the maternity and mortality narrative is further complicated by a flawed data collection system and an overworked obstetric workforce. Deaths are only categorized as maternal deaths if they occur up to six weeks postpartum; yet, many people die after six weeks and up to a year. To reduce postpartum deaths and complications, WHO "recommends at least four health contacts in the first six weeks, yet U.S. women typically have a single

[34] Grant, *Birth*, 117.

[35] "[T]here is no universal agreement or standards on what necessitates a C-section or when to perform one. C-section rates vary wildly from hospital to hospital, and patient characteristics alone do not account for these swings. A national study on cesarean rates by hospital, which was published in the journal *Health Affairs* in 2015, found that C-section delivery rates at hospitals in the United States varied from 7 percent to 80. As Dr. [Neel] Shah put it, 'Your biggest risk factor for the most common surgery is not your preferences or your medical risks, but which door you walk through.'…Because NIH and ACOG have given providers little direction on how to decide whether it is safer for a woman to give birth by planned c-section or a planned vaginal delivery, maternity providers have been left to assess risk on their own, which, of course, is not an ideal situation,' said Morris. 'It allows for their own collective biases, fears, and preferences to affect how risk is assessed and to transfer this perception to women.'" *See* Grant, *Birth*, 121-122; Katy Backes Kozhimannil et al., "Cesarean Delivery Rates Vary Tenfold Among US Hospitals: Reducing Variation may Address Quality And Cost Issues," *Health Affairs* 32, no. 3 (2013): 527-535; Robert Wachter, "In Conversation With…Neel Shah, MD MPP," AHQR PSNet Collection, last modified October 30, 2019, https://psnet.ahrq.gov/perspective/conversation-neel-shah-md-mpp; Theresa Morris, *Cut It Out: The C-Section Epidemic in America* (New York: NYU Press, 2013).

office-based physician visit within this period, and some don't have one at all."[36] Single office-based visits in the U.S. is a widespread practice due to a shortage of maternity care providers compared to the number of births that occur. Compared to other nations who invest in their obstetric workforce (*i.e.,* obstetricians, gynecologists, midwives, and doulas), the U.S. has one of the lowest number of midwives and OB/GYN's—twelve midwives per 1,000 live births.

This workforce is two to six times higher in nations with robust midwifery programs whose maternal care statistics evidence that midwives "provide care that is comparable to, or sometimes even better than, that provided by obstetrician-gynecologists."[37] As a right to non-discriminatory health, WHO even recommends mid-wives as a necessity in reducing maternal mortality and morbidity, making more efficient use of healthcare resources, reducing potentially harmful and unnecessary interventions (*e.g.,* cesarean sections) for low-risk births, and improving maternal mental health.[38]

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[36] Tikkanen et al., *Maternal Mortality and Maternity*; WHO et al., *Postnatal Care for Mothers and Newborns* (Geneva: Word Health Organization, 2015); ACOG, "ACOG Committee Opinion No. 736: Optimizing Postpartum Care," *Obstetrics and Gynecology* 131, no. 5 (June 2016): e140–e150.

[37] "Midwives in many countries are key providers trained to provide a wide range of services. Among these are helping to manage a normal pregnancy, assisting with childbirth, and providing care during the postpartum period. Placing a priority on natural reproduction processes and relationship-building, midwives also can help address social and personal needs of mother, baby, and family. Ob-gyns, meanwhile, are physicians trained to identify and intervene in abnormal conditions that come up before, during, and after pregnancy. They typically provide care in hospital-based settings." *See* Tikkanen et al., *Maternal Mortality and Maternity*; Jennifer E. Moore et al., *Improving Maternal Health Access, Coverage, and Outcomes in Medicaid: A Resource for State Medicaid Agencies and Medicaid Managed Care Organizations* (Washington D.C.: Institute for Medicaid Innovation, 2020).

[38] United Nations Population Fund, *The State of World's Midwifery 2014: A Universal Pathway. A Woman's Right to Health* (New York: UNFPA, 2014).

The norm of birthing people presenting to emergency departments in the absence of a holistic gynecologic and obstetric health system leads to pregnancy being treated as a disease instead of a normal physiologic process. This framing represents issues of personhood and the devaluation of various communities across the nation, the most egregious of which is seen through the lens of obstetric violence, obstetric racism, and birth rape. In 2000, Argentinians began working to reform birthing care policies and reduce the violence birthing people experienced pre-and-postpartum, eventually codifying the Law on Humanized Childbirth in 2004 granting the right to a humanized pregnancy and birth.[39] Venezuela built on this movement and legally defined obstetric violence three years later as,

> the appropriation of the body and reproductive processes of women by health personnel, which is expressed as dehumanized treatment, an abuse of medication, and to convert the natural processes into pathological ones, bringing with it loss of autonomy and the ability to decide freely about their bodies and sexuality, negatively impacting the quality of life of women.[40]

[39] "The Law on Humanized Childbirth declares that a pregnant woman has, among others, the right to be treated with respect of her person, intimacy and her cultural customs; to be considered as a healthy person, in such a way that she can participate actively in her own delivery; to have a natural birth, according to her biological and psychological timing; to be informed about the different possible medical interventions, to choose freely among the alternatives, and to avoid invasive and unnecessary practices; to be accompanied by a trusted person chosen by her during the labor, delivery and postpartum period; to have her baby with her during her stay at the care facility; and to be informed on and to receive assistance with the breastfeeding. The law also defines the right of the newborn to be treated in a respectful and dignified manner and the rights of parents to participate in the child's care. This and subsequent laws, enacted to protect the rights of women and patients (Law no. 25,673) for the implementation of the National Programme of Sexual Health established in 2006 and the National Law on Patients' Rights (2009), constitute the legal framework establishing Argentina's definition of obstetric violence." *See* Patrizia Quattrocchi, "Obstetric Violence Observatory: Contributions of Argentina to the International Debate," *Medical Anthropology* 38, no. 8 (2019): 762-776.

[40] República Bolivariana de Venezuela, *Ley Orgánica sobre el derecho de las mujeres a una vida libre de violencia* (Caracas, Venezuela: República Bolivariana de Venezuela, 2007); Rogelio Perez D'Gregorio, "Obstetric violence: A New legal term introduced in Venezuela," *International Journal of Gynecology and Obstetrics* 111, no. 3 (2010): 201-202.

Under the Organic Law on the Right of Women to a Life Free of Violence, nonconsensual cesareans and inductions are criminalized under human rights law, effectively representing gender-based violence.[41]

As the concept of obstetric violence took hold in Argentina and Venezuela, the "[r]acial disparities in birthing experiences, outcomes, mortality, and postpartum health…suggest that Black women's perinatal experiences are the quintessential case of obstetric violence, most deeply and explicitly indicative of the violence of birth."[42] This suggestion led Dana-Ain Davis to further develop the concept of obstetric violence into obstetric racism to characterize the experiences of black birthing people. She places obstetric racism at the intersection of obstetric violence and medical racism, defining it as "a form of gender-based violence experienced by people giving birth who are subjected to acts of violence that result in their being subordinated *because* they are obstetric patients…Obstetric violence includes dehumanizing treatment and medical abuse such as birth rape, or violations experienced during childbearing."[43] Together, obstetric violence, obstetric racism, and birth rape contribute to dehumanizing care for black birthing people

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[41] Nash, *Birthing Black Mothers*, 79; Elizabeth Kukura, "Obstetric Violence," *The Georgetown Law Journal* 106 (2018): 712-801; WHO, *The Prevention and Elimination of Disrespect and Abuse During Facility-Based Childbirth* (2015), http://www.who.int/reproductivehealth/topics/maternal_perinatal/statement-childbirth/en/.

[42] Nash, *Birthing Black Mothers*, 79; Grant, *Birth*, 122.

[43] Scott Dunlop defines birth rape as "happening when a medical professional uses forced or unnecessary procedures in order to facilitate a birth, without the mother's consent (or even in direct contradiction of her wishes). It could be the insertion of forceps into the woman's birth canal, or, as shocking as it sounds—as bad as the experience of a mom who was drugged with general anesthetic and given a C-section without even being aware that it was being done." *See* Dana-Ain Davis, "Obstetric Racism: The Racial Politics of Pregnancy, Labor, and Birthing," *Med Anthropol* 38, no. 7 (2019): 560-573; Scott Dunlop, "Is 'birth rape' too shocking?", news24, last modified May 18, 2012, https://www.news24.com/life/archive/is-birth-rape-too-shocking-20120518.

who are viewed as less than persons in the eyes of the medical establishment. These actions are temporary manifestations of generations-long beliefs, all of which continue to inform poor health outcomes and worsening disparities and inequities. If birthing people cannot get the care they need from trained clinicians specializing in birth and pregnancy due to social, economic, legal, and policy limitations, a cultural shift is required to create a better supported system.

Social Burdens

An improved culture for black birthing people must also account for the field of reproductive health writ large. The field has incorporated into practice many racial biases affecting racial and ethnic minorities seeking contraception, "sexually transmitted infection care and human papillomavirus vaccination among younger women aged 18-25 years, [and medical treatment of] reproductive cancers, preterm deliveries and low-birth-weight neonates, and maternal morbidity and mortality."[44] Systemic barriers, such as limited community-based care, insurance coverage, environmental toxins, and clinician bias negatively impact reproductive care for people of color and has been rightly named a human rights issue by the Center for Reproductive Rights.[45]

The wider social context matters, too. Biases and systemic barriers that have previously led society to excuse maternal deaths due to patients being older, more ill, and more overweight are insufficient. These excuses blame the victim and have been further

[44] Madeline Y. Sutton et al., "Racial and Ethnic Disparities in Reproductive Health Services and Outcomes, 2020," *Obstet Gynecol* 137, no. 2 (2021): 225-233.

[45] "Addressing disparities in reproductive and sexual health care in the U.S.," Center for Reproductive Rights, last modified October 14, 2020, http://reproductiverights.org/en/node/861

complicated by "[s]tereotypes about women being irrational, poor decision-makers, and of Black women as aggressive, irresponsible, and undeserving of care…sprinkled throughout U.S. medical records documenting 'non-compliant' and uncooperative patients," none of which was heavily critiqued until the 2002 landmark report, *Unequal Treatment*.[46]

In this report, one hundred studies researching mistreatment along the lines of race and class were examined. Physicians and researchers found black women were forty percent more likely than white women to receive cesarean sections, black patients were undertreated and inadequately treated for pain compared to white patients and World Health Organization guidelines, and black and Hispanic pregnant people "reported poor treatment from hospital staff because of race, ethnicity, cultural background or language, compared with 8 percent of white mothers."[47] This poor treatment, also known as medical racism, included feeling humiliated, coerced, and threatened; being verbally abused and restricted to hospital beds during labor; being forced to birth without companions; being treated as teaching aids for medical students; being racially profiled for referrals to child protection services and drug testing; and being denied information to

[46] Abortion Care Network et al., *Systemic Racism and Reproductive Justice in the United States: A Report for the UN Committee on the Elimination of Racial Disparities* (2022), 6.

[47] "For example, many thought, falsely, that blacks have less-sensitive nerve endings than whites, that black people's blood coagulates more quickly than whites and that black skin is thicker than whites. For these assumptions, researchers blamed not individual prejudice but deeply ingrained unconscious stereotypes about people of color, as well as physicians' difficulty in empathizing with patients whose experiences differ from their own." *See* Villarosa, "Why America's Black Mothers and Babies Are in a Life-or-Death Crisis"; Institute of Medicine, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* (Washington, DC: The National Academies Press, 2003); Eugene Declercq et al., "Major Survey Findings of Listening to Mothers(SM) III: Pregnancy and Birth: Report of the Third National U.S. Survey of Women's Childbearing Experiences," *J Perinat Educ.* 23, no. 1 (2014): 9-16.

provide informed consent.[48] Those birthing people with poor treatment experiences also reported holding back in communication because their providers seemed rushed, the birthing person wanted care that differed from what the provider suggested, or they feared their provider would deem them difficult to work with.[49]

Patients' reported experiences align with studies on provider bias evidencing the relationship between black patients' treatment recommendations and pro-white bias—an increase in pro-white bias leads to a decrease in recommended treatments for black patients.[50]

> This finding is further compounded by a study which evaluated implicit preference of medical doctors for White Americans compared to Black Americans using the Implicit Association Test (IAT), a well-established measure of implicit bias. Except for African American doctors, all doctors in the study which also included Asian, Hispanic, and White doctors had an implicit preference for White Americans over Black Americans. Many clinicians, therefore, may be discriminating against their patients without realizing it, while thinking all along that they are giving their patients the very best care, regardless of race. But they are not.[51]

In the case of black birthing people, pro-white and implicit biases contribute to the social stress they experience during pregnancy. Black and Indigenous communities "report the

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[48] Abortion Care Network et al., *Systemic Racism,* 8; Maureen McTeer, "Women's Health is a human Right*," Health Law and Policy Brief* 2, no. 2 (2009): Article 5.

[49] Declercq et al., "Major Survey Findings of Listening to Mothers(SM) III," 10.

[50] Rainford, *Pregnant While Black*, 19.

[51] Rainford, *Pregnant While Black*, 19-20; Elizabeth N. Chapman et al., "Physicians and Implicit Bias: How Doctors May Unwittingly Perpetuate Health Care Disparities," *Journal of General Internal Medicine* 28, no. 11 (2013): 1504-1510; Janice A. Sabin et al., "Physicians' Implicit and Explicit Attitudes About Race by MD Race, Ethnicity, and Gender," *Journal of Health Care for the Poor and Underserved* 20, no. 3 (2009): 896-913.

highest number of stressful life events in the year before birth."[52] Social stress compounded with clinicians' biases create a dangerous situation for an already highly vulnerable demographic. Linda Villarosa's 2016 *New York Times* article captures this dangerous situation well,

> For black women in America, an inescapable atmosphere of society and systemic racism can create a kind of toxic physiological stress, resulting in conditions—including hypertension and pre-eclampsia—that lead directly to higher rates of infant and maternal death. And that societal racism is further expressed in a pervasive, longstanding racial bias in health care—including the dismissal of legitimate concerns and symptoms that can help explain poor birth outcomes even in the case of black women with the most advantages.[53]

The expansiveness of the U.S. and the disproportionate distribution of healthcare resources is a final contributing factor to the stress and marginalized health experiences of black birthing people. There is inconsistency across states regarding the care that is provided, the forms of insurance accepted, the costs of care, and constant political

[52] Pregnancy discrimination in the workplace is a contributing factor to stressful life events due to many pregnant people being denied workplace accommodations or fearing to request accommodations because of potential workplace retaliation. These denials and fears resulted in 50,000 pregnancy discrimination claims field with the Equal Employment Opportunity Commission between 2010 and 2020, "28.6 percent of which were filed by Black women, who are disproportionately impacted, despite making up 14.3 percent of the female workforce." The effects last throughout pregnancy and into the postpartum period with many pregnant people experiencing heightened postpartum depression and their newborns experiencing lower birthweights, gestational ages, and more frequent pediatric visits. A measure towards remedying workplace pregnancy discrimination is The Pregnant Workers Fairness Act, introduced in 2021, which requires employers to provide reasonable workplace accommodations for pregnant people in need based on clinical recommendation. Unfortunately, "reasonable" has not yet been standardized to ensure fair workplace conditions across industries and workplace settings despite examples being provided. *See* Grant, *Birth*, 143, 172; Kaylee Hackney et al., "Examining the effects of perceived pregnancy discrimination on mother and baby health," *J Appl Psychol* 106, no. 5 (2021): 774-783; Chairman Robert C. Scott, H.R.1065—Pregnant Workers Fairness Act of 2021, 117th Cong. (2021-2022), https://www.congress.gov/congressional-report/117th-congress/house-report/27/1?overview=closed

[53] Villarosa, "Why America's Black Mothers and Babies Are in a Life-or-Death Crisis."

movement across the far right and far left continuum that leave black birthing people in a care void with their right to health almost obliterated in some locations.[54]

> To obtain health care during pregnancy, women of color must navigate complex and fragmented health care delivery and payment systems, often with minimal assistance or empathy from providers and policymakers. By placing many of the burdens of health care coordination on patients, the health care system exacerbates inequities and barriers to care that women and girls of color already face, including disproportionate poverty, childcare responsibilities, pregnancy discrimination in employment and housing, and unmet transportation needs…
>
> Moreover, many women of color in the U.S. are segregated into dysfunctional health systems by poverty, location, or insurance status. Nearly half of all U.S. counties lack an obstetric provider and hospitals that provide critical maternity and emergency care to rural areas, Native Americans, and communities of color are closing across the country. The hospitals that primarily serve Black patients provide lower quality care and have worse maternal health outcomes. Indian Health Service hospitals, which are responsible for providing federal health services to American Indians and Alaska Natives—have also been found to provide low quality labor and delivery care, including failure to follow national clinical guidelines and best practices.[55]

Even states with robust healthcare systems offering award-winning care are experiencing alarming rates of maternal and pregnancy-related complications for black birthing people. For example, from 2011 to 2020, pregnancy-related complications nearly doubled across Massachusetts and black birthing people were hit hardest. The Massachusetts Department of Public Health recently released a report identifying 4,092 incidents of severe pregnancy-related complications, with a nine percent increase each year.[56] Once race was

[54] Abortion Care Network et al., *Systemic Racism*, 15-16; Xiao Xu et al., "Wide Variation Found In Hospital Facility Costs For Maternity Stays Involving Low-Risk Childbirth," *Health Affairs* 34, no. 7 (2015): 1212-1219.

[55] Abortion Care Network et al., *Systemic Racism*, 7-8.

factored, researchers found black patients "experienced severe complications two and half times more often than white patients—a disparity that grew more stark over time."[57]

The Department of Public Health's report was the first of its kind conducted by the state and provides important statistics affirming the racial disparities in care and experience navigating the health system, even in a medical destination state. "The state report analyzed data from 678,382 deliveries, including live births and fetal deaths. In addition to the worst outcomes for Black patients, it highlighted higher rates of complications for people with disabilities."[58] The report represents the interconnected and interdependent nature of health disparities and inequities that proliferate across a broken system that upholds arbitrary identities and denies personhood and the right to health across the nation.

Moral Repair

A New Anthropological Subject

It bears repeating that black birthing people in the U.S. are dying at disproportionate rates often from preventable conditions that have worsened over time. Many agents are needed in the reparative work of protecting and valuing black birthing

[56] The state report analyzed complications including, "heart attacks, kidney failure, sepsis and eclampsia, a dangerous condition of high blood pressure. It also counted incidents that required a birthing person to be placed on a ventilator or have their uterus removed." *See* Priyanka Dayal McCluskey, "Dangerous complications are increasing for pregnant patients in Mass., report finds," WBUR, last modified July 12, 2023, https://www.wbur.org/news/2023/07/12/dangerous-complications-increasing-pregnant-patients-massachusetts; Commonwealth of Massachusetts Department of Public Health, *Data Brief: An Assessment of Severe Maternal Morbidity in Massachusetts: 2011-2020* (Boston: Department of Public Health, 2023).

[57] McCluskey, "Dangerous complications are increasing for pregnant."

[58] McCluskey, "Dangerous complications are increasing for pregnant."

people's lives and new questions must be asked to come to new solutions that are person and rights oriented. Asking a new anthropological question that grapples "with concrete data to discern, understand, and evaluate their emerging patterns in order to interpret their meaning" allows this chapter to take the preceding narratives and data and develop interventions that honor the lives of black birthing people and their personhood.[59]

This begins with Maritain's ontological anthropology. As individual and spiritual beings bearing absolute dignity and God's image, black birthing people (and all health-disparate groups) are equal to all other persons. They require engagement in a society that is actively working toward the communal good, and they require social bonds with others who share resources through reason and virtue to help them increase in their capacity to live good, free, autonomous lives.[60] Yet, society has failed black birthing people. And in failing black birthing people, society has failed God, their supreme analogue. By rejecting the personhood of black birthing people, U.S. society has become a warped reflection of divine society. Instead of subordinating themselves to the good of society, dominant groups and marginalizing health systems continue to work against the common good and squandered the lives of marginalized communities.

To overcome this, we draw inspiration from a Catholic humanism that foregrounds the "realities of poor women, particularly poor women of color" and turns

[59] M. Shawn Copeland, *Enfleshing Freedom*: *body, race, and being* (Minneapolis, MN: Fortress Press, 2010), 86.

