

## **Democracy and Health: Situating Health Rights within a Republic of Reasons**

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**Abstract:**

Patterns of population health are keen reflections of structural inequities in societies, yet they are rarely subject to the requirements of democratic justification that other systemic inequalities provoke. Nor are health systems generally subject to societal scrutiny regarding fidelity to normative commitments of dignity and equality. Increased recognition of social determinants of health has challenged the narrow biomedical view of health as a stochastic phenomenon. More recently the sweeping devastation of the COVID-19 pandemic has laid bare structural injustices across many democracies, which contributed to widely disparate rates of infection and mortality. However, a lack of clarity remains regarding the conceptual linkages between the right to health and the institutional arrangements required for diverse people to live flourishing lives in a plural democracy. Here we attempt to contribute to a deeper understanding of the right to health by examining the implications of three related claims: (1) the content of a right to health (public health preconditions and care) reflects the arrangement of social institutions and the negotiation of difference in a plural democracy; (2) health systems are democratic institutions that should be organized around showing diverse persons equal moral consideration; and (3) democratic accountability can enhance health protections across borders. We argue that understanding the connections between health and democracy has profound implications for health system financing, priority-setting, and the organization and delivery of health goods and services, as well as oversight. Further, underscoring the connections between health and democracy inexorably calls upon us to enlarge our conception of the way legal determinants of health function and health rights are theorized.

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TABLE OF CONTENTS

**INTRODUCTION ..... 98**

**I. CONCEPTUALIZING HEALTH IN TERMS OF MORAL AND LEGAL RIGHTS WITHIN A DEMOCRACY..... 102**

    A. GROUNDING THE MORAL RIGHT TO HEALTH..... 102

    B. DEFINITION AND SCOPE OF A LEGAL RIGHT TO HEALTH IN INTERNATIONAL LAW..... 104

    C. TRANSFORMATIVE IMPLICATIONS OF NAVIGATING DEMOCRATIC DIFFERENCE THROUGH HEALTH..... 106

        1. DISABILITY ..... 107

        2. WOMEN’S SEXUAL AND REPRODUCTIVE HEALTH ..... 110

        3. TRANS PEOPLE’S RIGHTS IN HEALTH ..... 112

**II. THE IMPLICATIONS OF ORGANIZING HEALTH SYSTEMS AROUND HEALTH RIGHTS ..... 114**

    A. FAIRNESS IN FINANCING ..... 117

    B. FAIR AND DEMOCRATIC PRIORITY-SETTING ..... 121

    C. HEALTH SERVICE ORGANIZATION AND DELIVERY ..... 126

    D. INFORMATION TO BE ACTIVE CITIZENS REGARDING HEALTH ..... 128

    E. OVERSIGHT: REGULATION AND REMEDIES..... 131

**III. HEALTH AND DEMOCRACY IN A GLOBALIZED WORLD..... 136**

    A. MIGRANTS..... 136

    B. TRANSNATIONAL DRIVERS OF HEALTH, AND EXTRATERRITORIAL OBLIGATIONS (ETOS) ..... 138

**CONCLUSION ..... 144**

## INTRODUCTION

The global COVID-19 pandemic caused by the novel coronavirus SARS-CoV-2 has focused the world's attention on the central importance of population health and health systems to the economic and social well-being of societies, and to the globalized interconnected world. It has also highlighted the challenges to the democratic rule of law through widely varying actions, and justifications for such actions, adopted by governments in response. For example, South Korea has adopted a detailed system of contact tracing that includes the publishing of personal information about infected persons' movements and medical care.<sup>1</sup> In countless countries, governments imposed near-total lockdowns, with police enforcement and criminal penalties for those who venture outside for non-permissible reasons.<sup>2</sup> And faced with evidence of rising gender-based violence due to such lockdowns, national and sub-national governments haven't taken different measures, including, in Bogotá, Colombia, authorizing men and women to leave their homes to seek essentials on alternating days, with trans persons authorized to leave home on the days that accord with their gender identity.<sup>3</sup> The essence of democracy—and human rights—is that a government's authority depends upon its making decisions that diverse members of the public perceive as justified and accept as legitimate.<sup>4</sup> The crisis has thus brought to the fore long-standing questions about when and how governments can impose limitations on well-enshrined democratic rights and rule of law principles, in relation, for example, to declarations of states of exception and emergency, restrictions on freedoms of movement and association, and intrusions into privacy through surveillance of data or movements.<sup>5</sup>

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1. Max S. Kim, *Seoul's Radical Experiment in Digital Contact Tracing*, NEW YORKER (April 17, 2020), <https://www.newyorker.com/news/news-desk/seouls-radical-experiment-in-digital-contact-tracing> [https://perma.cc/DP7V-KCNQ].