[60] Maritain, *The Rights of Man*, 9; Maritain, *The Person*, 41.

the "spotlight on God's invisible creatures—the exploited, despised, marginalized."[61] Then we can begin to view maternal deaths and the diminished personhood experienced by black birthing people differently. The remainder of this chapter will center the humanity and lived experiences of these communities as a means of moving toward morally reparative actions that eliminate health inequities and promote their flourishing.[62] As the anthropological subject of this chapter, the abhorrent situation of black birthing people in the U.S. will challenge us to probe present policies and necessary steps that will move us towards equity. Such exploration binds us in solidarity to black birthing people, "whose presence reorients notions of personhood and praxis. If personhood is now understood to flow from formative living in community rather than individualism, from the embrace of difference and interdependence rather than their exclusion, then we [must] realize our personhood only in solidarity with [black birthing people]."[63]

Further, by standing in solidarity with black birthing people, we affirm them as God's creation deserving of a community of people committed to just relationships, individual freedom, and difference, all of which recognize black birthing people's flourishing and humanity.[64] Our solidarity with black birthing people allows us to recognize their suffering and confront the systems and issues that have caused said

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[61] Copeland, *Enfleshing Freedom*, 88.

[62] Copeland, *Enfleshing Freedom*, 87-88.

[63] Copeland, *Enfleshing Freedom*, 89.

[64] Copeland, *Enfleshing Freedom*, 92; Jacques Maritain, *The Rights of Man and Natural Law* (London: Geoffrey Bles, 1944), 7-8, 38.

suffering and oppression. We reject the ordinary vices of domination that allow our flourishing and black birthing people's oppression, instead accepting our responsibility to the past and present as a means of promoting the common good for all citizens. This requires addressing healthcare education, health policy, and making wider social adjustments.

Education

One step toward solidarity and improved health rights and outcomes for black birthing people is to change the way we conduct healthcare education. There is a need "for improved education of all clinicians who deliver obstetric care, including emergency room clinicians, and assurance that these clinicians exhibit core competencies based on the known factors that drive the maternal morbidity and mortality rates."[65] Improved education includes cultural competency, ethics, and stabilizing skills to ensure patients remain healthy as they wait to be transferred to clinicians with advanced skills in high-risk conditions.

A first step towards evolved healthcare education is acknowledging the long history of pseudoscientific racism that has driven much of healthcare praxis in this country. As noted in chapter one, it is difficult to separate historic health inequities and disparities from chattel slavery. Despite the initial traumas occurring centuries ago, stereotypes and racial biases towards black birthing people remain intricately linked to

[65] Rainford, *Pregnant While Black*, 70.

centuries-old beliefs.[66] Acknowledging the root of pseudoscientific racism represents accountability for centuries of flawed beliefs and resulting, arbitrary marginalization. This acknowledgement also initiates the work of equity and justice for racism to be dismantled because arbitrary differences can no longer be justified.

Acknowledging racist histories and systemic inequities makes space for clinicians to be trained in intersectionality, recognizing that race and ethnicity should not be the sole determining factor in deciding the care a patient receives.[67] Such an approach

[66] A recent interview conducted by *JAMA'*s editor-in-chief, Kirsten Bibbins-Domingo, with three black OB/GYN's—Joia Crear-Perry, Monica McLemore, Audra Meadows—revealed that as recently as the late 1990's, medical students were taught black women have higher rates of cesarean sections because of their anthropoid (oval-shaped) pelvises, whereas white women have a gynecoid (perfectly circular) pelvis that allows them to experience physiologic birth at higher rates. These beliefs were first devised by Drs. William Edgar Caldwell and Howard Carman Moloy in the 1930's and later "codified in textbooks" as the Caldwell-Moloy classification system, informing gynecological and obstetric-related policies in hospitals across the country for decades. The Caldwell-Moloy system requires that measurements be performed to verify pelvis shape, which link to specific birth outcomes as charted in their classification system. This system was meant to determine the frequency of different types of pelvises but provided no "evidence demonstrating a correlation between pelvic inlet size and shape and particular birth outcomes, in fact, such evidence remains elusive today." This model informs racial bias, overconfidence in determining which births will be classified as difficult births since they still largely occur along racial lines, and reduced acceptance that "obstetric pelvis variation is normal and complex." *See* Jennifer Abbasi, "US Maternal Mortality is Unacceptably High, Unequal, and Getting Worse—What Can Be Done About It?," *JAMA* 330, no. 4 (2023): 302-305; Carolina VanSickle et al., "Textbook typologies: Challenge the myth of the perfect obstetric pelvis," *The Anatomical Record* 305, no. 4 (2022): 952-67.

[67] "Originating from black feminism, intersectionality recognizes that a single classification does not represent an individual enmeshed within a social context, but that the convergence of multiple vectors shape their lived experience (Crenshaw, 1989). The convergence of social inequities and marginalizations, like racism, poverty, religious persecution, sexism, or homophobia, produces unique vulnerabilities and social inequities. Recognizing these lived experiences, intersectional work aims to improve our understanding of the complexity of social processes and oppressive vectors affecting illness experiences (Hankivsky 2012). For example, in studying intersecting identities, Burton and colleagues (2017) demonstrated that racial disparities in birth outcomes among black women were likely manifestations of structural oppression and are congruent with the weathering hypothesis—that the impact of a lifetime of experiences of racism causes health to deteriorate with age." *See* Amal Cheema et al., "Multiple Marginalizations: What Bioethics Can Learn from Black Feminism," *The American Journal of Bioethics* 19, no. 2 (2019): 1; Kimberlee Crenshaw, "Demarginalizing the intersection of race and sex: A black feminist critique of antidiscrimination doctrine, feminist theory and antiracist politics," *University of Chicago Legal Forum* 139 (1989); Olena Hankivsky, "Women's health, men's health, and gender and health: implications of intersectionality," *Soc Sci Med* 74, no. 11 (2012): 1712-1720; Wanda Burton et al.,

addresses the multiple forms of oppression and inequities patients may face—including the power dynamic between clinician and patient that represents cultural oppressions and hidden assumptions of marginalized communities—while pursuing shared morals and values that can inform a patient's care. An immediate benefit should be the shift away from black birthing people's over-and under-medicalization.

Specifically in maternal care, black birthing people either "[receive] aggressive interventions they may not need sooner than they might need them, which can lead to complications, or [face] complications that they are unable to get taken seriously, resulting in missed opportunities to protect their health and safety."[68] Shifting medical education away from negative beliefs of black birthing people rooted in racist histories can result in these patients receiving appropriate physiologic care because their health narratives and symptoms are taken seriously as opposed to codified within an implicit personal system of biases and stereotypes. Just as clinicians are trained on physiologic complications, they must also be trained in cultural humility, transparent communication, and methods of acknowledging historical injustices and inequities to create safe and trusting environments for patients already socially and medically marginalized.

Finally, obstetric toolkits and education around their proper use must be shared with clinicians involved at any level of maternal care.[69] California has developed a robust

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"Addressing the Racial Disparity in Birth Outcomes: Implications for Maternal Racial Identity in Birthweight," *Journal of Health Disparities Research and Practice* 10, no. 2 (2017): 142-155.

[68] Grant, *Birth*, 109.

model, the California Maternal Quality Care Collaborative (CMQCC), to address severe maternal complications, such as "obstetric hemorrhage, severe hypertension in pregnancy, safe reduction of primary cesarean birth, cardiac conditions, care for people with substance use disorders, and postpartum discharge," and sepsis in every hospital servicing birthing people, resulting in expanded obstetric education and healthy interventions.[70] These proven approaches also move towards a standard of care that can positively define birthing people's expectations when pursuing hospital care in the U.S.

Today, approximately one third of birthing people and their children can expect to enter a hospital understaffed and under resourced where they will receive unnecessary medical interventions that more closely align with a health system failing to prioritize preventative care and physiologic birth.[71] If those same hospitals adopt the toolkits and

[69] The California Maternal Quality Care Collaborative (CMQCC) uses "research, quality improvement toolkits, state-wide outreach collaboratives and its innovative Maternal Data Center to improve health outcomes for mothers and infants" to end racial disparities in maternal care. This collaborative incorporates rapid-cycle performance metrics on maternity care services for hospital participants to generate computational policy simulation to understand the changes needed in healthcare systems across California and propose specific policies that have resulted in a three-fold decrease in maternal mortality rates across the state compared to the remainder of the U.S. These policies begin with clinicians and healthcare administrators. Beginning with in-depth reviews of medical records related to pregnancy deaths across several years, the gathered data has been used to identify opportunities for improvement. Since the establishment of the Maternal Data Center, CMQCC has broadened its scope and developed several toolkits aimed at improving "the health care response to leading causes of preventable death among pregnant and postpartum women as well as to reduce harm to infants and women from overuse of obstetric procedures. All Toolkits include a compendium of best practice tools and articles, care guidelines in multiple formats, hospital-level implementation guide, and professional education slide sets." *See* "Toolkits," California Maternal Quality Care Collaborative, last modified September 20, 2022, https://www.cmqcc.org/resources-tool-kits/toolkits; "What We Do," California Maternal Quality Care Collaborative, last modified 2023, https://www.cmqcc.org/about-cmqcc/what-we-do; Elliott K. Main et al., "Reduction of severe maternal morbidity from hemorrhage using a state perinatal quality collaborative," *Am J Obstet Gynecol* 2016, no. 298 (2017): e1-11.

[70] "Toolkits."

[71] Grant, *Birth*, 117.

educational frameworks of CMQCC, their clinicians can be better trained in supporting physiologic birth and connecting birthing people with culturally-aware advocates in the form of community health workers. When clinicians have a shared understanding of positive interventions that promote healthy birth outcomes, more space is created for patients to be heard, their personhood to be respected, and their symptoms to be taken seriously and treated thoroughly. Removing fear of making the wrong choice may increase clinicians' opportunities to treat all patients with dignity and respect as opposed to proliferating chances of obstetric violence and birth rape as happens too often today. Moving away from racist narratives also affords the U.S. health system the opportunity to shift the health narrative away from a Western context overemphasizing "health promotion and disease prevention in such a manner that there is little or no meaningful participation of peoples and their cultures in positive behavioral transformation."[72] By acknowledging health as a cultural production, inclusive of history, demographics, politics, and philosophies, we can include more society members to help better the healthcare system.

Policy

Education is only one pillar of shifting the healthcare culture and system. Public and private insurance expansion is also critical for black birthing people. "If equity is truly the goal, the level of funding needs to increase in proportion to the level of the

[72] emilie m. townes, *Breaking the Fine Rain of Death: African American Health Issues and a Womanist Ethic of Care* (Eugene, OR: Wipf and Stock Publishers, 1998), 49.

disparities."[73] A renewed health system must expand public and private healthcare funding, the healthcare workforce, and access to health services, specifically reproductive health services for black birthing people.[74] As urged by the UN and WHO to uphold citizens' right to health in the U.S., payment reform must include "government expenditure on health per [birthing] person above the minimum required."[75]

Nationally expanding Medicaid eligibility and coverage for birthing people from sixty days postpartum to one year postpartum will drastically improve maternal health outcomes, specifically for communities impacted by multiple historic health disparities and inequities.[76] Currently, sixty-five percent of black birthing people's births are

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[73] Rainford, *Pregnant While Black*, 29.

[74] While it is imperative to reform private payer models, there is too much complexity to address needed reforms in this work. Attention will remain on the public payer, Medicaid, given the robust amount of research evidenced from the Affordable Care Act, and its role as a bare minimum measure of upholding citizens' right to health.

[75] Gillian Backman et al., "Health systems and the right to health: An assessment of 194 countries," *The Lancet* 372 (2008): 2077.

[76] To date, thirty-six states including Washington D.C. have implemented a twelve-month extension, which was a provision under the 2021 American Rescue Plan granting states "a new option to extend Medicaid postpartum coverage to 12 months via a state plan amendment (SPA)." This provision is available for five years. Ten states plan to implement the extension, while two states argue for limited coverage. The SPA "requires states to offer continuous eligibility for full benefits for anyone eligible for Medicaid or CHIP during pregnancy, ending 12 months after the end of pregnancy. A smaller subset of states has used an 1115 waiver to lengthen the postpartum coverage period, and in some cases, attempted to limit the population of people or cover a shorter duration than the state plan amendment requires. If all states adopt the coverage extension, an estimated 720,000 additional people each year would gain access to a full year of postpartum health coverage who might have otherwise lost coverage just two months after the end of pregnancy." *See* "Medicaid Postpartum Coverage Extension Tracker," KFF, last modified August 9, 2023, https://www.kff.org/medicaid/issue-brief/medicaid-postpartum-coverage-extension-tracker/; Maggie Clark and Maya Millette, "More States Extend Postpartum Medicaid Coverage as Three States Fall Behind," Georgetown University McCourt School of Public Health Center for Children and Families, last modified May 12, 2023, https://ccf.georgetown.edu/2023/05/12/more-states-extend-postpartum-medicaid-coverage-as-three-states-fall-behind/; Rose L. Molina and Lydia E. Pace, "A renewed focus on maternal health in the United States," *New Engl J Med*. 377, no. 18 (2017): 1705-1707.

covered by Medicaid, and the public insurance is accepted in ninety percent of community health centers and seventy-seven percent of private practices. "Furthermore, 46% of people on Medicaid get their care at community clinics compared to 24% who get their care at private practices."[77] Over the past twenty years, various presidents and legislators have worked diligently to incorporate wider reproductive health coverage in Medicaid reform, but the U.S.'s strained relationship with actualizing the right to health under domestic protections continues to leave large swaths of the nation health-disparate.[78] This posture of defeatism and accepting a broken health system is insufficient given the benefits that can be afforded to birthing people.

Year-long coverage would also aid those in need of long-acting reversible contraceptives (*e.g.,* intrauterine implants) as an effective family-planning method to space out pregnancies. Birthing people would also have increased access to health programs, which support "payment for screening, brief intervention, and referral to treatment for substance abuse disorders."[79] Due to the volume of marginalized patients seeking care in settings primarily funded by public insurance, additional funding to these programs comes with the stipulation that high-risk birthing people receive additional

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[77] Rainford, *Pregnant While Black,* 41.

[78] "Analysis of Federal Bills to Strengthen Maternal Health Care," Women's Health Policy KFF, December 21, 2020, https://www.kff.org/womens-health-policy/fact-sheet/analysis-of-federal-bills-to-strengthen-maternal-health-care/; Rep. Robin L. Kelly, H.R.4387—Maternal Health Quality Improvement Act of 2021, 117th Cong. (2021-2022), https://www.congress.gov/bill/117th-congress/house-bill/4387; Rep. Lauren Underwood, H.R.959—Black Maternal health Momnibus Act of 2021, 117th Cong. (2021-2022), https://www.congress.gov/bill/117th-congress/house-bill/959.

[79] Texas Senate Bill 17, 85th Legislature, First Special Session, 2017, "Relating to maternal health and safety, pregnancy-related deaths, and maternal morbidity, including postpartum depression," https://capitol.texas.gov/tlodocs/851/billtext/html/SB00017F.htm.

health benefits and are closely monitored throughout pregnancy. This equitable step in health reform requires Medicaid to increase compensation rates for patient visits and births involving midwives and doulas, ensuring that birthing people in all socioeconomic classes have access to quality maternal care in facilities they find most comfortable.[80]

A secondary level of support comes through grants that are awarded to clinics to subsidize care operations.[81] These expanded resources will attract more clinicians skilled in various levels of health risk, allowing them to spend more time with patients, which can result in better relationships between clinicians and patients. If the goal is reducing disparities, "[t]he level of support should be commensurate with the level of risk."[82] Clinicians attracted to better funded community health centers must make space for midwives and doulas. Their presence helps alleviate provider burnout, improve pregnancy and birth experiences, and expand postpartum services. Research has proven birthing people with access to more regular postpartum visits, especially by midwives or doulas, benefit from improved breastfeeding outcomes and providers report greater opportunities to assess "social determinants of health, including needs for food, housing, financial security, and protection from domestic violence," all of which can contribute to reduced pregnancy-related deaths up to one year postpartum.[83]

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[80] Moore et al., *Improving Maternal Health Access*.

[81] Rainford, *Pregnant While Black,* 43.

[82] Rainford, *Pregnant While Black,* 63.

[83] Tikkanen et al., *Maternal Mortality and Maternity*.

Researchers have also noted that pregnant people receiving continuous pregnancy and birthing support from doulas were thirty-nine percent less likely to have cesarean sections and they birthed healthier infants.[84]

> In the wake of a new public attention to the Black maternal mortality crisis, birthworkers—particularly birth doulas—have become increasingly visible agents of birth justice. Doula-assisted pregnancies have been described as successful not only in transforming some birthers' perinatal experiences, but also, some argue, in improving the health of mothers and infants, even as there remains debate about what precisely it is that makes doulas' presence in the birthing room transformative.[85]

> Other studies have shown that doula support has helped decrease the overall cesarean rate by half, the length of labor by a quarter, and requests for an epidural—among Medicaid enrollees, the C-section rate is 22.3 percent with doulas and 31.5 percent without. After birth, it can increase rates of breastfeeding and decrease postpartum depression. And because doulas increase the likelihood of vaginal birth, they help to contribute to lowering the costs of maternity care. In one study, doula support in the United States was associated with Medicaid expenditure savings averaging around $1,000 per birth.[86]

For black birthing people, doulas serve as "bodyguards" and "shields" from obstetric violence, helping protect their lives and ensuring they leave healthcare institutions

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[84] Villarosa, "Why America's Black Mothers and Babies Are in a Life-or-Death Crisis"; "Severe Maternal Morbidity in the United States," Centers for Disease Control and Prevention, last modified February 2, 2021, https://www.cdc.gov/reproductivehealth/maternalinfanthealth/severematernalmorbidity.html#:~:text=Severe%20Maternal%20Morbidity%2C%201993–2014&text=The%20overall%20rate%20of%20SMM,1993%20to%20122.3%20in%202014.

[85] Nash, *Birthing Black Mothers*, 70.

[86] Grant, *Birth*, 167; Katy Backes Kozhimmanil et al., "Doula Care, Birth Outcomes, and Costs Among Medicaid Beneficiaries," *Am J Public Health* 103, no. 4 (2013): e113-e121; Kathleen Knocke et al., "Doula Care and Maternal Health: An Evidence Review," ASPE Office of Health Policy Issue Brief, last modified December 13, 2022, https://aspe.hhs.gov/sites/default/files/documents/dfcd768f1caf6fabf3d281f762e8d068/ASPE-Doula-Issue-Brief-12-13-22.pdf.

healthy and with their children. As doulas protect their patients, their presence also positively reduces the obstetric racism often experienced by black birthing people.[87]

Historically rooted in the 1970's women's health movement, doulas represent holistic birthing care and feminist principles of "expanding reproductive choices for women, centralizing embodied knowledge, and promoting self-help and solidarity among mothers."[88] This historic culture continues to inform the benefits doulas provide during a vulnerable stage of a birthing person's life when encountering potentially life-altering and traumatic decisions. Doulas represent new forms of birthing and maternal health justice that recenter personhood and the rights owed to black birthing people with actions including, "juridical recognition (and redress) for birthing injuries, shifting conceptions of medicine that make birthing a space for more compassionate and humane forms of being-together, and by a cultural recognition of birth as a profound site of psychic pain and institutional injury."[89]

As an integral part of a well-funded and well-trained community-based team, and with support from the American College of Obstetricians and Gynecologists (ACOG), doulas are able to bridge clinical issues and communal relationships to positively alter maternal health outcomes.[90] Having doula support covered by insurance is a worthy

[87] Grant, *Birth*, 122.

[88] Nash, *Birthing Black Mothers*, 72.

[89] Nash, *Birthing Black Mothers*, 82.

[90] "ACOG Committee Opinion No. 766: Approaches to Limit Intervention During Labor and Birth," *Obstetrics & Gynecology* 133, no. 2 (2019): e164-e173.

investment that would provide standardized and accessible care for pregnant people of all financial classes, as well as pay parity for doulas whose service positively impacts maternal mortality statistics.[91]

Connected with investing in doulas is the need to invest in more locations for birthing care. Birthing center startup costs are between one and two million dollars and only five percent of U.S. birthing centers are owned by black people.[92] Statistics have shown black birthing people and their newborns have better health outcomes when treated by black clinicians. A step towards equity is the U.S. government providing grants for black clinicians—obstetricians, gynecologists, doulas, and midwives—interested in starting community-based birthing centers. These centers would share maternal health outcomes with their cities, states, and the federal government to begin the process of standardized data collection for metric reviews in the future.

Finally, through federal policy measures, the U.S. can standardize data-collection systems to ensure consistency in data collected on maternal mortality and morbidity rates as opposed to allowing states to share whichever data they choose each collection period. While forty-nine states and the District of Columbia have formal maternal mortality

[91] April Falconi et al., "Doula care across the maternity continuum and impact on maternal health: Evaluation of doula programs across three states using propensity score matching," *Lancet* 50, no. 101531 (2022): 1-11.

[92] Currently there are several prominent birth centers around the country serving birthing people of color and low income patients: Birth Detroit (offering community-based maternal and infant healthcare); Family Health and Birth Center in northeast Washington D.C. (serving low-risk women); Community Birth Center in Los Angeles; Kindred Space LA; Birth Center in Union, NJ (primarily serving people of color); Roots Birth Center in Minneapolis, MN; Buffalo Women's Services in Buffalo, NY; Changing Woman Initiative in New Mexico (primarily serving Indigenous women in need of care beyond Indian Health Services); Village of Healing Center in Euclid, OH; and Jamaa Birth Village in Ferguson, MI. *See* Grant, *Birth*, 308-309.

review committees, there is no consistency in mortality reporting. Of the forty-nine states, only thirty-six review deaths up to one year postpartum, thirty-two investigate all pregnancy-associated deaths, and fourteen determine if any pregnancy-related deaths were preventable.[93] By standardizing maternal mortality and morbidity review committees across the country, the U.S. will begin fulfilling its responsibility to uphold

[93] The Guttmacher Institute collected in-depth data on maternal mortality review committees across the country that report to the CDC. Their surveys revealed large inconsistencies in reporting. Looking closely at state-reported data, fourteen states evaluate maternal morbidity, twelve of which review trends in maternal morbidity, five track maternal morbidity data, and none consider potential racial disparities and inequities contributing to maternal morbidity.

Committee Structure and Information

- 48 states, DC, New York City, Philadelphia and Puerto Rico have requirements for committee membership, access to data and confidentiality.
    - 37 states, DC, New York City and Puerto Rico require multidisciplinary committee membership, such as representation of midwifery, obstetrics and gynecology, mental and behavioral health, doulas, nurses, public health experts, Native tribes or nations, and patients or family members affected by a death.
        - 24 states, DC, New York City and Puerto Rico require specific membership expertise.
        - 14 states require committee membership to be representative of the jurisdiction's demographic composition (*e.g*., geographic, racial, socioeconomic status, communities most affected) or require such representation to be considered when selecting members.
    - 47 states, DC, New York City, Philadelphia and Puerto Rico permit committee access to certain data and institutional records, such as medical files, vital statistics data, law enforcement reports or court records.
    - 45 states, DC, and Puerto Rico require confidentiality of the review process and records and information considered by the committee, and provide legal protections for reviewers and participants.

Committee Report Requirements

- 43 states, DC, New York City, Philadelphia and Puerto Rico have requirements about the frequency and content of reports.
    - 38 states, DC, New York City, Philadelphia and Puerto Rico require committees or departments of health to publish reports at certain intervals (e.g., annually, twice a year, every two years).
    - 38 states, DC, New York City and Puerto Rico require the committee to provide recommendations focused on preventing future pregnancy-related deaths.
    - 6 states and New York City require the committee's reports to address racial disparities.

Standardized Review Process

- 42 states and New York City have adopted a standardized review process developed by the CDC, including consistent data gathering, decision making and recommendations.

See "Maternal Mortality Review Committees," Guttmacher Institute, last modified May 1, 2023, https://www.guttmacher.org/state-policy/explore/maternal-mortality-review-committees#%205/1/2023.

the right to health by learning what exactly is going wrong in births and how to improve maternal care to reduce and eliminate mistakes that continue causing preventable deaths. It must be noted, this is no easy task. While balancing individuals' rights, states' rights, and federal protections, the federal government must allocate funding through a centralized federal agency tasked with gathering and streamlining mortality and morbidity data.

An initial step is to provide incentives for hospitals to opt-in to sharing patient discharge reports that include perinatal performance metrics from maternal care appointments. This leads to the establishment of a database of perinatal metrics in each state that can provide real-time insights to birthing statistics and gaps in care. As the data is collected and analyzed regularly by a dedicated team trained the same way across states, quality improvement tools can be developed to design specific actions that should be taken to treat the most popular preventable symptoms in pregnant people (*e.g.*, preeclampsia, early delivery, and hemorrhaging). Examples of specific actions to be taken from data collection include regular unit-based drills with debriefs to prepare for birthing people who present with preventable symptoms, accurate and active assessments of patients' risks followed by steady measurements of vitals and blood levels, establishing plans for high-risk patients, and post-event debriefs to discuss what went well and what should be improved.[94]

[94] Main et al., "Reduction of severe maternal morbidity," e4-e5.

The practical policy actions mentioned in this chapter are direct examples of society prioritizing Maritainian personalism and the common good. Black birthing people have served for too long as one of the U.S.'s prophetic shock-minorities, challenging the nation to recognize their inherent worth and dignity all the while dying at disproportionate rates due to widespread neglect. It is time for black birthing people to evolve beyond prophetic shock-minorities and have their full personhood honored. These practical actions are some of the initial steps needed to attend to the material needs of black birthing people's individuality with hopes of advancing to the intellectual and spiritual needs of their personality, all of which provide liberation from inequities.[95] These actions also represent the catalyst for change, that is urgently needed, when we ground our actions in the dignity of all persons.

Additional funding into public insurance, proven to improve care and reduce mortality rates—a common social good which black birthing member as dignified members of society with rights to health and adequate care are entitled—fosters "the proper good of each person and the overall flourishing of society."[96] Doulas and midwives, who serve as protectors and foreground the personhood of the vulnerable, respect the humanity of black birthing people and their value as ends unto themselves. This respect of persons positively impacts clinical birthing encounters, allowing birthing people to enjoy their right to exist and trust that clinicians and healthcare systems will not

[95] Scrandis, "Jacques Maritain on the Rights of Man and the Common Good," 617.

[96] Wallace, "Jacques Maritain and Alasdair MacIntyre," 130.

interfere in this right.[97] Federal support of clinicians seeking to diversify birthing centers emboldens birthing peoples' allies to follow their reason-informed consciences, which are in direct relationship with God's eternal law. Standardizing data at a federal level to better identify health-disparate communities is a bare minimum standard that affirms a healthy norm and informs legislative protections to improve the lives of those communities below that norm and excluded from the category of healthy persons.

Because all humans are persons according to Maritainian personalism, our needs must be met in communion with others through fundamental rights that are owed to us by virtue of our human nature. To avoid meeting these needs threatens the common good of society and our collective human nature. We see this through the overall declining health of the nation. The rejection of any group's personhood moves beyond moral wrong, causing exponential moral damage to the entire nation. In the absence of moral motivation, grounded in the inherent dignity of everyone's human nature, as an impetus to address health disparities and inequities, U.S. society will remain outside the bounds of a natural law that effectively provides the communal goods owed all persons.

Conclusion: *Society*

Finally, to reduce the burdens of stress, racism, and discrimination for black birthing people, we must make social adjustments prioritizing black birthing people as persons endowed with inalienable rights. In 2022 a collaboration[98] of reproductive justice

[97] Jacques Maritain, *The Rights of Man and Natural Law* (London: Geoffrey Bles, 1944), 65, 81-82.

networks submitted a report to the United Nations Committee on the Elimination of All Forms of Racial Discrimination (UN CERD), requesting six critical measures be taken upon conducting the U.S.'s tenth progress review on racial discrimination:

> We urge the CERD Committee to condemn violations of reproductive rights during its upcoming periodic review of the United States and to recommend that the U.S. government:
>
> 1. Ensure the meaningful participation of women of color in all decision-making processes that impact their reproductive health
> 2. Remove barriers to accessible, high quality, comprehensive reproductive health care
> 3. Address and eliminate racial and intersectional discrimination in reproductive health care settings, including birthing facilities and criminal and immigration detention settings
> 4. Ensure that communities of color can access and provide culturally aligned services that improve maternal health, including midwifery and doula care
> 5. Halt and remedy retrogression of the right to abortion, and ensure abortion access
> 6. Address the impact of environmental racism on reproductive health[99]

Violations to the right to health, such as discrimination and experiences of racial bias in maternal care and health outcomes and widespread sterilization of birthing people who are immigrants and detained in detention centers along the U.S./Mexico border reveal the depth of racial and health inequities that continue to run rampant in the U.S, proving that the U.S. has failed to both eliminate all forms of racial discrimination and uphold the universal right to health to which it agreed.

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[98] These organizations included: Abortion Care Network, Ancient Song Doula Services, Birthmark Doula Collective, Black Mamas Matter Alliance, Center for Reproductive Rights, Changing Woman Initiative, Human Rights & Gender Justice Clinic: CUNY School of Law, If/When/How, Indigenous Women Rising, National Birth Equity Collaborative, Movement for Family Power, Restoring Our Own Through Transformation, and SisterSong Women of Color Reproductive Justice Collective.

[99] Abortion Care Network et al., *Systemic Racism,* 1.

Since 2014, the UN has been concerned about the intersections of racial and health disparities as they pertain to black birthing people and immigrants.[100] The UN advised the U.S. to ensure concrete measures are taken to provide "effective access to affordable and adequate health-care services" for these vulnerable populations; eliminate racial disparities related to sexual and reproductive health; standardize maternal and infant health data collection; and, improve monitoring mechanisms across states to reduce preventable maternal deaths.[101] Those same measures are being advised ten years later as the U.S. continues failing its vulnerable populace. This culture cannot prevail.

The U.S.'s failure to adequately attend to health is unnecessary given there are explicitly named global standards for recognizing and protecting the rights of women and birthing people. The U.S. must improve in honoring the "rights to life, health, equality and non-discrimination, and freedom from ill-treatment."[102] Birthing people must have access to good quality healthcare during pregnancy and the postpartum period, and this

[100] "Right to health and access to health care: 15. While commending the adoption of the Patient Protection and Affordable Care Act in March 2010, the Committee is concerned that many states with substantial numbers of racial and ethnic minorities have opted out of the Medicaid expansion programme, following the Supreme Court decision of June 2012 in the National Federation of Independent Business v. Sebelius case, thus failing to fully address racial disparities in access to affordable and quality health care. It is also concerned at the exclusion of undocumented immigrants and their children from coverage under the Affordable Care Act, as well as the limited coverage of undocumented immigrants and immigrants residing lawfully in the United States for less than five years by Medicaid and Children's Health Insurance Programme, resulting in difficulties for immigrants in accessing adequate health care. It also reiterates its previous concern at the persistence of racial disparities in the field of sexual and reproductive health, particularly with regard to the high maternal and infant mortality rates among African American communities (para. 33) (art. 5 (e))." *See* UN International Convention on the Elimination of All Forms of Racial Discrimination, *Concluding Observations on the combined seventh to ninth periodic reports of the United States of America* (New York: United Nations, 2014), 7.

[101] UN, *Concluding Remarks*, 7.

[102] Abortion Care Network et al., *Systemic Racism*, 13.

healthcare should be discrimination-free, violence-free, and coercion-free. These freedoms require an explicit stand from the U.S. against racism and racial biases in healthcare, as well as an explicit stand naming the right to health and measures to protect this right. In one of the planet's wealthiest nations, these freedoms also include "[u]niversal access to family planning resources [and] contraception."[103] While the nation prioritizes states' rights, federal regulations must be put in place to expand standardized reproductive educational resources and reproductive health access.

Policies must be put in place, such as affirmative action in education, to help diversify medical practice and education specifically as they intersect with maternal health.[104] Diversified medical student bodies and clinical communities provide new insights, varied cultural experiences, and wider community support to ensure healthcare systems look like the larger nation. A diverse healthcare workforce also provides more opportunities for subdisciplines to evolve, such as maternal mental healthcare to assistance birthing people with the physical, mental, and emotional evolutions they experience from conception to at least one year postpartum.

Midwifery and doula care are also sites in need of diversification to increase opportunities for culturally competent care across the U.S.'s social fabric as opposed to marginalizing already underserved communities due to issues of legality and

[103] Grant, *Birth*, 311.

[104] Despite the U.S. Supreme Court deciding on 29 June 2023 to end affirmative action, this work still calls for legal racial and ethnic diversification of the medical field given the generations of policies used to legally uphold racial segregation among the medical workforces. *See Students for Fair Admissions, Inc v. President and Fellows of Harvard College* 20 U.S. 1129 (2023).

affordability. Midwifery must also become legal in every state, which requires more expansive insurance coverage and payment reform to ensure all members of maternal care teams and all sites of maternal care are paid justly, as well as ensuring standardization in training and a more welcoming mentality from hospital-based clinicians.

To promote a culture respecting and protecting our right to health and personhood, each person must work toward the common good and health of the society over against simply "accepting an inadequate health-care system that does not deliver good health to many [black birthing people]."[105] This common good expands the discourse and praxis involved in "restructuring society while also recognizing multiple identities" and recognizing the political and biological nature of justice work, all to better the lives of health-marginal communities in the U.S. boldly proclaiming, "I am just as human as the men who colonized this country."[106] In the words of Dr. Monique Rainford, "[o]f course, we should ensure that pregnant Black women have access to unbiased prenatal care; of course, we should ensure that they are provided culturally sensitive prenatal education; of course, we should close the gap on access to resources, such as healthy food and housing (we should have been doing that already), *and* we should strengthen the social support."[107]

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[105] townes, *Breaking the Fine Rain of Death*, 156.

[106] Zakiya Luna, *Reproductive Rights as Human Rights: Women of Color and the Fight for Reproductive Justice* (New York: NYU Press, 2020), 12-20.

[107] Rainford, *Pregnant While Black*, 96.

CONCLUSION

On June 22, 2021, at approximately 6:56 p.m., my niece, Emory I'elle Jacobs, was born. She weighed five pounds and fourteen ounces and was the loudest crying newborn on the maternity wing. I had the privilege of being by my sister's side as her birthing partner. I incessantly engaged the staff, requesting explanations for every action and comment. I asked the surgeon for moments of pause to ensure my sister understood everything he said and to ensure she agreed to his plan of care. I tried my best to connect with each person's humanity as I questioned them about their birthing experiences and what they wished they had. I wanted every staff person to know my sister had an advocate.

My niece's birth was the first birth I have ever attended. I have never been pregnant, and prior to her birth I never felt the internal dread of the lives of people I loved being in the hands of clinicians. I had the privilege of both holding my sister's hand and cutting my niece's umbilical cord. As precious as that day was, I was internally terrified that my sister, a twenty-seven-year-old birthing person in Louisiana, would become a mortality statistic. I clung to every sense of hope in my body, praying fervently that I would not have to return to our family without my sister because something went fatally wrong. I am beyond grateful to have my sister and my niece alive and well two years later, and I realize how privileged my family is to have avoided an all-too-common fate for black birthing people in this nation.

While our story is a success, innumerable individuals and communities remain burdened by health disparities and systemic inequities that threaten their lives daily.

These realities are the result of a moral wrong, health disparities. This dissertation has worked to articulate their moral wrongness and deep violation of personhood through a sustained analysis of historic and contemporary health disparities plaguing marginalized communities in the U.S.

Health disparities and inequities in the U.S. date back to chattel slavery and the invention of pseudoscientific racism that valued some bodies and devalued others. This "science" has run throughout the U.S. healthcare system and wider society, harming demographically identifiable groups, and contributing to negative social determinants of health that keep these groups below a bare minimum level of health. Further, these negative determinants of health violate the rights to health and adequate healthcare owed to all citizens of nations that have signed the Universal Declaration of Human Rights and its supporting covenants. Although black birthing people are but one health-disparate demographic in the U.S., they were a focused case study to explore the ways international rights rhetoric and Maritainian personalism could address health disparities through theoethically-informed policies.

Historically impacted communities have struggled with poor health and limited access to healthcare for generations, and recent decades have seen individual and communal health worsen substantially. These communities, examined in chapter one, include birthing people, women, low-income people, incarcerated people, disabled people, LGBTQIA+ people, racial and ethnic minorities, and veterans, to name a few. Contemporarily, intersecting social systems (*e.g.*, food deserts, underfunded community health centers, the movement of low-skills jobs) have maintained the factors that inform

poor health outcomes for a majority of the nation. To counter these oppressive health dynamics, Margaret Urban Walker's six-step framework was used as a guide to frame moral repair philosophically and pragmatically. Providing steps to moral repair created space for chapter two to engage the morality and duty inherent in international rights documents addressing rights to health.

Despite the difficulties in implementing a human rights framework in U.S. domestic law, many activists are turning towards the international instruments to create a new domestic culture in which the U.S. holds itself accountable to the wellbeing of its citizenry. Accountability begins with acknowledging the history informing contemporary health disparities, then rightly naming it a moral wrong. The U.S. must then acknowledge the complaints and fears of health-disparate communities to overcome a culture of normative abandonment. Holding wrongdoers responsible provides opportunities for health-disparate communities to increase their trust in systems meant to protect them. Through the revolutionary domestication of human rights, morally reparative actions are developed from international rights agreements focused on bettering the health and lived experiences of marginalized communities, specifically black birthing people.

Moving beyond identification and secular accountability, I invoked Jacques Maritain's Thomist-informed personalism to articulate both the deep violations of personhood and the conditions to activate full humanity without diminishing individual value. Put in conversation with health disparities, Maritain's philosophy theologically critiqued U.S. society for its implicit support of systems maintaining health-disparate conditions that violate personhood and God. Concluding with the case study of

disproportionate mortality and morbidity statistics among black birthing people, who served as a new anthropological subject, I provided practical policy solutions that integrated rights to health and Maritainian personalism. These actions included expanded public insurance (*i.e.*, Medicaid), a diversified maternal care workforce inclusive of doulas and midwives who have pay parity and standardized training, and standardized data collection at the federal level to gauge the depth of maternal mortality and morbidity.

These policy solutions have been posed in various iterations for years, and they have been recommended by the United Nations each reporting period, but they remain insufficient in the absence of moral motivation. To addressed this, I returned to Maritain's ontological anthropology to articulate how these solutions serve the common good of individuals and societies, thereby honoring the inherent personhood of black birthing people and providing the conditions that allow them to exercise their right to life. Policies that are informed by inherent human dignity and attend to the material needs of our human nature serve as moral repair and represent the contemporary moral consciousness of the nation. In the absence of a connection between personhood, rights, and moral repair, the nation will continue to experience the consequences of moral damage that have informed our relationships with one another throughout history.

Through a reclamation of personhood, the utilization of international rights instruments and Maritainian personalism, and the clarification of medical and theological ethics in U.S. healthcare policy and praxis, this dissertation contributes to different ways of engaging citizens' embodiment theologically and bioethically. These different ways of

engaging embodiment include culturally-informed clinicians who have the time to devote to patients and their concerns; sufficient funding to pay healthcare workers and subsidize healthcare facilities specialized in high-risk procedures in geographic areas serving high-risk populations; policy makers who craft policies with our sacred human nature in mind, not merely profit; all demographics meeting a baseline of health; and, health facilities providing care of which the U.S. is capable. These new ways of being are rooted in clear moral terms and standards that provide paths for redressal and inspire trust and hope in the healthcare system and supporting social systems.

It must be restated that technical policy measures and secular human rights discourse embodied in the United Nations' conventions and treaties do attend to improved health. Unfortunately, these measures are not working in the U.S. A long history of neglecting human rights laws and avoiding their inclusion in domestic law makes it difficult for the international instruments alone to effectively improve the health of marginalized communities. Health, especially among black birthing people, continues to deteriorate.

A theologically informed moral consciousness is necessary to catalyze attention and motivate moral repair. This dissertation has proposed Maritainian personalism because of its compelling vision of human nature and the human person that grounds human rights. A nature and personality rooted in inherent dignity because of its reflection of God's image grounds the rights and duties owed to human beings, as well as goes beyond rights to name our sacred obligations to one another. Maritain's ontological anthropology and theological ethics offers this, and it is a moral vision and consciousness

compatible with the UN's rights discourse and with the theological imagination prevalent within the U.S.

Still, even more is required, and additional research is needed to strengthen the limitations of this work. By limiting myself to Jacques Maritain's personalism, I did not account for other personalist traditions nor personalist alternatives that could also bridge rights and moral repair. As mentioned in chapter three, Jennifer Blumenthal-Barby proposed an alternative framework to personhood that successfully informs how we ought to engage one another. Such alternatives may provide better solutions to address and solve health inequities.

The case study of maternal mortality among black birthing people also requires additional research. While the solutions I have recommended focus on black communities, they can also benefit many health-disparate groups, and indeed different and equally promising solutions may be applicable to another demographic. For example, limited research has been conducted with Indigenous communities, yet addressing their unique health concerns would greatly change the provision of care for all demographics.

From a bioethics perspective, this work did not attend to the specific challenges that arise when actualizing the right to health, nor did it factor in the many philosophical positions that exist when considering if health is actually a right. Accepting health as a right that should be actualized, and grounding my definition of health in the World Health Organization's constitution, I did not engage critical conversations that impact the delivery of care for dominant versus disparate groups. More research is needed to understand the nuanced positions to protect the right to health in this nation, from the

challenges of states' rights to the justice orientation required if ever scarce resources must be allocated to differences in care that occur in private versus publicly funded healthcare settings. Each of these limitations provides fertile ground for future research aimed at improving the health and health experiences of the citizens of this nation.

In this work, black birthing people opened an important door to the ways we can engage one another to support our health equity and reimagine how to deploy available resources. When these methods of engagement respect our inalienable rights and our sacred human nature, we are on a morally reparative trajectory. However, if either of these pillars is disregarded, we remain rooted in poor health through our support of fraught systems that devalue and violate our very being. Health disparities are a moral wrong that have caused significant moral damage to the U.S., but the UDHR and Maritain provide a morally informed path forward that richly attends to our individuality, spirituality, and sociality.

APPENDIX

Appendix 1: Universal Declaration of Human Rights

Preamble

Whereas recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world,

Whereas disregard and contempt for human rights have resulted in barbarous acts which have outraged the conscience of mankind, and the advent of a world in which human beings shall enjoy freedom of speech and belief and freedom from fear and want has been proclaimed as the highest aspiration of the common people,

Whereas it is essential, if man is not to be compelled to have recourse, as a last resort, to rebellion against tyranny and oppression, that human rights should be protected by the rule of law,

Whereas it is essential to promote the development of friendly relations between nations,

Whereas the peoples of the United Nations have in the Charter reaffirmed their faith in fundamental human rights, in the dignity and worth of the human person and in the equal rights of men and women and have determined to promote social progress and better standards of life in larger freedom,

Whereas Member States have pledged themselves to achieve, in cooperation with the United Nations, the promotion of universal respect for and observance of human rights and fundamental freedoms,

Whereas a common understanding of these rights and freedoms is of the greatest

importance for the full realization of this pledge,

Now, therefore,

The General Assembly,

Proclaims this Universal Declaration of Human Rights as a common standard of achievement for all peoples and all nations, to the end that every individual and every organ of society, keeping this Declaration constantly in mind, shall strive by teaching and education to promote respect for these rights and freedoms and by progressive measures, national and international, to secure their universal and effective recognition and observance, both among the peoples of Member States themselves and among the peoples of territories under their jurisdiction.

Article 1

All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.

Article 2

Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status. Furthermore, no distinction shall be made on the basis of the political, jurisdictional or international status of the country or territory to which a person belongs, whether it be independent, trust, non-self-governing or under any other limitation of sovereignty.

Article 3

Everyone has the right to life, liberty and the security of person.

Article 4

No one shall be held in slavery or servitude; slavery and the slave trade shall be prohibited in all their forms.

Article 5

No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment.

Article 6

Everyone has the right to recognition everywhere as a person before the law.

Article 7

All are equal before the law and are entitled without any discrimination to equal protection of the law. All are entitled to equal protection against any discrimination in violation of this Declaration and against any incitement to such discrimination.

Article 8

Everyone has the right to an effective remedy by the competent national tribunals for acts violating the fundamental rights granted him by the constitution or by law.

Article 9

No one shall be subjected to arbitrary arrest, detention or exile.

Article 10

Everyone is entitled in full equality to a fair and public hearing by an independent and impartial tribunal, in the determination of his rights and obligations and of any criminal charge against him.

Article 11

1. Everyone charged with a penal offence has the right to be presumed innocent until proved guilty according to law in a public trial at which he has had all the guarantees necessary for his defence.
2. No one shall be held guilty of any penal offence on account of any actor omission which did not constitute a penal offence, under national or international law, at the time when it was committed. Nor shall a heavier penalty be imposed than the one that was applicable at the time the penal offence was committed.

Article 12

No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honour and reputation. Everyone has the right to the protection of the law against such interference or attacks.

Article 13

1. Everyone has the right to freedom of movement and residence within the borders of each State.
2. Everyone has the right to leave any country, including his own, and to return to his country.

Article 14

1. Everyone has the right to seek and to enjoy in other countries asylum from persecution.
2. This right may not be invoked in the case of prosecutions genuinely arising from non-political crimes or from acts contrary to the purposes and principles of the United Nations.

Article 15

1. Everyone has the right to a nationality.
2. No one shall be arbitrarily deprived of his nationality nor denied the right to change his nationality.

Article 16

1. Men and women of full age, without any limitation due to race, nationality or religion, have the right to marry and to found a family. They are entitled to equal rights as to marriage, during marriage and at its dissolution.
2. Marriage shall be entered into only with the free and full consent of the intending spouses.
3. The family is the natural and fundamental group unit of society and is entitled to protection by society and the State.

Article 17

1. Everyone has the right to own property alone as well as in association with others.
2. No one shall be arbitrarily deprived of his property.

Article 18

Everyone has the right to freedom of thought, conscience and religion; this right includes freedom to change his religion or belief, and freedom, either alone or in community with others and in public or private, to manifest his religion or belief in teaching, practice, worship and observance.

Article 19

Everyone has the right to freedom of opinion and expression; this right includes freedom to hold opinions without interference and to seek, receive and impart information and ideas through any media and regardless of frontiers.

Article 20

1. Everyone has the right to freedom of peaceful assembly and association.
2. No one may be compelled to belong to an association.

Article 21

1. Everyone has the right to take part in the government of his country, directly or through freely chosen representatives.
2. Everyone has the right to equal access to public service in his country.
3. The will of the people shall be the basis of the authority of government; this will shall be expressed in periodic and genuine elections which shall be by universal and equal suffrage and shall be held by secret vote or by equivalent free voting procedures.

Article 22

Everyone, as a member of society, has the right to social security and is entitled to realization, through national effort and international co-operation and in accordance with the organization and resources of each State, of the economic, social and cultural rights indispensable for his dignity and the free development of his personality.

Article 23

1. Everyone has the right to work, to free choice of employment, to just and favourable conditions of work and to protection against unemployment.

2. Everyone, without any discrimination, has the right to equal pay for equal work.
3. Everyone who works has the right to just and favourable remuneration ensuring for himself and his family an existence worthy of human dignity, and supplemented, if necessary, by other means of social protection.
4. Everyone has the right to form and to join trade unions for the protection of his interests.

Article 24

Everyone has the right to rest and leisure, including reasonable limitation of working hours and periodic holidays with pay.

Article 25

1. 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, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.
2. Motherhood and childhood are entitled to special care and assistance. All children, whether born in or out of wedlock, shall enjoy the same social protection.

Article 26

1. Everyone has the right to education. Education shall be free, at least in the elementary and fundamental stages. Elementary education shall be compulsory.

Technical and professional education shall be made generally available and higher education shall be equally accessible to all on the basis of merit.

2. Education shall be directed to the full development of the human personality and to the strengthening of respect for human rights and fundamental freedoms. It shall promote understanding, tolerance and friendship among all nations, racial or religious groups, and shall further the activities of the United Nations for the maintenance of peace.
3. Parents have a prior right to choose the kind of education that shall be given to their children.

Article 27

1. Everyone has the right freely to participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits.
2. Everyone has the right to the protection of the moral and material interests resulting from any scientific, literary or artistic production of which he is the author.

Article 28

Everyone is entitled to a social and international order in which the rights and freedoms set forth in this Declaration can be fully realized.

Article 29

1. Everyone has duties to the community in which alone the free and full development of his personality is possible.

2. In the exercise of his rights and freedoms, everyone shall be subject only to such limitations as are determined by law solely for the purpose of securing due recognition and respect for the rights and freedoms of others and of meeting the just requirements of morality, public order and the general welfare in a democratic society.
3. These rights and freedoms may in no case be exercised contrary to the purposes and principles of the United Nations.

Article 30

Nothing in this Declaration may be interpreted as implying for any State, group or person any right to engage in any activity or to perform any act aimed at the destruction of any of the rights and freedoms set forth herein.

Appendix 2: Convention on the Elimination of All Forms of Discrimination against Women

Adopted and opened for signature, ratification and accession by General Assembly resolution 34/180 of 18 December 1979

entry into force 3 September 1981, in accordance with article 27(1)

The States Parties to the present Convention,

Noting that the Charter of the United Nations reaffirms faith in fundamental human rights, in the dignity and worth of the human person and in the equal rights of men and women,

Noting that the Universal Declaration of Human Rights affirms the principle of the inadmissibility of discrimination and proclaims that all human beings are born free and equal in dignity and rights and that everyone is entitled to all the rights and freedoms set forth therein, without distinction of any kind, including distinction based on sex,

Noting that the States Parties to the International Covenants on Human Rights have the obligation to ensure the equal rights of men and women to enjoy all economic, social, cultural, civil and political rights,

Considering the international conventions concluded under the auspices of the United Nations and the specialized agencies promoting equality of rights of men and women,

Noting also the resolutions, declarations and recommendations adopted by the United Nations and the specialized agencies promoting equality of rights of men and women,

Concerned, however, that despite these various instruments extensive discrimination against women continues to exist,

Recalling that discrimination against women violates the principles of equality of rights and respect for human dignity, is an obstacle to the participation of women, on equal terms with men, in the political, social, economic and cultural life of their countries, hampers the growth of the prosperity of society and the family and makes more difficult the full development of the potentialities of women in the service of their countries and of humanity,

Concerned that in situations of poverty women have the least access to food, health, education, training and opportunities for employment and other needs,

Convinced that the establishment of the new international economic order based on equity and justice will contribute significantly towards the promotion of equality between men and women,

Emphasizing that the eradication of apartheid, all forms of racism, racial discrimination, colonialism, neo-colonialism, aggression, foreign occupation and domination and interference in the internal affairs of States is essential to the full enjoyment of the rights of men and women,

Affirming that the strengthening of international peace and security, the relaxation of international tension, mutual co-operation among all States irrespective of their social and economic systems, general and complete disarmament, in particular nuclear disarmament under strict and effective international control, the affirmation of the principles of justice, equality and mutual benefit in relations among countries and the realization of the right of peoples under alien and colonial domination and foreign occupation to self-determination and independence, as well as respect for national sovereignty and territorial integrity, will

promote social progress and development and as a consequence will contribute to the attainment of full equality between men and women,

Convinced that the full and complete development of a country, the welfare of the world and the cause of peace require the maximum participation of women on equal terms with men in all fields,

Bearing in mind the great contribution of women to the welfare of the family and to the development of society, so far not fully recognized, the social significance of maternity and the role of both parents in the family and in the upbringing of children, and aware that the role of women in procreation should not be a basis for discrimination but that the upbringing of children requires a sharing of responsibility between men and women and society as a whole,

Aware that a change in the traditional role of men as well as the role of women in society and in the family is needed to achieve full equality between men and women,

Determined to implement the principles set forth in the Declaration on the Elimination of Discrimination against Women and, for that purpose, to adopt the measures required for the elimination of such discrimination in all its forms and manifestations,

Have agreed on the following:

PART I

Article 1

For the purposes of the present Convention, the term "discrimination against women" shall mean any distinction, exclusion or restriction made on the basis of sex which has the effect or purpose of impairing or nullifying the recognition, enjoyment or exercise by

women, irrespective of their marital status, on a basis of equality of men and women, of human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field.

Article 2

States Parties condemn discrimination against women in all its forms, agree to pursue by all appropriate means and without delay a policy of eliminating discrimination against women and, to this end, undertake:

(a) To embody the principle of the equality of men and women in their national constitutions or other appropriate legislation if not yet incorporated therein and to ensure, through law and other appropriate means, the practical realization of this principle;

(b) To adopt appropriate legislative and other measures, including sanctions where appropriate, prohibiting all discrimination against women; (c) To establish legal protection of the rights of women on an equal basis with men and to ensure through competent national tribunals and other public institutions the effective protection of women against any act of discrimination;

(d) To refrain from engaging in any act or practice of discrimination against women and to ensure that public authorities and institutions shall act in conformity with this obligation;

(e) To take all appropriate measures to eliminate discrimination against women by any person, organization or enterprise;

(f) To take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices which constitute discrimination against women;

(g) To repeal all national penal provisions which constitute discrimination against women.

Article 3

States Parties shall take in all fields, in particular in the political, social, economic and cultural fields, all appropriate measures, including legislation, to ensure the full development and advancement of women, for the purpose of guaranteeing them the exercise and enjoyment of human rights and fundamental freedoms on a basis of equality with men.

Article 4

1. Adoption by States Parties of temporary special measures aimed at accelerating de facto equality between men and women shall not be considered discrimination as defined in the present Convention, but shall in no way entail as a consequence the maintenance of unequal or separate standards; these measures shall be discontinued when the objectives of equality of opportunity and treatment have been achieved.

2. Adoption by States Parties of special measures, including those measures contained in the present Convention, aimed at protecting maternity shall not be considered discriminatory.

Article 5

States Parties shall take all appropriate measures:

(a) To modify the social and cultural patterns of conduct of men and women, with a view to achieving the elimination of prejudices and customary and all other practices which are

based on the idea of the inferiority or the superiority of either of the sexes or on stereotyped roles for men and women;

(b) To ensure that family education includes a proper understanding of maternity as a social function and the recognition of the common responsibility of men and women in the upbringing and development of their children, it being understood that the interest of the children is the primordial consideration in all cases.

Article 6

States Parties shall take all appropriate measures, including legislation, to suppress all forms of traffic in women and exploitation of prostitution of women.

PART II

Article 7

States Parties shall take all appropriate measures to eliminate discrimination against women in the political and public life of the country and, in particular, shall ensure to women, on equal terms with men, the right:

(a) To vote in all elections and public referenda and to be eligible for election to all publicly elected bodies;

(b) To participate in the formulation of government policy and the implementation thereof and to hold public office and perform all public functions at all levels of government;

(c) To participate in non-governmental organizations and associations concerned with the public and political life of the country.

Article 8

States Parties shall take all appropriate measures to ensure to women, on equal terms with men and without any discrimination, the opportunity to represent their Governments at the international level and to participate in the work of international organizations.

Article 9

1. States Parties shall grant women equal rights with men to acquire, change or retain their nationality. They shall ensure in particular that neither marriage to an alien nor change of nationality by the husband during marriage shall automatically change the nationality of the wife, render her stateless or force upon her the nationality of the husband. 2. States Parties shall grant women equal rights with men with respect to the nationality of their children.

PART III

Article 10

States Parties shall take all appropriate measures to eliminate discrimination against women in order to ensure to them equal rights with men in the field of education and in particular to ensure, on a basis of equality of men and women:

(a) The same conditions for career and vocational guidance, for access to studies and for the achievement of diplomas in educational establishments of all categories in rural as well as in urban areas; this equality shall be ensured in pre-school, general, technical, professional and higher technical education, as well as in all types of vocational training;

(b) Access to the same curricula, the same examinations, teaching staff with qualifications of the same standard and school premises and equipment of the same quality;

(c) The elimination of any stereotyped concept of the roles of men and women at all levels and in all forms of education by encouraging coeducation and other types of education which will help to achieve this aim and, in particular, by the revision of textbooks and school programmes and the adaptation of teaching methods;

(d) The same opportunities to benefit from scholarships and other study grants;

(e) The same opportunities for access to programmes of continuing education, including adult and functional literacy programmes, particularly those aimed at reducing, at the earliest possible time, any gap in education existing between men and women;

(f) The reduction of female student drop-out rates and the organization of programmes for girls and women who have left school prematurely;

(g) The same Opportunities to participate actively in sports and physical education;

(h) Access to specific educational information to help to ensure the health and well-being of families, including information and advice on family planning.

Article 11

1. States Parties shall take all appropriate measures to eliminate discrimination against women in the field of employment in order to ensure, on a basis of equality of men and women, the same rights, in particular:

(a) The right to work as an inalienable right of all human beings;

(b) The right to the same employment opportunities, including the application of the same criteria for selection in matters of employment;

(c) The right to free choice of profession and employment, the right to promotion, job security and all benefits and conditions of service and the right to receive vocational

training and retraining, including apprenticeships, advanced vocational training and recurrent training;

(d) The right to equal remuneration, including benefits, and to equal treatment in respect of work of equal value, as well as equality of treatment in the evaluation of the quality of work;

(e) The right to social security, particularly in cases of retirement, unemployment, sickness, invalidity and old age and other incapacity to work, as well as the right to paid leave;

(f) The right to protection of health and to safety in working conditions, including the safeguarding of the function of reproduction.

2. In order to prevent discrimination against women on the grounds of marriage or maternity and to ensure their effective right to work, States Parties shall take appropriate measures:

(a) To prohibit, subject to the imposition of sanctions, dismissal on the grounds of pregnancy or of maternity leave and discrimination in dismissals on the basis of marital status;

(b) To introduce maternity leave with pay or with comparable social benefits without loss of former employment, seniority or social allowances;

(c) To encourage the provision of the necessary supporting social services to enable parents to combine family obligations with work responsibilities and participation in public life, in particular through promoting the establishment and development of a network of child-care facilities;

(d) To provide special protection to women during pregnancy in types of work proved to be harmful to them.

3. Protective legislation relating to matters covered in this article shall be reviewed periodically in the light of scientific and technological knowledge and shall be revised, repealed or extended as necessary.

Article 12

1. States Parties shall take all appropriate measures to eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, access to health care services, including those related to family planning.

2. Notwithstanding the provisions of paragraph I of this article, States Parties shall ensure to women appropriate services in connection with pregnancy, confinement and the post-natal period, granting free services where necessary, as well as adequate nutrition during pregnancy and lactation.

Article 13

States Parties shall take all appropriate measures to eliminate discrimination against women in other areas of economic and social life in order to ensure, on a basis of equality of men and women, the same rights, in particular:

(a) The right to family benefits;

(b) The right to bank loans, mortgages and other forms of financial credit;

(c) The right to participate in recreational activities, sports and all aspects of cultural life.

Article 14

1. States Parties shall take into account the particular problems faced by rural women and the significant roles which rural women play in the economic survival of their families, including their work in the non-monetized sectors of the economy, and shall take all appropriate measures to ensure the application of the provisions of the present Convention to women in rural areas.

2. States Parties shall take all appropriate measures to eliminate discrimination against women in rural areas in order to ensure, on a basis of equality of men and women, that they participate in and benefit from rural development and, in particular, shall ensure to such women the right:

(a) To participate in the elaboration and implementation of development planning at all levels;

(b) To have access to adequate health care facilities, including information, counselling and services in family planning;

(c) To benefit directly from social security programmes;

(d) To obtain all types of training and education, formal and non-formal, including that relating to functional literacy, as well as, inter alia, the benefit of all community and extension services, in order to increase their technical proficiency;

(e) To organize self-help groups and co-operatives in order to obtain equal access to economic opportunities through employment or self employment;

(f) To participate in all community activities;

(g) To have access to agricultural credit and loans, marketing facilities, appropriate technology and equal treatment in land and agrarian reform as well as in land resettlement schemes;

(h) To enjoy adequate living conditions, particularly in relation to housing, sanitation, electricity and water supply, transport and communications.

PART IV

Article 15

1. States Parties shall accord to women equality with men before the law.

2. States Parties shall accord to women, in civil matters, a legal capacity identical to that of men and the same opportunities to exercise that capacity. In particular, they shall give women equal rights to conclude contracts and to administer property and shall treat them equally in all stages of procedure in courts and tribunals.

3. States Parties agree that all contracts and all other private instruments of any kind with a legal effect which is directed at restricting the legal capacity of women shall be deemed null and void.

4. States Parties shall accord to men and women the same rights with regard to the law relating to the movement of persons and the freedom to choose their residence and domicile.

Article 16

1. States Parties shall take all appropriate measures to eliminate discrimination against women in all matters relating to marriage and family relations and in particular shall ensure, on a basis of equality of men and women:

(a) The same right to enter into marriage;

(b) The same right freely to choose a spouse and to enter into marriage only with their free and full consent;

(c) The same rights and responsibilities during marriage and at its dissolution;

(d) The same rights and responsibilities as parents, irrespective of their marital status, in matters relating to their children; in all cases the interests of the children shall be paramount;

(e) The same rights to decide freely and responsibly on the number and spacing of their children and to have access to the information, education and means to enable them to exercise these rights;

(f) The same rights and responsibilities with regard to guardianship, wardship, trusteeship and adoption of children, or similar institutions where these concepts exist in national legislation; in all cases the interests of the children shall be paramount;

(g) The same personal rights as husband and wife, including the right to choose a family name, a profession and an occupation;

(h) The same rights for both spouses in respect of the ownership, acquisition, management, administration, enjoyment and disposition of property, whether free of charge or for a valuable consideration.

2. The betrothal and the marriage of a child shall have no legal effect, and all necessary action, including legislation, shall be taken to specify a minimum age for marriage and to make the registration of marriages in an official registry compulsory.

PART V

Article 17

1. For the purpose of considering the progress made in the implementation of the present Convention, there shall be established a Committee on the Elimination of Discrimination against Women (hereinafter referred to as the Committee) consisting, at the time of entry into force of the Convention, of eighteen and, after ratification of or accession to the Convention by the thirty-fifth State Party, of twenty-three experts of high moral standing and competence in the field covered by the Convention. The experts shall be elected by States Parties from among their nationals and shall serve in their personal capacity, consideration being given to equitable geographical distribution and to the representation of the different forms of civilization as well as the principal legal systems.

2. The members of the Committee shall be elected by secret ballot from a list of persons nominated by States Parties. Each State Party may nominate one person from among its own nationals.

3. The initial election shall be held six months after the date of the entry into force of the present Convention. At least three months before the date of each election the Secretary-General of the United Nations shall address a letter to the States Parties inviting them to submit their nominations within two months. The Secretary-General shall prepare a list in alphabetical order of all persons thus nominated, indicating the States Parties which have nominated them, and shall submit it to the States Parties.

4. Elections of the members of the Committee shall be held at a meeting of States Parties convened by the Secretary-General at United Nations Headquarters. At that meeting, for which two thirds of the States Parties shall constitute a quorum, the persons elected to the

Committee shall be those nominees who obtain the largest number of votes and an absolute majority of the votes of the representatives of States Parties present and voting.

5. The members of the Committee shall be elected for a term of four years. However, the terms of nine of the members elected at the first election shall expire at the end of two years; immediately after the first election the names of these nine members shall be chosen by lot by the Chairman of the Committee.

6. The election of the five additional members of the Committee shall be held in accordance with the provisions of paragraphs 2, 3 and 4 of this article, following the thirty-fifth ratification or accession. The terms of two of the additional members elected on this occasion shall expire at the end of two years, the names of these two members having been chosen by lot by the Chairman of the Committee.

7. For the filling of casual vacancies, the State Party whose expert has ceased to function as a member of the Committee shall appoint another expert from among its nationals, subject to the approval of the Committee.

8. The members of the Committee shall, with the approval of the General Assembly, receive emoluments from United Nations resources on such terms and conditions as the Assembly may decide, having regard to the importance of the Committee's responsibilities.

9. The Secretary-General of the United Nations shall provide the necessary staff and facilities for the effective performance of the functions of the Committee under the present Convention.

Article 18

1. States Parties undertake to submit to the Secretary-General of the United Nations, for consideration by the Committee, a report on the legislative, judicial, administrative or other measures which they have adopted to give effect to the provisions of the present Convention and on the progress made in this respect:

(a) Within one year after the entry into force for the State concerned;

(b) Thereafter at least every four years and further whenever the Committee so requests.

2. Reports may indicate factors and difficulties affecting the degree of fulfilment of obligations under the present Convention.

Article 19

1. The Committee shall adopt its own rules of procedure. 2. The Committee shall elect its officers for a term of two years.

Article 20

1. The Committee shall normally meet for a period of not more than two weeks annually in order to consider the reports submitted in accordance with article 18 of the present Convention.

2. The meetings of the Committee shall normally be held at United Nations Headquarters or at any other convenient place as determined by the Committee.

Article 21

1. The Committee shall, through the Economic and Social Council, report annually to the General Assembly of the United Nations on its activities and may make suggestions and general recommendations based on the examination of reports and information received

from the States Parties. Such suggestions and general recommendations shall be included in the report of the Committee together with comments, if any, from States Parties.

2. The Secretary-General of the United Nations shall transmit the reports of the Committee to the Commission on the Status of Women for its information.

Article 22

The specialized agencies shall be entitled to be represented at the consideration of the implementation of such provisions of the present Convention as fall within the scope of their activities. The Committee may invite the specialized agencies to submit reports on the implementation of the Convention in areas falling within the scope of their activities.

PART VI

Article 23

Nothing in the present Convention shall affect any provisions that are more conducive to the achievement of equality between men and women which may be contained:

(a) In the legislation of a State Party; or

(b) In any other international convention, treaty or agreement in force for that State.

Article 24

States Parties undertake to adopt all necessary measures at the national level aimed at achieving the full realization of the rights recognized in the present Convention.

Article 25

1. The present Convention shall be open for signature by all States.

2. The Secretary-General of the United Nations is designated as the depositary of the present Convention.

3. The present Convention is subject to ratification. Instruments of ratification shall be deposited with the Secretary-General of the United Nations.

4. The present Convention shall be open to accession by all States. Accession shall be effected by the deposit of an instrument of accession with the Secretary-General of the United Nations.

Article 26

1. A request for the revision of the present Convention may be made at any time by any State Party by means of a notification in writing addressed to the Secretary-General of the United Nations.

2. The General Assembly of the United Nations shall decide upon the steps, if any, to be taken in respect of such a request.

Article 27

1. The present Convention shall enter into force on the thirtieth day after the date of deposit with the Secretary-General of the United Nations of the twentieth instrument of ratification or accession.

2. For each State ratifying the present Convention or acceding to it after the deposit of the twentieth instrument of ratification or accession, the Convention shall enter into force on the thirtieth day after the date of the deposit of its own instrument of ratification or accession.

Article 28

1. The Secretary-General of the United Nations shall receive and circulate to all States the text of reservations made by States at the time of ratification or accession.

2. A reservation incompatible with the object and purpose of the present Convention shall not be permitted.

3. Reservations may be withdrawn at any time by notification to this effect addressed to the Secretary- General of the United Nations, who shall then inform all States thereof. Such notification shall take effect on the date on which it is received.

Article 29

1. Any dispute between two or more States Parties concerning the interpretation or application of the present Convention which is not settled by negotiation shall, at the request of one of them, be submitted to arbitration. If within six months from the date of the request for arbitration the parties are unable to agree on the organization of the arbitration, any one of those parties may refer the dispute to the International Court of Justice by request in conformity with the Statute of the Court.

2. Each State Party may at the time of signature or ratification of the present Convention or accession thereto declare that it does not consider itself bound by paragraph I of this article. The other States Parties shall not be bound by that paragraph with respect to any State Party which has made such a reservation.

3. Any State Party which has made a reservation in accordance with paragraph 2 of this article may at any time withdraw that reservation by notification to the Secretary-General of the United Nations.

Article 30

The present Convention, the Arabic, Chinese, English, French, Russian and Spanish texts of which are equally authentic, shall be deposited with the Secretary-General of the

United Nations. IN WITNESS WHEREOF the undersigned, duly authorized, have signed the present Convention.

Appendix 3: Convention on the Elimination of All Forms of Racial Discrimination

Adopted and opened for signature and ratification by General Assembly resolution 2106 (XX) of 21 December 1965

entry into force 4 January 1969, in accordance with Article 19

The States Parties to this Convention,

Considering that the Charter of the United Nations is based on the principles of the dignity and equality inherent in all human beings, and that all Member States have pledged themselves to take joint and separate action, in co-operation with the Organization, for the achievement of one of the purposes of the United Nations which is to promote and encourage universal respect for and observance of human rights and fundamental freedoms for all, without distinction as to race, sex, language or religion,

Considering that the Universal Declaration of Human Rights proclaims that all human beings are born free and equal in dignity and rights and that everyone is entitled to all the rights and freedoms set out therein, without distinction of any kind, in particular as to race, colour or national origin,

Considering that all human beings are equal before the law and are entitled to equal protection of the law against any discrimination and against any incitement to discrimination,

Considering that the United Nations has condemned colonialism and all practices of segregation and discrimination associated therewith, in whatever form and wherever they exist, and that the Declaration on the Granting of Independence to Colonial Countries and Peoples of 14 December 1960 (General Assembly resolution 1514 (XV)) has affirmed

and solemnly proclaimed the necessity of bringing them to a speedy and unconditional end,

Considering that the United Nations Declaration on the Elimination of All Forms of Racial Discrimination of 20 November 1963 (General Assembly resolution 1904 (XVIII)) solemnly affirms the necessity of speedily eliminating racial discrimination throughout the world in all its forms and manifestations and of securing understanding of and respect for the dignity of the human person,

Convinced that any doctrine of superiority based on racial differentiation is scientifically false, morally condemnable, socially unjust and dangerous, and that there is no justification for racial discrimination, in theory or in practice, anywhere,

Reaffirming that discrimination between human beings on the grounds of race, colour or ethnic origin is an obstacle to friendly and peaceful relations among nations and is capable of disturbing peace and security among peoples and the harmony of persons living side by side even within one and the same State,

Convinced that the existence of racial barriers is repugnant to the ideals of any human society,

Alarmed by manifestations of racial discrimination still in evidence in some areas of the world and by governmental policies based on racial superiority or hatred, such as policies of apartheid, segregation or separation,

Resolved to adopt all necessary measures for speedily eliminating racial discrimination in all its forms and manifestations, and to prevent and combat racist doctrines and practices

in order to promote understanding between races and to build an international community free from all forms of racial segregation and racial discrimination,

Bearing in mind the Convention concerning Discrimination in respect of Employment and Occupation adopted by the International Labour Organisation in 1958, and the Convention against Discrimination in Education adopted by the United Nations Educational, Scientific and Cultural Organization in 1960,

Desiring to implement the principles embodied in the United Nations Declaration on the Elimination of Al l Forms of Racial Discrimination and to secure the earliest adoption of practical measures to that end,

Have agreed as follows:

PART I

Article 1

1. In this Convention, the term "racial discrimination" shall mean any distinction, exclusion, restriction or preference based on race, colour, descent, or national or ethnic origin which has the purpose or effect of nullifying or impairing the recognition, enjoyment or exercise, on an equal footing, of human rights and fundamental freedoms in the political, economic, social, cultural or any other field of public life.

2. This Convention shall not apply to distinctions, exclusions, restrictions or preferences made by a State Party to this Convention between citizens and non-citizens.

3. Nothing in this Convention may be interpreted as affecting in any way the legal provisions of States Parties concerning nationality, citizenship or naturalization, provided that such provisions do not discriminate against any particular nationality.

4. Special measures taken for the sole purpose of securing adequate advancement of certain racial or ethnic groups or individuals requiring such protection as may be necessary in order to ensure such groups or individuals equal enjoyment or exercise of human rights and fundamental freedoms shall not be deemed racial discrimination, provided, however, that such measures do not, as a consequence, lead to the maintenance of separate rights for different racial groups and that they shall not be continued after the objectives for which they were taken have been achieved.

Article 2

1. States Parties condemn racial discrimination and undertake to pursue by all appropriate means and without delay a policy of eliminating racial discrimination in all its forms and promoting understanding among all races, and, to this end: (a) Each State Party undertakes to engage in no act or practice of racial discrimination against persons, groups of persons or institutions and to ensure that all public authorities and public institutions, national and local, shall act in conformity with this obligation; (b) Each State Party undertakes not to sponsor, defend or support racial discrimination by any persons or organizations;

(c) Each State Party shall take effective measures to review governmental, national and local policies, and to amend, rescind or nullify any laws and regulations which have the effect of creating or perpetuating racial discrimination wherever it exists;

(d) Each State Party shall prohibit and bring to an end, by all appropriate means, including legislation as required by circumstances, racial discrimination by any persons, group or organization;

(e) Each State Party undertakes to encourage, where appropriate, integrationist multiracial organizations and movements and other means of eliminating barriers between races, and to discourage anything which tends to strengthen racial division.

2. States Parties shall, when the circumstances so warrant, take, in the social, economic, cultural and other fields, special and concrete measures to ensure the adequate development and protection of certain racial groups or individuals belonging to them, for the purpose of guaranteeing them the full and equal enjoyment of human rights and fundamental freedoms. These measures shall in no case entail as a con sequence the maintenance of unequal or separate rights for different racial groups after the objectives for which they were taken have been achieved.

Article 3

States Parties particularly condemn racial segregation and apartheid and undertake to prevent, prohibit and eradicate all practices of this nature in territories under their jurisdiction.

Article 4

States Parties condemn all propaganda and all organizations which are based on ideas or theories of superiority of one race or group of persons of one colour or ethnic origin, or which attempt to justify or promote racial hatred and discrimination in any form, and undertake to adopt immediate and positive measures designed to eradicate all incitement to, or acts of, such discrimination and, to this end, with due regard to the principles embodied in the Universal Declaration of Human Rights and the rights expressly set forth in article 5 of this Convention, inter alia:

(a) Shall declare an offence punishable by law all dissemination of ideas based on racial superiority or hatred, incitement to racial discrimination, as well as all acts of violence or incitement to such acts against any race or group of persons of another colour or ethnic origin, and also the provision of any assistance to racist activities, including the financing thereof;

(b) Shall declare illegal and prohibit organizations, and also organized and all other propaganda activities, which promote and incite racial discrimination, and shall recognize participation in such organizations or activities as an offence punishable by law;

(c) Shall not permit public authorities or public institutions, national or local, to promote or incite racial discrimination.

Article 5

In compliance with the fundamental obligations laid down in article 2 of this Convention, States Parties undertake to prohibit and to eliminate racial discrimination in all its forms and to guarantee the right of everyone, without distinction as to race, colour, or national or ethnic origin, to equality before the law, notably in the enjoyment of the following rights:

(a) The right to equal treatment before the tribunals and all other organs administering justice;

(b) The right to security of person and protection by the State against violence or bodily harm, whether inflicted by government officials or by any individual group or institution;

(c) Political rights, in particular the right to participate in elections-to vote and to stand for election-on the basis of universal and equal suffrage, to take part in the Government

as well as in the conduct of public affairs at any level and to have equal access to public service;

(d) Other civil rights, in particular:

(i) The right to freedom of movement and residence within the border of the State;

(ii) The right to leave any country, including one's own, and to return to one's country;

(iii) The right to nationality;

(iv) The right to marriage and choice of spouse;

(v) The right to own property alone as well as in association with others;

(vi) The right to inherit;

(vii) The right to freedom of thought, conscience and religion;

(viii) The right to freedom of opinion and expression;

(ix) The right to freedom of peaceful assembly and association;

(e) Economic, social and cultural rights, in particular:

(i) The rights to work, to free choice of employment, to just and favourable conditions of work, to protection against unemployment, to equal pay for equal work, to just and favourable remuneration;

(ii) The right to form and join trade unions;

(iii) The right to housing;

(iv) The right to public health, medical care, social security and social services;

(v) The right to education and training;

(vi) The right to equal participation in cultural activities;

(f) The right of access to any place or service intended for use by the general public, such as transport hotels, restaurants, cafes, theatres and parks.

Article 6

States Parties shall assure to everyone within their jurisdiction effective protection and remedies, through the competent national tribunals and other State institutions, against any acts of racial discrimination which violate his human rights and fundamental freedoms contrary to this Convention, as well as the right to seek from such tribunals just and adequate reparation or satisfaction for any damage suffered as a result of such discrimination.

Article 7

States Parties undertake to adopt immediate and effective measures, particularly in the fields of teaching, education, culture and information, with a view to combating prejudices which lead to racial discrimination and to promoting understanding, tolerance and friendship among nations and racial or ethnical groups, as well as to propagating the purposes and principles of the Charter of the United Nations, the Universal Declaration of Human Rights, the United Nations Declaration on the Elimination of All Forms of Racial Discrimination, and this Convention.

PART II

Article 8

1. There shall be established a Committee on the Elimination of Racial Discrimination (hereinafter referred to as the Committee) consisting of eighteen experts of high moral standing and acknowledged impartiality elected by States Parties from among their

nationals, who shall serve in their personal capacity, consideration being given to equitable geographical distribution and to the representation of the different forms of civilization as well as of the principal legal systems. 2. The members of the Committee shall be elected by secret ballot from a list of persons nominated by the States Parties. Each State Party may nominate one person from among its own nationals.

3. The initial election shall be held six months after the date of the entry into force of this Convention. At least three months before the date of each election the Secretary-General of the United Nations shall address a letter to the States Parties inviting them to submit their nominations within two months. The Secretary-General shall prepare a list in alphabetical order of all persons thus nominated, indicating the States Parties which have nominated them, and shall submit it to the States Parties.

4. Elections of the members of the Committee shall be held at a meeting of States Parties convened by the Secretary-General at United Nations Headquarters. At that meeting, for which two thirds of the States Parties shall constitute a quorum, the persons elected to the Committee shall be nominees who obtain the largest number of votes and an absolute majority of the votes of the representatives of States Parties present and voting.

5.

(a) The members of the Committee shall be elected for a term of four years. However, the terms of nine of the members elected at the first election shall expire at the end of two years; immediately after the first election the names of these nine members shall be chosen by lot by the Chairman of the Committee;

(b) For the filling of casual vacancies, the State Party whose expert has ceased to function as a member of the Committee shall appoint another expert from among its nationals, subject to the approval of the Committee.

6. States Parties shall be responsible for the expenses of the members of the Committee while they are in performance of Committee duties.

Article 9

1. States Parties undertake to submit to the Secretary-General of the United Nations, for consideration by the Committee, a report on the legislative, judicial, administrative or other measures which they have adopted and which give effect to the provisions of this Convention: (a) within one year after the entry into force of the Convention for the State concerned; and

(b) thereafter every two years and whenever the Committee so requests. The Committee may request further information from the States Parties.

2. The Committee shall report annually, through the Secretary General, to the General Assembly of the United Nations on its activities and may make suggestions and general recommendations based on the examination of the reports and information received from the States Parties. Such suggestions and general recommendations shall be reported to the General Assembly together with comments, if any, from States Parties.

Article 10

1. The Committee shall adopt its own rules of procedure. 2. The Committee shall elect its officers for a term of two years.

3. The secretariat of the Committee shall be provided by the Secretary General of the United Nations. 4. The meetings of the Committee shall normally be held at United Nations Headquarters.

Article 11

1. If a State Party considers that another State Party is not giving effect to the provisions of this Convention, it may bring the matter to the attention of the Committee. The Committee shall then transmit the communication to the State Party concerned. Within three months, the receiving State shall submit to the Committee written explanations or statements clarifying the matter and the remedy, if any, that may have been taken by that State. 2. If the matter is not adjusted to the satisfaction of both parties, either by bilateral negotiations or by any other procedure open to them, within six months after the receipt by the receiving State of the initial communication, either State shall have the right to refer the matter again to the Committee by notifying the Committee and also the other State.

3. The Committee shall deal with a matter referred to it in accordance with paragraph 2 of this article after it has ascertained that all available domestic remedies have been invoked and exhausted in the case, in conformity with the generally recognized principles of international law. This shall not be the rule where the application of the remedies is unreasonably prolonged.

4. In any matter referred to it, the Committee may call upon the States Parties concerned to supply any other relevant information.

5. When any matter arising out of this article is being considered by the Committee, the States Parties concerned shall be entitled to send a representative to take part in the proceedings of the Committee, without voting rights, while the matter is under consideration.

Article 12

1. (a) After the Committee has obtained and collated all the information it deems necessary, the Chairman shall appoint an ad hoc Conciliation Commission (hereinafter referred to as the Commission) comprising five persons who may or may not be members of the Committee. The members of the Commission shall be appointed with the unanimous consent of the parties to the dispute, and its good offices shall be made available to the States concerned with a view to an amicable solution of the matter on the basis of respect for this Convention; (b) If the States parties to the dispute fail to reach agreement within three months on all or part of the composition of the Commission, the members of the Commission not agreed upon by the States parties to the dispute shall be elected by secret ballot by a two-thirds majority vote of the Committee from among its own members.

2. The members of the Commission shall serve in their personal capacity. They shall not be nationals of the States parties to the dispute or of a State not Party to this Convention.

3. The Commission shall elect its own Chairman and adopt its own rules of procedure.

4. The meetings of the Commission shall normally be held at United Nations Headquarters or at any other convenient place as determined by the Commission.

5. The secretariat provided in accordance with article 10, paragraph 3, of this Convention shall also service the Commission whenever a dispute among States Parties brings the Commission into being.

6. The States parties to the dispute shall share equally all the expenses of the members of the Commission in accordance with estimates to be provided by the Secretary-General of the United Nations.

7. The Secretary-General shall be empowered to pay the expenses of the members of the Commission, if necessary, before reimbursement by the States parties to the dispute in accordance with paragraph 6 of this article.

8. The information obtained and collated by the Committee shall be made available to the Commission, and the Commission may call upon the States concerned to supply any other relevant information.

Article 13

1. When the Commission has fully considered the matter, it shall prepare and submit to the Chairman of the Committee a report embodying its findings on all questions of fact relevant to the issue between the parties and containing such recommendations as it may think proper for the amicable solution of the dispute. 2. The Chairman of the Committee shall communicate the report of the Commission to each of the States parties to the dispute. These States shall, within three months, inform the Chairman of the Committee whether or not they accept the recommendations contained in the report of the Commission.

3. After the period provided for in paragraph 2 of this article, the Chairman of the Committee shall communicate the report of the Commission and the declarations of the States Parties concerned to the other States Parties to this Convention.

Article 14

1. A State Party may at any time declare that it recognizes the competence of the Committee to receive and consider communications from individuals or groups of individuals within its jurisdiction claiming to be victims of a violation by that State Party of any of the rights set forth in this Convention. No communication shall be received by the Committee if it concerns a State Party which has not made such a declaration. 2. Any State Party which makes a declaration as provided for in paragraph I of this article may establish or indicate a body within its national legal order which shall be competent to receive and consider petitions from individuals and groups of individuals within its jurisdiction who claim to be victims of a violation of any of the rights set forth in this Convention and who have exhausted other available local remedies.

3. A declaration made in accordance with paragraph 1 of this article and the name of any body established or indicated in accordance with paragraph 2 of this article shall be deposited by the State Party concerned with the Secretary-General of the United Nations, who shall transmit copies thereof to the other States Parties. A declaration may be withdrawn at any time by notification to the Secretary- General, but such a withdrawal shall not affect communications pending before the Committee.

4. A register of petitions shall be kept by the body established or indicated in accordance with paragraph 2 of this article, and certified copies of the register shall be filed annually

through appropriate channels with the Secretary-General on the understanding that the contents shall not be publicly disclosed.

5. In the event of failure to obtain satisfaction from the body established or indicated in accordance with paragraph 2 of this article, the petitioner shall have the right to communicate the matter to the Committee within six months.

6.

(a) The Committee shall confidentially bring any communication referred to it to the attention of the State Party alleged to be violating any provision of this Convention, but the identity of the individual or groups of individuals concerned shall not be revealed without his or their express consent. The Committee shall not receive anonymous communications;

(b) Within three months, the receiving State shall submit to the Committee written explanations or statements clarifying the matter and the remedy, if any, that may have been taken by that State.

7.

(a) The Committee shall consider communications in the light of all information made available to it by the State Party concerned and by the petitioner. The Committee shall not consider any communication from a petitioner unless it has ascertained that the petitioner has exhausted all available domestic remedies. However, this shall not be the rule where the application of the remedies is unreasonably prolonged;

(b) The Committee shall forward its suggestions and recommendations, if any, to the State Party concerned and to the petitioner.

8. The Committee shall include in its annual report a summary of such communications and, where appropriate, a summary of the explanations and statements of the States Parties concerned and of its own suggestions and recommendations. 9. The Committee shall be competent to exercise the functions provided for in this article only when at least ten States Parties to this Convention are bound by declarations in accordance with paragraph I of this article.

Article 15

1. Pending the achievement of the objectives of the Declaration on the Granting of Independence to Colonial Countries and Peoples, contained in General Assembly resolution 1514 (XV) of 14 December 1960, the provisions of this Convention shall in no way limit the right of petition granted to these peoples by other international instruments or by the United Nations and its specialized agencies. 2.

(a) The Committee established under article 8, paragraph 1, of this Convention shall receive copies of the petitions from, and submit expressions of opinion and recommendations on these petitions to, the bodies of the United Nations which deal with matters directly related to the principles and objectives of this Convention in their consideration of petitions from the inhabitants of Trust and Non-Self-Governing Territories and all other territories to which General Assembly resolution 1514 (XV) applies, relating to matters covered by this Convention which are before these bodies;

(b) The Committee shall receive from the competent bodies of the United Nations copies of the reports concerning the legislative, judicial, administrative or other measures directly related to the principles and objectives of this Convention applied by the

administering Powers within the Territories mentioned in subparagraph (a) of this paragraph, and shall express opinions and make recommendations to these bodies.

3. The Committee shall include in its report to the General Assembly a summary of the petitions and reports it has received from United Nations bodies, and the expressions of opinion and recommendations of the Committee relating to the said petitions and reports.

4. The Committee shall request from the Secretary-General of the United Nations all information relevant to the objectives of this Convention and available to him regarding the Territories mentioned in paragraph 2 (a) of this article.

Article 16

The provisions of this Convention concerning the settlement of disputes or complaints shall be applied without prejudice to other procedures for settling disputes or complaints in the field of discrimination laid down in the constituent instruments of, or conventions adopted by, the United Nations and its specialized agencies, and shall not prevent the States Parties from having recourse to other procedures for settling a dispute in accordance with general or special international agreements in force between them.

PART III

Article 17

1. This Convention is open for signature by any State Member of the United Nations or member of any of its specialized agencies, by any State Party to the Statute of the International Court of Justice, and by any other State which has been invited by the General Assembly of the United Nations to become a Party to this Convention. 2. This

Convention is subject to ratification. Instruments of ratification shall be deposited with the Secretary-General of the United Nations.

Article 18

1. This Convention shall be open to accession by any State referred to in article 17, paragraph 1, of the Convention. 2. Accession shall be effected by the deposit of an instrument of accession with the Secretary-General of the United Nations.

Article 19

1. This Convention shall enter into force on the thirtieth day after the date of the deposit with the Secretary-General of the United Nations of the twenty-seventh instrument of ratification or instrument of accession. 2. For each State ratifying this Convention or acceding to it after the deposit of the twenty-seventh instrument of ratification or instrument of accession, the Convention shall enter into force on the thirtieth day after the date of the deposit of its own instrument of ratification or instrument of accession.

Article 20

1. The Secretary-General of the United Nations shall receive and circulate to all States which are or may become Parties to this Convention reservations made by States at the time of ratification or accession. Any State which objects to the reservation shall, within a period of ninety days from the date of the said communication, notify the Secretary-General that it does not accept it. 2. A reservation incompatible with the object and purpose of this Convention shall not be permitted, nor shall a reservation the effect of which would inhibit the operation of any of the bodies established by this Convention be

allowed. A reservation shall be considered incompatible or inhibitive if at least two thirds of the States Parties to this Convention object to it.

3. Reservations may be withdrawn at any time by notification to this effect addressed to the Secretary- General. Such notification shall take effect on the date on which it is received.

Article 21

A State Party may denounce this Convention by written notification to the Secretary-General of the United Nations. Denunciation shall take effect one year after the date of receipt of the notification by the Secretary General.

Article 22

Any dispute between two or more States Parties with respect to the interpretation or application of this Convention, which is not settled by negotiation or by the procedures expressly provided for in this Convention, shall, at the request of any of the parties to the dispute, be referred to the International Court of Justice for decision, unless the disputants agree to another mode of settlement.

Article 23

1. A request for the revision of this Convention may be made at any time by any State Party by means of a notification in writing addressed to the Secretary-General of the United Nations. 2. The General Assembly of the United Nations shall decide upon the steps, if any, to be taken in respect of such a request.

Article 24

The Secretary-General of the United Nations shall inform all States referred to in article 17, paragraph 1, of this Convention of the following particulars:

(a) Signatures, ratifications and accessions under articles 17 and 18;

(b) The date of entry into force of this Convention under article 19;

(c) Communications and declarations received under articles 14, 20 and 23; (d) Denunciations under article 21.

Article 25

1. This Convention, of which the Chinese, English, French, Russian and Spanish texts are equally authentic, shall be deposited in the archives of the United Nations. 2. The Secretary-General of the United Nations shall transmit certified copies of this Convention to all States belonging to any of the categories mentioned in article 17, paragraph 1, of the Convention.

Appendix 4: International Covenant on Economic, Social and Cultural Rights

Adopted and opened for signature, ratification and accession by General Assembly resolution 2200A (XXI)

of 16 December 1966

entry into force 3 January 1976, in accordance with article 27

Preamble

The States Parties to the present Covenant,

Considering that, in accordance with the principles proclaimed in the Charter of the United Nations, recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world,

Recognizing that these rights derive from the inherent dignity of the human person,

Recognizing that, in accordance with the Universal Declaration of Human Rights, the ideal of free human beings enjoying freedom from fear and want can only be achieved if conditions are created whereby everyone may enjoy his economic, social and cultural rights, as well as his civil and political rights,

Considering the obligation of States under the Charter of the United Nations to promote universal respect for, and observance of, human rights and freedoms,

Realizing that the individual, having duties to other individuals and to the community to which he belongs, is under a responsibility to strive for the promotion and observance of the rights recognized in the present Covenant,

Agree upon the following articles:

PART I

Article 1

1. All peoples have the right of self-determination. By virtue of that right they freely determine their political status and freely pursue their economic, social and cultural development.

2. All peoples may, for their own ends, freely dispose of their natural wealth and resources without prejudice to any obligations arising out of international economic co-operation, based upon the principle of mutual benefit, and international law. In no case may a people be deprived of its own means of subsistence.

3. The States Parties to the present Covenant, including those having responsibility for the administration of Non-Self-Governing and Trust Territories, shall promote the realization of the right of self-determination, and shall respect that right, in conformity with the provisions of the Charter of the United Nations.

PART II

Article 2

1. Each State Party to the present Covenant undertakes to take steps, individually and through international assistance and co-operation, especially economic and technical, to the maximum of its available resources, with a view to achieving progressively the full realization of the rights recognized in the present Covenant by all appropriate means, including particularly the adoption of legislative measures.

2. The States Parties to the present Covenant undertake to guarantee that the rights enunciated in the present Covenant will be exercised without discrimination of any kind

as to race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.

3. Developing countries, with due regard to human rights and their national economy, may determine to what extent they would guarantee the economic rights recognized in the present Covenant to non- nationals.

Article 3

The States Parties to the present Covenant undertake to ensure the equal right of men and women to the enjoyment of all economic, social and cultural rights set forth in the present Covenant.

Article 4

The States Parties to the present Covenant recognize that, in the enjoyment of those rights provided by the State in conformity with the present Covenant, the State may subject such rights only to such limitations as are determined by law only in so far as this may be compatible with the nature of these rights and solely for the purpose of promoting the general welfare in a democratic society.

Article 5

1. Nothing in the present Covenant may be interpreted as implying for any State, group or person any right to engage in any activity or to perform any act aimed at the destruction of any of the rights or freedoms recognized herein, or at their limitation to a greater extent than is provided for in the present Covenant.

2. No restriction upon or derogation from any of the fundamental human rights recognized or existing in any country in virtue of law, conventions, regulations or custom

shall be admitted on the pretext that the present Covenant does not recognize such rights or that it recognizes them to a lesser extent.

PART III

Article 6

1. The States Parties to the present Covenant recognize the right to work, which includes the right of everyone to the opportunity to gain his living by work which he freely chooses or accepts, and will take appropriate steps to safeguard this right.

2. The steps to be taken by a State Party to the present Covenant to achieve the full realization of this right shall include technical and vocational guidance and training programmes, policies and techniques to achieve steady economic, social and cultural development and full and productive employment under conditions safeguarding fundamental political and economic freedoms to the individual.

Article 7

The States Parties to the present Covenant recognize the right of everyone to the enjoyment of just and favourable conditions of work which ensure, in particular:

(a) Remuneration which provides all workers, as a minimum, with:

(i) Fair wages and equal remuneration for work of equal value without distinction of any kind, in particular women being guaranteed conditions of work not inferior to those enjoyed by men, with equal pay for equal work;

(ii) A decent living for themselves and their families in accordance with the provisions of the present Covenant;

(b) Safe and healthy working conditions; (c) Equal opportunity for everyone to be promoted in his employment to an appropriate higher level, subject to no considerations other than those of seniority and competence;

(d) Rest, leisure and reasonable limitation of working hours and periodic holidays with pay, as well as remuneration for public holidays

Article 8

1. The States Parties to the present Covenant undertake to ensure:

(a) The right of everyone to form trade unions and join the trade union of his choice, subject only to the rules of the organization concerned, for the promotion and protection of his economic and social interests. No restrictions may be placed on the exercise of this right other than those prescribed by law and which are necessary in a democratic society in the interests of national security or public order or for the protection of the rights and freedoms of others;

(b) The right of trade unions to establish national federations or confederations and the right of the latter to form or join international trade-union organizations;

(c) The right of trade unions to function freely subject to no limitations other than those prescribed by law and which are necessary in a democratic society in the interests of national security or public order or for the protection of the rights and freedoms of others;

(d) The right to strike, provided that it is exercised in conformity with the laws of the particular country.

2. This article shall not prevent the imposition of lawful restrictions on the exercise of these rights by members of the armed forces or of the police or of the administration of

the State. 3. Nothing in this article shall authorize States Parties to the International Labour Organisation Convention of 1948 concerning Freedom of Association and Protection of the Right to Organize to take legislative measures which would prejudice, or apply the law in such a manner as would prejudice, the guarantees provided for in that Convention.

Article 9

The States Parties to the present Covenant recognize the right of everyone to social security, including social insurance.

Article 10

The States Parties to the present Covenant recognize that:

1. The widest possible protection and assistance should be accorded to the family, which is the natural and fundamental group unit of society, particularly for its establishment and while it is responsible for the care and education of dependent children. Marriage must be entered into with the free consent of the intending spouses.

2. Special protection should be accorded to mothers during a reasonable period before and after childbirth. During such period working mothers should be accorded paid leave or leave with adequate social security benefits.

3. Special measures of protection and assistance should be taken on behalf of all children and young persons without any discrimination for reasons of parentage or other conditions. Children and young persons should be protected from economic and social exploitation. Their employment in work harmful to their morals or health or dangerous to life or likely to hamper their normal development should be punishable by law. States

should also set age limits below which the paid employment of child labour should be prohibited and punishable by law.

Article 11

1. The States Parties to the present Covenant recognize the right of everyone to an adequate standard of living for himself and his family, including adequate food, clothing and housing, and to the continuous improvement of living conditions. The States Parties will take appropriate steps to ensure the realization of this right, recognizing to this effect the essential importance of international co- operation based on free consent.

2. The States Parties to the present Covenant, recognizing the fundamental right of everyone to be free from hunger, shall take, individually and through international co-operation, the measures, including specific programmes, which are needed:

(a) To improve methods of production, conservation and distribution of food by making full use of technical and scientific knowledge, by disseminating knowledge of the principles of nutrition and by developing or reforming agrarian systems in such a way as to achieve the most efficient development and utilization of natural resources;

(b) Taking into account the problems of both food-importing and food-exporting countries, to ensure an equitable distribution of world food supplies in relation to need.

Article 12

1. The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.

2. The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for:

(a) The provision for the reduction of the stillbirth-rate and of infant mortality and for the healthy development of the child;

(b) The improvement of all aspects of environmental and industrial hygiene;

(c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases;

(d) The creation of conditions which would assure to all medical service and medical attention in the event of sickness.

Article 13

1. The States Parties to the present Covenant recognize the right of everyone to education. They agree that education shall be directed to the full development of the human personality and the sense of its dignity, and shall strengthen the respect for human rights and fundamental freedoms. They further agree that education shall enable all persons to participate effectively in a free society, promote understanding, tolerance and friendship among all nations and all racial, ethnic or religious groups, and further the activities of the United Nations for the maintenance of peace.

2. The States Parties to the present Covenant recognize that, with a view to achieving the full realization of this right:

(a) Primary education shall be compulsory and available free to all;

(b) Secondary education in its different forms, including technical and vocational secondary education, shall be made generally available and accessible to all by every appropriate means, and in particular by the progressive introduction of free education;

(c) Higher education shall be made equally accessible to all, on the basis of capacity, by every appropriate means, and in particular by the progressive introduction of free education;

(d) Fundamental education shall be encouraged or intensified as far as possible for those persons who have not received or completed the whole period of their primary education;

(e) The development of a system of schools at all levels shall be actively pursued, an adequate fellowship system shall be established, and the material conditions of teaching staff shall be continuously improved.

3. The States Parties to the present Covenant undertake to have respect for the liberty of parents and, when applicable, legal guardians to choose for their children schools, other than those established by the public authorities, which conform to such minimum educational standards as may be laid down or approved by the State and to ensure the religious and moral education of their children in conformity with their own convictions.

4. No part of this article shall be construed so as to interfere with the liberty of individuals and bodies to establish and direct educational institutions, subject always to the observance of the principles set forth in paragraph I of this article and to the requirement that the education given in such institutions shall conform to such minimum standards as may be laid down by the State.

Article 14

Each State Party to the present Covenant which, at the time of becoming a Party, has not been able to secure in its metropolitan territory or other territories under its jurisdiction compulsory primary education, free of charge, undertakes, within two years, to work out

and adopt a detailed plan of action for the progressive implementation, within a reasonable number of years, to be fixed in the plan, of the principle of compulsory education free of charge for all.

Article 15

1. The States Parties to the present Covenant recognize the right of everyone:

(a) To take part in cultural life;

(b) To enjoy the benefits of scientific progress and its applications;

(c) To benefit from the protection of the moral and material interests resulting from any scientific, literary or artistic production of which he is the author.

2. The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for the conservation, the development and the diffusion of science and culture. 3. The States Parties to the present Covenant undertake to respect the freedom indispensable for scientific research and creative activity.

4. The States Parties to the present Covenant recognize the benefits to be derived from the encouragement and development of international contacts and co-operation in the scientific and cultural fields.

PART IV

Article 16

1. The States Parties to the present Covenant undertake to submit in conformity with this part of the Covenant reports on the measures which they have adopted and the progress made in achieving the observance of the rights recognized herein.

2.

(a) All reports shall be submitted to the Secretary-General of the United Nations, who shall transmit copies to the Economic and Social Council for consideration in accordance with the provisions of the present Covenant;

(b) The Secretary-General of the United Nations shall also transmit to the specialized agencies copies of the reports, or any relevant parts therefrom, from States Parties to the present Covenant which are also members of these specialized agencies in so far as these reports, or parts therefrom, relate to any matters which fall within the responsibilities of the said agencies in accordance with their constitutional instruments.

Article 17

1. The States Parties to the present Covenant shall furnish their reports in stages, in accordance with a programme to be established by the Economic and Social Council within one year of the entry into force of the present Covenant after consultation with the States Parties and the specialized agencies concerned.

2. Reports may indicate factors and difficulties affecting the degree of fulfilment of obligations under the present Covenant.

3. Where relevant information has previously been furnished to the United Nations or to any specialized agency by any State Party to the present Covenant, it will not be necessary to reproduce that information, but a precise reference to the information so furnished will suffice.

Article 18

Pursuant to its responsibilities under the Charter of the United Nations in the field of human rights and fundamental freedoms, the Economic and Social Council may make arrangements with the specialized agencies in respect of their reporting to it on the progress made in achieving the observance of the provisions of the present Covenant falling within the scope of their activities. These reports may include particulars of decisions and recommendations on such implementation adopted by their competent organs.

Article 19

The Economic and Social Council may transmit to the Commission on Human Rights for study and general recommendation or, as appropriate, for information the reports concerning human rights submitted by States in accordance with articles 16 and 17, and those concerning human rights submitted by the specialized agencies in accordance with article 18.

Article 20

The States Parties to the present Covenant and the specialized agencies concerned may submit comments to the Economic and Social Council on any general recommendation under article 19 or reference to such general recommendation in any report of the Commission on Human Rights or any documentation referred to therein.

Article 21

The Economic and Social Council may submit from time to time to the General Assembly reports with recommendations of a general nature and a summary of the information received from the States Parties to the present Covenant and the specialized

agencies on the measures taken and the progress made in achieving general observance of the rights recognized in the present Covenant.

Article 22

The Economic and Social Council may bring to the attention of other organs of the United Nations, their subsidiary organs and specialized agencies concerned with furnishing technical assistance any matters arising out of the reports referred to in this part of the present Covenant which may assist such bodies in deciding, each within its field of competence, on the advisability of international measures likely to contribute to the effective progressive implementation of the present Covenant.

Article 23

The States Parties to the present Covenant agree that international action for the achievement of the rights recognized in the present Covenant includes such methods as the conclusion of conventions, the adoption of recommendations, the furnishing of technical assistance and the holding of regional meetings and technical meetings for the purpose of consultation and study organized in conjunction with the Governments concerned.

Article 24

Nothing in the present Covenant shall be interpreted as impairing the provisions of the Charter of the United Nations and of the constitutions of the specialized agencies which define the respective responsibilities of the various organs of the United Nations and of the specialized agencies in regard to the matters dealt with in the present Covenant.

Article 25

Nothing in the present Covenant shall be interpreted as impairing the inherent right of all peoples to enjoy and utilize fully and freely their natural wealth and resources.

PART V

Article 26

1. The present Covenant is open for signature by any State Member of the United Nations or member of any of its specialized agencies, by any State Party to the Statute of the International Court of Justice, and by any other State which has been invited by the General Assembly of the United Nations to become a party to the present Covenant.

2. The present Covenant is subject to ratification. Instruments of ratification shall be deposited with the Secretary-General of the United Nations.

3. The present Covenant shall be open to accession by any State referred to in paragraph 1 of this article.

4. Accession shall be effected by the deposit of an instrument of accession with the Secretary-General of the United Nations.

5. The Secretary-General of the United Nations shall inform all States which have signed the present Covenant or acceded to it of the deposit of each instrument of ratification or accession.

Article 27

1. The present Covenant shall enter into force three months after the date of the deposit with the Secretary-General of the United Nations of the thirty-fifth instrument of ratification or instrument of accession.

2. For each State ratifying the present Covenant or acceding to it after the deposit of the thirty-fifth instrument of ratification or instrument of accession, the present Covenant shall enter into force three months after the date of the deposit of its own instrument of ratification or instrument of accession.

Article 28

The provisions of the present Covenant shall extend to all parts of federal States without any limitations or exceptions.

Article 29

1. Any State Party to the present Covenant may propose an amendment and file it with the Secretary- General of the United Nations. The Secretary-General shall thereupon communicate any proposed amendments to the States Parties to the present Covenant with a request that they notify him whether they favour a conference of States Parties for the purpose of considering and voting upon the proposals. In the event that at least one third of the States Parties favours such a conference, the Secretary-General shall convene the conference under the auspices of the United Nations. Any amendment adopted by a majority of the States Parties present and voting at the conference shall be submitted to the General Assembly of the United Nations for approval.

2. Amendments shall come into force when they have been approved by the General Assembly of the United Nations and accepted by a two-thirds majority of the States Parties to the present Covenant in accordance with their respective constitutional processes.

3. When amendments come into force they shall be binding on those States Parties which have accepted them, other States Parties still being bound by the provisions of the present Covenant and any earlier amendment which they have accepted.

Article 30

Irrespective of the notifications made under article 26, paragraph 5, the Secretary-General of the United Nations shall inform all States referred to in paragraph I of the same article of the following particulars:

(a) Signatures, ratifications and accessions under article 26;

(b) The date of the entry into force of the present Covenant under article 27 and the date of the entry into force of any amendments under article 29.

Article 31

1. The present Covenant, of which the Chinese, English, French, Russian and Spanish texts are equally authentic, shall be deposited in the archives of the United Nations.

2. The Secretary-General of the United Nations shall transmit certified copies of the present Covenant to all States referred to in article 26.

Appendix 5: International Covenant on Civil and Political Rights

Adopted and opened for signature, ratification and accession by General Assembly resolution 2200A (XXI) of 16 December 1966,

entry into force 23 March 1976, in accordance with Article 49

Preamble

The States Parties to the present Covenant,

Considering that, in accordance with the principles proclaimed in the Charter of the United Nations, recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world,

Recognizing that these rights derive from the inherent dignity of the human person,

Recognizing that, in accordance with the Universal Declaration of Human Rights, the ideal of free human beings enjoying civil and political freedom and freedom from fear and want can only be achieved if conditions are created whereby everyone may enjoy his civil and political rights, as well as his economic, social and cultural rights,

Considering the obligation of States under the Charter of the United Nations to promote universal respect for, and observance of, human rights and freedoms,

Realizing that the individual, having duties to other individuals and to the community to which he belongs, is under a responsibility to strive for the promotion and observance of the rights recognized in the present Covenant,

Agree upon the following articles:

PART I

Article 1

1. All peoples have the right of self-determination. By virtue of that right they freely determine their political status and freely pursue their economic, social and cultural development.

2. All peoples may, for their own ends, freely dispose of their natural wealth and resources without prejudice to any obligations arising out of international economic co-operation, based upon the principle of mutual benefit, and international law. In no case may a people be deprived of its own means of subsistence.

3. The States Parties to the present Covenant, including those having responsibility for the administration of Non-Self-Governing and Trust Territories, shall promote the realization of the right of self-determination, and shall respect that right, in conformity with the provisions of the Charter of the United Nations.

PART II

Article 2

1. Each State Party to the present Covenant undertakes to respect and to ensure to all individuals within its territory and subject to its jurisdiction the rights recognized in the present Covenant, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.

2. Where not already provided for by existing legislative or other measures, each State Party to the present Covenant undertakes to take the necessary steps, in accordance with its constitutional processes and with the provisions of the present Covenant, to adopt such

laws or other measures as may be necessary to give effect to the rights recognized in the present Covenant.

3. Each State Party to the present Covenant undertakes:

(a) To ensure that any person whose rights or freedoms as herein recognized are violated shall have an effective remedy, notwithstanding that the violation has been committed by persons acting in an official capacity;

(b) To ensure that any person claiming such a remedy shall have his right thereto determined by competent judicial, administrative or legislative authorities, or by any other competent authority provided for by the legal system of the State, and to develop the possibilities of judicial remedy;

(c) To ensure that the competent authorities shall enforce such remedies when granted.

Article 3

The States Parties to the present Covenant undertake to ensure the equal right of men and women to the enjoyment of all civil and political rights set forth in the present Covenant.

Article 4

1. In time of public emergency which threatens the life of the nation and the existence of which is officially proclaimed, the States Parties to the present Covenant may take measures derogating from their obligations under the present Covenant to the extent strictly required by the exigencies of the situation, provided that such measures are not inconsistent with their other obligations under international law and do not involve discrimination solely on the ground of race, colour, sex, language, religion or social origin.

2. No derogation from articles 6, 7, 8 (paragraphs I and 2), 11, 15, 16 and 18 may be made under this provision.

3. Any State Party to the present Covenant availing itself of the right of derogation shall immediately inform the other States Parties to the present Covenant, through the intermediary of the Secretary- General of the United Nations, of the provisions from which it has derogated and of the reasons by which it was actuated. A further communication shall be made, through the same intermediary, on the date on which it terminates such derogation.

Article 5

1. Nothing in the present Covenant may be interpreted as implying for any State, group or person any right to engage in any activity or perform any act aimed at the destruction of any of the rights and freedoms recognized herein or at their limitation to a greater extent than is provided for in the present Covenant.

2. There shall be no restriction upon or derogation from any of the fundamental human rights recognized or existing in any State Party to the present Covenant pursuant to law, conventions, regulations or custom on the pretext that the present Covenant does not recognize such rights or that it recognizes them to a lesser extent.

PART III

Article 6

1. Every human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his life.

2. In countries which have not abolished the death penalty, sentence of death may be imposed only for the most serious crimes in accordance with the law in force at the time of the commission of the crime and not contrary to the provisions of the present Covenant and to the Convention on the Prevention and Punishment of the Crime of Genocide. This penalty can only be carried out pursuant to a final judgement rendered by a competent court.

3. When deprivation of life constitutes the crime of genocide, it is understood that nothing in this article shall authorize any State Party to the present Covenant to derogate in any way from any obligation assumed under the provisions of the Convention on the Prevention and Punishment of the Crime of Genocide.

4. Anyone sentenced to death shall have the right to seek pardon or commutation of the sentence. Amnesty, pardon or commutation of the sentence of death may be granted in all cases.

5. Sentence of death shall not be imposed for crimes committed by persons below eighteen years of age and shall not be carried out on pregnant women.

6. Nothing in this article shall be invoked to delay or to prevent the abolition of capital punishment by any State Party to the present Covenant.

Article 7

No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his free consent to medical or scientific experimentation.

Article 8

1. No one shall be held in slavery; slavery and the slave-trade in all their forms shall be prohibited.

2. No one shall be held in servitude.

3.

(a) No one shall be required to perform forced or compulsory labour;

(b) Paragraph 3 (a) shall not be held to preclude, in countries where imprisonment with hard labour may be imposed as a punishment for a crime, the performance of hard labour in pursuance of a sentence to such punishment by a competent court;

(c) For the purpose of this paragraph the term "forced or compulsory labour" shall not include:

(i) Any work or service, not referred to in subparagraph (b), normally required of a person who is under detention in consequence of a lawful order of a court, or of a person during conditional release from such detention;

(ii) Any service of a military character and, in countries where conscientious objection is recognized, any national service required by law of conscientious objectors;

(iii) Any service exacted in cases of emergency or calamity threatening the life or well-being of the community;

(iv) Any work or service which forms part of normal civil obligations.

Article 9

1. Everyone has the right to liberty and security of person. No one shall be subjected to arbitrary arrest or detention. No one shall be deprived of his liberty except on such grounds and in accordance with such procedure as are established by law.

2. Anyone who is arrested shall be informed, at the time of arrest, of the reasons for his arrest and shall be promptly informed of any charges against him.

3. Anyone arrested or detained on a criminal charge shall be brought promptly before a judge or other officer authorized by law to exercise judicial power and shall be entitled to trial within a reasonable time or to release. It shall not be the general rule that persons awaiting trial shall be detained in custody, but release may be subject to guarantees to appear for trial, at any other stage of the judicial proceedings, and, should occasion arise, for execution of the judgement.

4. Anyone who is deprived of his liberty by arrest or detention shall be entitled to take proceedings before a court, in order that that court may decide without delay on the lawfulness of his detention and order his release if the detention is not lawful.

5. Anyone who has been the victim of unlawful arrest or detention shall have an enforceable right to compensation.

Article 10

1. All persons deprived of their liberty shall be treated with humanity and with respect for the inherent dignity of the human person.

2.

(a) Accused persons shall, save in exceptional circumstances, be segregated from convicted persons and shall be subject to separate treatment appropriate to their status as unconvicted persons;

(b) Accused juvenile persons shall be separated from adults and brought as speedily as possible for adjudication.

3. The penitentiary system shall comprise treatment of prisoners the essential aim of which shall be their reformation and social rehabilitation. Juvenile offenders shall be segregated from adults and be accorded treatment appropriate to their age and legal status.

Article 11

No one shall be imprisoned merely on the ground of inability to fulfil a contractual obligation.

Article 12

1. Everyone lawfully within the territory of a State shall, within that territory, have the right to liberty of movement and freedom to choose his residence.

2. Everyone shall be free to leave any country, including his own.

3. The above-mentioned rights shall not be subject to any restrictions except those which are provided by law, are necessary to protect national security, public order (ordre public), public health or morals or the rights and freedoms of others, and are consistent with the other rights recognized in the present Covenant.

4. No one shall be arbitrarily deprived of the right to enter his own country.

Article 13

An alien lawfully in the territory of a State Party to the present Covenant may be expelled therefrom only in pursuance of a decision reached in accordance with law and shall, except where compelling reasons of national security otherwise require, be allowed to submit the reasons against his expulsion and to have his case reviewed by, and be

represented for the purpose before, the competent authority or a person or persons especially designated by the competent authority.

Article 14

1. All persons shall be equal before the courts and tribunals. In the determination of any criminal charge against him, or of his rights and obligations in a suit at law, everyone shall be entitled to a fair and public hearing by a competent, independent and impartial tribunal established by law. The press and the public may be excluded from all or part of a trial for reasons of morals, public order (order public) or national security in a democratic society, or when the interest of the private lives of the parties so requires, or to the extent strictly necessary in the opinion of the court in special circumstances where publicity would prejudice the interests of justice; but any judgement rendered in a criminal case or in a suit at law shall be made public except where the interest of juvenile persons otherwise requires or the proceedings concern matrimonial disputes or the guardianship of children.

2. Everyone charged with a criminal offence shall have the right to be presumed innocent until proved guilty according to law.

3. In the determination of any criminal charge against him, everyone shall be entitled to the following minimum guarantees, in full equality: (a) To be informed promptly and in detail in a language which he understands of the nature and cause of the charge against him;

(b) To have adequate time and facilities for the preparation of his defence and to communicate with counsel of his own choosing;

(c) To be tried without undue delay;

(d) To be tried in his presence, and to defend himself in person or through legal assistance of his own choosing; to be informed, if he does not have legal assistance, of this right; and to have legal assistance assigned to him, in any case where the interests of justice so require, and without payment by him in any such case if he does not have sufficient means to pay for it;

(e) To examine, or have examined, the witnesses against him and to obtain the attendance and examination of witnesses on his behalf under the same conditions as witnesses against him;

(f) To have the free assistance of an interpreter if he cannot understand or speak the language used in court;

(g) Not to be compelled to testify against himself or to confess guilt.

4. In the case of juvenile persons, the procedure shall be such as will take account of their age and the desirability of promoting their rehabilitation. 5. Everyone convicted of a crime shall have the right to his conviction and sentence being reviewed by a higher tribunal according to law.

6. When a person has by a final decision been convicted of a criminal offence and when subsequently his conviction has been reversed or he has been pardoned on the ground that a new or newly discovered fact shows conclusively that there has been a miscarriage of justice, the person who has suffered punishment as a result of such conviction shall be compensated according to law, unless it is proved that the non-disclosure of the unknown fact in time is wholly or partly attributable to him.

7. No one shall be liable to be tried or punished again for an offence for which he has already been finally convicted or acquitted in accordance with the law and penal procedure of each country.

Article 15

1. No one shall be held guilty of any criminal offence on account of any act or omission which did not constitute a criminal offence, under national or international law, at the time when it was committed. Nor shall a heavier penalty be imposed than the one that was applicable at the time when the criminal offence was committed. If, subsequent to the commission of the offence, provision is made by law for the imposition of the lighter penalty, the offender shall benefit thereby.

2. Nothing in this article shall prejudice the trial and punishment of any person for any act or omission which, at the time when it was committed, was criminal according to the general principles of law recognized by the community of nations.

Article 16

Everyone shall have the right to recognition everywhere as a person before the law.

Article 17

1. No one shall be subjected to arbitrary or unlawful interference with his privacy, family, home or correspondence, nor to unlawful attacks on his honour and reputation.

2. Everyone has the right to the protection of the law against such interference or attacks.

Article 18

1. Everyone shall have the right to freedom of thought, conscience and religion. This right shall include freedom to have or to adopt a religion or belief of his choice, and

freedom, either individually or in community with others and in public or private, to manifest his religion or belief in worship, observance, practice and teaching.

2. No one shall be subject to coercion which would impair his freedom to have or to adopt a religion or belief of his choice.

3. Freedom to manifest one's religion or beliefs may be subject only to such limitations as are prescribed by law and are necessary to protect public safety, order, health, or morals or the fundamental rights and freedoms of others.

4. The States Parties to the present Covenant undertake to have respect for the liberty of parents and, when applicable, legal guardians to ensure the religious and moral education of their children in conformity with their own convictions.

Article 19

1. Everyone shall have the right to hold opinions without interference.

2. Everyone shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of his choice.

3. The exercise of the rights provided for in paragraph 2 of this article carries with it special duties and responsibilities. It may therefore be subject to certain restrictions, but these shall only be such as are provided by law and are necessary:

(a) For respect of the rights or reputations of others;

(b) For the protection of national security or of public order (order public), or of public health or morals.

Article 20

1. Any propaganda for war shall be prohibited by law.

2. Any advocacy of national, racial or religious hatred that constitutes incitement to discrimination, hostility or violence shall be prohibited by law.

Article 21

The right of peaceful assembly shall be recognized. No restrictions may be placed on the exercise of this right other than those imposed in conformity with the law and which are necessary in a democratic society in the interests of national security or public safety, public order (order public), the protection of public health or morals or the protection of the rights and freedoms of others.

Article 22

1. Everyone shall have the right to freedom of association with others, including the right to form and join trade unions for the protection of his interests.

2. No restrictions may be placed on the exercise of this right other than those which are prescribed by law and which are necessary in a democratic society in the interests of national security or public safety, public order (order public), the protection of public health or morals or the protection of the rights and freedoms of others. This article shall not prevent the imposition of lawful restrictions on members of the armed forces and of the police in their exercise of this right.

3. Nothing in this article shall authorize States Parties to the International Labour Organisation Convention of 1948 concerning Freedom of Association and Protection of

the Right to Organize to take legislative measures which would prejudice, or to apply the law in such a manner as to prejudice, the guarantees provided for in that Convention.

Article 23

1. The family is the natural and fundamental group unit of society and is entitled to protection by society and the State.

2. The right of men and women of marriageable age to marry and to found a family shall be recognized.

3. No marriage shall be entered into without the free and full consent of the intending spouses.

4. States Parties to the present Covenant shall take appropriate steps to ensure equality of rights and responsibilities of spouses as to marriage, during marriage and at its dissolution. In the case of dissolution, provision shall be made for the necessary protection of any children.

Article 24

1. Every child shall have, without any discrimination as to race, colour, sex, language, religion, national or social origin, property or birth, the right to such measures of protection as are required by his status as a minor, on the part of his family, society and the State.

2. Every child shall be registered immediately after birth and shall have a name.

3. Every child has the right to acquire a nationality.

Article 25

Every citizen shall have the right and the opportunity, without any of the distinctions mentioned in article 2 and without unreasonable restrictions:

(a) To take part in the conduct of public affairs, directly or through freely chosen representatives;

(b) To vote and to be elected at genuine periodic elections which shall be by universal and equal suffrage and shall be held by secret ballot, guaranteeing the free expression of the will of the electors;

(c) To have access, on general terms of equality, to public service in his country.

Article 26

All persons are equal before the law and are entitled without any discrimination to the equal protection of the law. In this respect, the law shall prohibit any discrimination and guarantee to all

persons equal and effective protection against discrimination on any ground such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.

Article 27

In those States in which ethnic, religious or linguistic minorities exist, persons belonging to such minorities shall not be denied the right, in community with the other members of their group, to enjoy their own culture, to profess and practice their own religion, or to use their own language.

PART IV

Article 28

1. There shall be established a Human Rights Committee (hereafter referred to in the present Covenant as the Committee). It shall consist of eighteen members and shall carry out the functions hereinafter provided.

2. The Committee shall be composed of nationals of the States Parties to the present Covenant who shall be persons of high moral character and recognized competence in the field of human rights, consideration being given to the usefulness of the participation of some persons having legal experience.

3. The members of the Committee shall be elected and shall serve in their personal capacity.

Article 29

1. The members of the Committee shall be elected by secret ballot from a list of persons possessing the qualifications prescribed in article 28 and nominated for the purpose by the States Parties to the present Covenant.

2. Each State Party to the present Covenant may nominate not more than two persons. These persons shall be nationals of the nominating State.

3. A person shall be eligible for renomination.

Article 30

1. The initial election shall be held no later than six months after the date of the entry into force of the present Covenant.

2. At least four months before the date of each election to the Committee, other than an election to fill a vacancy declared in accordance with article 34, the Secretary-General of the United Nations shall address a written invitation to the States Parties to the present

Covenant to submit their nominations for membership of the Committee within three months.

3. The Secretary-General of the United Nations shall prepare a list in alphabetical order of all the persons thus nominated, with an indication of the States Parties which have nominated them, and shall submit it to the States Parties to the present Covenant no later than one month before the date of each election.

4. Elections of the members of the Committee shall be held at a meeting of the States Parties to the present Covenant convened by the Secretary General of the United Nations at the Headquarters of the United Nations. At that meeting, for which two thirds of the States Parties to the present Covenant shall constitute a quorum, the persons elected to the Committee shall be those nominees who obtain the largest number of votes and an absolute majority of the votes of the representatives of States Parties present and voting.

Article 31

1. The Committee may not include more than one national of the same State.

2. In the election of the Committee, consideration shall be given to equitable geographical distribution of membership and to the representation of the different forms of civilization and of the principal legal systems.

Article 32

1. The members of the Committee shall be elected for a term of four years. They shall be eligible for re-election if renominated. However, the terms of nine of the members elected at the first election shall expire at the end of two years; immediately after the first election, the names of these nine members shall be chosen by lot by the Chairman of the

meeting referred to in article 30, paragraph 4. 2. Elections at the expiry of office shall be held in accordance with the preceding articles of this part of the present Covenant.

Article 33

1. If, in the unanimous opinion of the other members, a member of the Committee has ceased to carry out his functions for any cause other than absence of a temporary character, the Chairman of the Committee shall notify the Secretary-General of the United Nations, who shall then declare the seat of that member to be vacant.

2. In the event of the death or the resignation of a member of the Committee, the Chairman shall immediately notify the Secretary-General of the United Nations, who shall declare the seat vacant from the date of death or the date on which the resignation takes effect.

Article 34

1. When a vacancy is declared in accordance with article 33 and if the term of office of the member to be replaced does not expire within six months of the declaration of the vacancy, the Secretary- General of the United Nations shall notify each of the States Parties to the present Covenant, which may within two months submit nominations in accordance with article 29 for the purpose of filling the vacancy.

2. The Secretary-General of the United Nations shall prepare a list in alphabetical order of the persons thus nominated and shall submit it to the States Parties to the present Covenant. The election to fill the vacancy shall then take place in accordance with the relevant provisions of this part of the present Covenant.

3. A member of the Committee elected to fill a vacancy declared in accordance with article 33 shall hold office for the remainder of the term of the member who vacated the seat on the Committee under the provisions of that article.

Article 35

The members of the Committee shall, with the approval of the General Assembly of the United Nations, receive emoluments from United Nations resources on such terms and conditions as the General Assembly may decide, having regard to the importance of the Committee's responsibilities.

Article 36

The Secretary-General of the United Nations shall provide the necessary staff and facilities for the effective performance of the functions of the Committee under the present Covenant.

Article 37

1. The Secretary-General of the United Nations shall convene the initial meeting of the Committee at the Headquarters of the United Nations.

2. After its initial meeting, the Committee shall meet at such times as shall be provided in its rules of procedure.

3. The Committee shall normally meet at the Headquarters of the United Nations or at the United Nations Office at Geneva.

Article 38

Every member of the Committee shall, before taking up his duties, make a solemn declaration in open committee that he will perform his functions impartially and conscientiously.

Article 39

1. The Committee shall elect its officers for a term of two years. They may be re-elected.

2. The Committee shall establish its own rules of procedure, but these rules shall provide, inter alia, that:

(a) Twelve members shall constitute a quorum;

(b) Decisions of the Committee shall be made by a majority vote of the members present.

Article 40

1. The States Parties to the present Covenant undertake to submit reports on the measures they have adopted which give effect to the rights recognized herein and on the progress made in the enjoyment of those rights: (a) Within one year of the entry into force of the present Covenant for the States Parties concerned;

(b) Thereafter whenever the Committee so requests.

2. All reports shall be submitted to the Secretary-General of the United Nations, who shall transmit them to the Committee for consideration. Reports shall indicate the factors and difficulties, if any, affecting the implementation of the present Covenant.

3. The Secretary-General of the United Nations may, after consultation with the Committee, transmit to the specialized agencies concerned copies of such parts of the reports as may fall within their field of competence.

4. The Committee shall study the reports submitted by the States Parties to the present Covenant. It shall transmit its reports, and such general comments as it may consider appropriate, to the States Parties. The Committee may also transmit to the Economic and Social Council these comments along with the copies of the reports it has received from States Parties to the present Covenant.

5. The States Parties to the present Covenant may submit to the Committee observations on any comments that may be made in accordance with paragraph 4 of this article.

Article 41

1. A State Party to the present Covenant may at any time declare under this article that it recognizes the competence of the Committee to receive and consider communications to the effect that a State Party claims that another State Party is not fulfilling its obligations under the present Covenant. Communications under this article may be received and considered only if submitted by a State Party which has made a declaration recognizing in regard to itself the competence of the Committee. No communication shall be received by the Committee if it concerns a State Party which has not made such a declaration. Communications received under this article shall be dealt with in accordance with the following procedure:

(a) If a State Party to the present Covenant considers that another State Party is not giving effect to the provisions of the present Covenant, it may, by written communication, bring the matter to the attention of that State Party. Within three months after the receipt of the communication the receiving State shall afford the State which sent the communication an explanation, or any other statement in writing clarifying the matter which should

include, to the extent possible and pertinent, reference to domestic procedures and remedies taken, pending, or available in the matter;

(b) If the matter is not adjusted to the satisfaction of both States Parties concerned within six months after the receipt by the receiving State of the initial communication, either State shall have the right to refer the matter to the Committee, by notice given to the Committee and to the other State;

(c) The Committee shall deal with a matter referred to it only after it has ascertained that all available domestic remedies have been invoked and exhausted in the matter, in conformity with the generally recognized principles of international law. This shall not be the rule where the application of the remedies is unreasonably prolonged;

(d) The Committee shall hold closed meetings when examining communications under this article;

(e) Subject to the provisions of subparagraph (c), the Committee shall make available its good offices to the States Parties concerned with a view to a friendly solution of the matter on the basis of respect for human rights and fundamental freedoms as recognized in the present Covenant;

(f) In any matter referred to it, the Committee may call upon the States Parties concerned, referred to in subparagraph (b), to supply any relevant information;

(g) The States Parties concerned, referred to in subparagraph (b), shall have the right to be represented when the matter is being considered in the Committee and to make submissions orally and/or in writing;

(h) The Committee shall, within twelve months after the date of receipt of notice under subparagraph (b), submit a report:

(i) If a solution within the terms of subparagraph (e) is reached, the Committee shall confine its report to a brief statement of the facts and of the solution reached;

(ii) If a solution within the terms of subparagraph (e) is not reached, the Committee shall confine its report to a brief statement of the facts; the written submissions and record of the oral submissions made by the States Parties concerned shall be attached to the report. In every matter, the report shall be communicated to the States Parties concerned.

2. The provisions of this article shall come into force when ten States Parties to the present Covenant have made declarations under paragraph I of this article. Such declarations shall be deposited by the States Parties with the Secretary-General of the United Nations, who shall transmit copies thereof to the other States Parties. A declaration may be withdrawn at any time by notification to the Secretary- General. Such a withdrawal shall not prejudice the consideration of any matter which is the subject of a communication already transmitted under this article; no further communication by any State Party shall be received after the notification of withdrawal of the declaration has been received by the Secretary-General, unless the State Party concerned has made a new declaration.

Article 42

1.

(a) If a matter referred to the Committee in accordance with article 41 is not resolved to the satisfaction of the States Parties concerned, the Committee may, with the prior

consent of the States Parties concerned, appoint an ad hoc Conciliation Commission (hereinafter referred to as the Commission). The good offices of the Commission shall be made available to the States Parties concerned with a view to an amicable solution of the matter on the basis of respect for the present Covenant;

(b) The Commission shall consist of five persons acceptable to the States Parties concerned. If the States Parties concerned fail to reach agreement within three months on all or part of the composition of the Commission, the members of the Commission concerning whom no agreement has been reached shall be elected by secret ballot by a two-thirds majority vote of the Committee from among its members.

2. The members of the Commission shall serve in their personal capacity. They shall not be nationals of the States Parties concerned, or of a State not Party to the present Covenant, or of a State Party which has not made a declaration under article 41.

3. The Commission shall elect its own Chairman and adopt its own rules of procedure.

4. The meetings of the Commission shall normally be held at the Headquarters of the United Nations or at the United Nations Office at Geneva. However, they may be held at such other convenient places as the Commission may determine in consultation with the Secretary-General of the United Nations and the States Parties concerned.

5. The secretariat provided in accordance with article 36 shall also service the commissions appointed under this article.

6. The information received and collated by the Committee shall be made available to the Commission and the Commission may call upon the States Parties concerned to supply any other relevant information.

7. When the Commission has fully considered the matter, but in any event not later than twelve months after having been seized of the matter, it shall submit to the Chairman of the Committee a report for communication to the States Parties concerned:

(a) If the Commission is unable to complete its consideration of the matter within twelve months, it shall confine its report to a brief statement of the status of its consideration of the matter;

(b) If an amicable solution to the matter on tie basis of respect for human rights as recognized in the present Covenant is reached, the Commission shall confine its report to a brief statement of the facts and of the solution reached;

(c) If a solution within the terms of subparagraph (b) is not reached, the Commission's report shall embody its findings on all questions of fact relevant to the issues between the States Parties concerned, and its views on the possibilities of an amicable solution of the matter. This report shall also contain the written submissions and a record of the oral submissions made by the States Parties concerned;

(d) If the Commission's report is submitted under subparagraph (c), the States Parties concerned shall, within three months of the receipt of the report, notify the Chairman of the Committee whether or not they accept the contents of the report of the Commission.

8. The provisions of this article are without prejudice to the responsibilities of the Committee under article 41.

9. The States Parties concerned shall share equally all the expenses of the members of the Commission in accordance with estimates to be provided by the Secretary-General of the United Nations.

10. The Secretary-General of the United Nations shall be empowered to pay the expenses of the members of the Commission, if necessary, before reimbursement by the States Parties concerned, in accordance with paragraph 9 of this article.

Article 43

The members of the Committee, and of the ad hoc conciliation commissions which may be appointed under article 42, shall be entitled to the facilities, privileges and immunities of experts on mission for the United Nations as laid down in the relevant sections of the Convention on the Privileges and Immunities of the United Nations.

Article 44

The provisions for the implementation of the present Covenant shall apply without prejudice to the procedures prescribed in the field of human rights by or under the constituent instruments and the conventions of the United Nations and of the specialized agencies and shall not prevent the States Parties to the present Covenant from having recourse to other procedures for settling a dispute in accordance with general or special international agreements in force between them.

Article 45

The Committee shall submit to the General Assembly of the United Nations, through the Economic and Social Council, an annual report on its activities.

PART V

Article 46

Nothing in the present Covenant shall be interpreted as impairing the provisions of the Charter of the United Nations and of the constitutions of the specialized agencies which

define the respective responsibilities of the various organs of the United Nations and of the specialized agencies in regard to the matters dealt with in the present Covenant.

Article 47

Nothing in the present Covenant shall be interpreted as impairing the inherent right of all peoples to enjoy and utilize fully and freely their natural wealth and resources.

PART VI

Article 48

1. The present Covenant is open for signature by any State Member of the United Nations or member of any of its specialized agencies, by any State Party to the Statute of the International Court of Justice, and by any other State which has been invited by the General Assembly of the United Nations to become a Party to the present Covenant.

2. The present Covenant is subject to ratification. Instruments of ratification shall be deposited with the Secretary-General of the United Nations.

3. The present Covenant shall be open to accession by any State referred to in paragraph 1 of this article.

4. Accession shall be effected by the deposit of an instrument of accession with the Secretary- General of the United Nations.

5. The Secretary-General of the United Nations shall inform all States which have signed this Covenant or acceded to it of the deposit of each instrument of ratification or accession.

Article 49

1. The present Covenant shall enter into force three months after the date of the deposit with the Secretary-General of the United Nations of the thirty-fifth instrument of ratification or instrument of accession.

2. For each State ratifying the present Covenant or acceding to it after the deposit of the thirty-fifth instrument of ratification or instrument of accession, the present Covenant shall enter into force three months after the date of the deposit of its own instrument of ratification or instrument of accession.

Article 50

The provisions of the present Covenant shall extend to all parts of federal States without any limitations or exceptions.

Article 51

1. Any State Party to the present Covenant may propose an amendment and file it with the Secretary-General of the United Nations. The Secretary-General of the United Nations shall thereupon communicate any proposed amendments to the States Parties to the present Covenant with a request that they notify him whether they favour a conference of States Parties for the purpose of considering and voting upon the proposals. In the event that at least one third of the States Parties favours such a conference, the Secretary-General shall convene the conference under the auspices of the United Nations. Any amendment adopted by a majority of the States Parties present and voting at the conference shall be submitted to the General Assembly of the United Nations for approval.

2. Amendments shall come into force when they have been approved by the General Assembly of the United Nations and accepted by a two-thirds majority of the States Parties to the present Covenant in accordance with their respective constitutional processes. 3. When amendments come into force, they shall be binding on those States Parties which have accepted them, other States Parties still being bound by the provisions of the present Covenant and any earlier amendment which they have accepted.

Article 52

1. Irrespective of the notifications made under article 48, paragraph 5, the Secretary-General of the United Nations shall inform all States referred to in paragraph I of the same article of the following particulars:

(a) Signatures, ratifications and accessions under article 48;

(b) The date of the entry into force of the present Covenant under article 49 and the date of the entry into force of any amendments under article 51.

Article 53

1. The present Covenant, of which the Chinese, English, French, Russian and Spanish texts are equally authentic, shall be deposited in the archives of the United Nations.

2. The Secretary-General of the United Nations shall transmit certified copies of the present Covenant to all States referred to in article 48.

Appendix 6: U.S. Maternal Mortality Review Committees

Maternal Mortality Review Committees

Jurisdiction	Scope of work							Committee structure	
	Reviews maternal mortalities	Pregnancy-associated deaths			Maternal morbidity		Investigate or consider racial disparities	Multidisciplinary membership or expertise beyond physicians	Demographic representation required or considered in membership composition†
		Review deaths up to one year after pregnancy ends	Investigate every pregnancy-associated death	Determine preventability of death	Review cases or trends	Track morbidity data			
State committees									
Alabama	X	X	X		X			X	
Alaska	X		X		X				
Arizona	X	X	X					DOH, HD, LE, PUB, ME or PATH, T, Other	
Arkansas	X	X	X	X				X	
California	X	X	X		X	X	X	CBO,D, DOH, MH, MW, N, P/FM	X
Colorado	X	X	X				X	X	X
Connecticut	X	X	X					X	
Delaware	X						X	CBO, DOH, LE, ME, PAS, Other	
Florida	X		X						
Georgia	X			X				X	
Hawaii	X	X						X	
Idaho	X	X	X	X				EMS, ME/C, MW, N, PATH, PH, SW	X
Illinois§	X	X	X		X		§	DOH, N, HA, HD, PATH, PUB, Other	
Indiana	X	X	X			X		AN, CBO, EPI, HA, HD, MH, MW, PAS, PATH, PH, RN, SW, SA	X
Iowa	X	X							
Kansas	X	X	X	X					
Kentucky	X	X							
Louisiana	X				X		X	CBO, D, DOH, HA, PAS, PQC, SU, Other	
Maine	X*	X	X					LE, SWPH, Other	
Maryland§	X	X	X	X				X	
Massachusetts	X								
Michigan	X	X			X				
Minnesota§	X	X							
Mississippi	X							X	
Missouri	X	X	X				X	X	X
Montana	X							DOH, EMS, HA, HD, LE, ME, MH, N, PATH, T, Other	
Nebraska	X	X	X	X				DOH, LE, PATH, Other	
Nevada	X	X	X		X		X	CBO, DOH, LE, SWPH	X
New Hampshire	X	X	X					DOH, EPI, ME/C MH, PAS, PUB	
New Mexico	X	X	X		X	X		DOH, HA, ME, N, PAS, PQC	X
New Jersey	X	X	X	X		X	X	AN, CBO, DOH, ME, MW, N, PAS, PATH, PQC, SU, Other	X
New York§	X	X	X	X	X			X	X
North Carolina	X		X	X				X	
North Dakota	X	X	X	X				X	X
Ohio	X	X	X						X
Oklahoma	X	X	X	X	X	X		DOH, EMS, HD, LE, ME, MH, PAS, P/FM, PQC, SU, T, Other	
Oregon	X	X	X		X		X	CBO, D, ME, MH, MW, N, PAS, PH, Other	X
Pennsylvania	X	X	X					AN, DOH, EMS, EPI, ME/C, MH, MW, N, PATH, SWPH, SU, Other	X
Rhode Island	X	X						P/FM, PATH, SA, Other	
South Carolina	X	X	X	X				X	
South Dakota	X*								
Tennessee	X	X	X	X				DOH, ME, N, Other	
Texas	X	X			X		X	DOH, EPI, ER, ME, MH, MW, N, PATH, SW/PH	X

Utah	X							DOH, HA, PAS, Other	
Virginia	X	X	X					CBO, DOH, EMS, LE, ME/C, MH, PAS, Other	
Washington	X	X	X	X				T, Other	
West Virginia	X	X	X				X	DOH, LE, ME, Other	
Wisconsin	X								
Wyoming	X*								
City and territory committees									
Dist. of Columbia	X	X	X				X	AN, CBO, D, DOH, EPI, HA, ME, MH, N, P/FM, PAS, SWPH, Other	
New York City§	X	X	X	X	X	X	X	CBO, D, DOH, EMS, Other	
Philadelphia	X		X						
Puerto Rico	X			X				AN, DOH, ER, EPI, PAS, PATH, SW, Other	
TOTAL	**49 + DC, PHL, NYC, PR**	**36 + DC, PHL, NYC**	**32 + DC, NYC**	**14 + NYC, PR**	**12 + NYC**	**5 + NYC**	**9 + DC**	**37 + DC, NYC, PR**	**14**

Notes:
Committee members: AN=anesthesiologist, CBO=community-based organization or local nonprofit, D=doula, DOH=department of health, EMS=emergency medical service worker/first responder, EPI=epidemiologist, ER=emergency department provider, HD=local health department, LE=law enforcement, ME/C=medical examiner or coroner, MH=mental health provider/expert, MW=midwife, N=nurse, PAS=professional associations (e.g., hospital association, medical society, provider association), P/FM=patient or family member affected by maternal mortality or near maternal mortality, PATH=pathologist, PQC=perinatal quality collaborative, PUB=member of the public, SU=substance use expert, SWPH=social worker or public health professional, T=representative of Native tribe/tribal government

* Jurisdiction reviews pregnancy-related deaths through another fatality committee, such as an infant and child fatality review committee; Wyoming's pregnancy-associated deaths are reviewed by Utah's review committee.
† Committee membership is required to be representative of the jurisdiction's demographic composition (e.g., geographic, racial, socioeconomic status, communities most affected) or such representation must be considered in selecting members.
§ Jurisdiction has an advisory council or task force that addresses racial disparities in maternal health outcomes and provides recommendations to the MMRC and other stakeholders.

Maternal Mortality Review Committees

Jurisdiction	Handling of information		Report requirements			Use standardized CDC system to review deaths
	Access to records	Members, data and review process protected by confidentiality	Report frequency	Recommendations to prevent pregnancy-related deaths	Recommendations to address racial disparities	
State committees						
Alabama	EMS, FW, H, LE, ME, SS, V, Other	X		X		X
Alaska	EMS, H, LE, ME, T, V, Other	X	Annually	X		X
Arizona	H, LE, ME, V	X				X
Arkansas	FW, H	X	Annually	X		X
California	H, ME	X	Every three years	X	X	
Colorado	FW, H, LE, ME, V		Every three years	X		X
Connecticut	H, ME, V	X	90 days after MMRC meeting	X		X
Delaware	FW, H, V	X	Annually	X		X
Florida	H, V	Only data				X
Georgia	FW, H	X	Annually	X		X
Hawaii	C, E, H, LE, ME, PP, SS, V, W	X	Annually	X		X
Idaho	EMS, FW, H, LE, ME, SS, V	X	Annually	X		X
Illinois§	ME, H, MH	Only data	Annually	X		X
Indiana	EMS, FW, H, LE, ME, MH, V, Other	X	Annually	X		X
Iowa	H, V		Every three years	X		X
Kansas	FW, H, LE, ME, SS, V	X		X		X
Kentucky	H, LE, ME, V	X	Annually			X
Louisiana	H, V	X		X	X	X
Maine	FW, H, V	X	Annually	X		
Maryland§	FW, H, LE, ME, PP, SS, V	X	Annually	X	X	X
Massachusetts	V	X				X
Michigan	H, V	X	Every five years			X
Minnesota§	FW, H, LE, ME	X		X		X
Mississippi	H, LE, ME, V	X	Annually	X		X
Missouri	H, LE, ME, SS, V, Other	X	Annually	X		X
Montana	C, H, T, Other	Only data				
Nebraska	E, EMS, H, LE, ME, MH, PP, SS, V	X	Annually	X		X
Nevada	EMS, FW, H, LE, ME, MH, SS, V	X	Annually; maternal morbidity report in even-numbered years	X		
New Hampshire	FW, H, ME, V	X	Annually	X		X
New Mexico	H, LE, ME, V, Other	X	Annually	X		x
New Jersey	FW, H, ME, SS, V	X	Annually	X	X	X
New York§	FW, H, LE, ME, V, Other	X	Every two years	X	X	X
North Carolina	FW, H	X		X		X
North Dakota	H	X	Annually	X		
Ohio	FW, H, LE, SS, V	X	Every two years	X		X
Oklahoma	C, EMS, FW, H, LE, ME, MH, SS, V	X				X
Oregon	FW, H, LE, ME, SS, V	X	Every two years	X		X
Pennsylvania	C, EMS, H, LE, ME, SS, V, Other	X	Every three years	X		X
Rhode Island	H, V	X	Annually	X		X
South Carolina	FW, H, LE, ME, V	X	Annually	X		X
South Dakota	H, V		Annually			X
Tennessee	H, LE, ME, SS, V, W	X	Annually	X		X
Texas	H, V	X	Even-numbered years	X		
Utah		X	Annually			X
Virginia	C, H, LE, ME, SS	X	Every three years	X		X
Washington	H, ME, SS, V	X	Every three years	X		X
West Virginia	H, ME, MH, SS, V, Other	X	Annually	X	X	X
Wisconsin	H, V	Only data	Annually			X
Wyoming						
City and territory committees						
Dist. of Columbia	FW, H, LE, ME, MH, V	X	Annually	X		
New York City§	FW, H, ME, V, Other	X	Annually	X	X	X
Philadelphia	H, V	Only data	Annually			
Puerto Rico	H, LE, SS	X	Biannually	X		
TOTAL	**47 + DC, NYC, PHL, PR**	**45 + DC, NYC, PHL, PR**	**38 + DC, NYC, PHL, PR**	**38 + DC, NYC, PR**	**6 + NYC**	**42 + NYC**

Notes:
Access to data and records: C=court records, E=educational records, FW=family or witness interviews, EMS=emergency medical service or first responder records, H=health care and medical records, LE=law enforcement records, ME=medical examiner or coroner records, MH=mental health records, PP=parole or probation records, T=tribal government records, V=vital statistics

§ Jurisdiction has an advisory council or task force that addresses racial disparities in maternal health outcomes and provides recommendations to the MMRC and other stakeholders.

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