2. Juliana Kaplan, Lauren Frias & Morgan McFall-Johnsen, *A Third of the Global Population Is on Coronavirus Lockdown — Here's Our Constantly Updated List of Countries and Restrictions*, BUS. INSIDER (April 17, 2020), <https://www.businessinsider.in/international/news/a-third-of-the-global-population-is-on-coronavirus-lockdown-x2014-hereaposs-our-constantly-updated-list-of-countries-and-restrictions/slideshow/75208623.cms> [https://perma.cc/8NUG-HWH7].

3. Julie Turkewitz, *To Beat the Virus, Colombia Tries Separating Men and Women*, N.Y. TIMES (April 15, 2020), <https://www.nytimes.com/2020/04/15/world/americas/virus-colombia-bogota-men-women.html> [https://perma.cc/K46R-EHQ8]. Bogotá's mayor, Claudia López, has expressly stated that transgender people can follow the gender with which they identify. *Id.*

4. G.A. Res. 217 (III) A, Universal Declaration of Human Rights, art. 21 (Dec. 10, 1948) [hereinafter UDHR].

5. See, e.g., *Governments Should Respect Rights in COVID-19 Surveillance*, HUM. RTS. WATCH (April 2, 2020), <https://www.hrw.org/news/2020/04/02/governments-should-respect-rights-covid-19-surveillance> [https://perma.cc/QD4M-WSZK]; *Human Rights Dimensions of COVID-19 Response*, HUM. RTS. WATCH (Mar. 19, 2020), <https://www.hrw.org/news/2020/03/19/human-rights-dimensions-covid-19-response> [https://perma.cc/NM2S-YP2C]; Francesco Martone, *Italy*,

Insisting upon adequate justification for limitations and derogation from civil rights established under constitutional and international legal frameworks is critical to our understandings of democratic orders. However, we focus here on situating the right to health itself—in normal times as well as crisis—in relation to a robust conception of democracy. The right to health under international law is neither a right to be healthy nor a right to health care only. Under international law, the right to health includes public health preconditions (water and sanitation) and health care that is available, accessible, acceptable, and of “adequate” quality.<sup>6</sup> Our argument is three-fold: (1) equitable public health measures and health care are essential to constructing and sustaining substantive democracy in the twenty-first century; (2) the health system itself is a social institution that both reflects and refracts social norms—akin to a justice system—and therefore should be organized and function so as to ensure equal concern and respect for everyone in a democracy; and (3) in a highly interconnected world, the accountability of democratic governments must encompass people and impacts that cross borders.

On one level, the notion that population health and democracy are intimately connected seems self-evident. For instance, in the United States, the lead contamination of the water supply in the overwhelmingly Black community of Flint, Michigan, vividly reflects the exclusionary nature of American society on the basis of race and class.<sup>7</sup> Indeed, at least since Rudolf Virchow’s work in the nineteenth century underscored the social origins of disease and the need to address epidemics through not merely medical but political means, there has been an awareness of health states and health systems as part of the fabric of a democratic polity.<sup>8</sup> The great movements for universal health *care* in the twentieth century, including the creation of the National Health Service in the United Kingdom,<sup>9</sup> were democratic struggles for inclusion in society—of organized labor, indigenous and

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*Democracy and COVID-19*, TRANSNATIONAL INSTITUTE (April 14, 2020), <https://www.tni.org/en/article/italy-democracy-and-covid-19> [https://perma.cc/75PB-625F] (describing how COVID-19 is impacting democratic governance in Italy, from constraining political debate on pandemic-related decisions to the lack of oversight by an independent human rights institution).

6. International Covenant on Economic, Social and Cultural Rights art. 12, *opened for signature* Dec. 16, 1966, 993 U.N.T.S. 3 [hereinafter ICESCR]; Comm. on Econ., Soc. & Cultural Rights, *General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12 of the Covenant on Economic, Social and Cultural Rights)*, ¶ 12(a)–(d), U.N. Doc. E/C.12/2000/4 (2000) [hereinafter *General Comment No. 14*].

7. Abby Goodnough, Monica Davey & Mitch Smith, *When the Water Turned Brown*, N.Y. TIMES (Jan. 23, 2016), <https://www.nytimes.com/2016/01/24/us/when-the-water-turned-brown.html> [https://perma.cc/44U3-9FUN].

8. RUDOLF VIRCHOW, *DISEASE, LIFE, AND MAN* (1958).

9. Christopher Newdick, *Can Judges Ration with Compassion? A Priority Setting Matrix*, 20 HEALTH & HUM. RTS. J. 107, 111 (2018).

landless persons, and the destitute.<sup>10</sup> The narrative of health constructed by the steady rise of medicalization, beginning in the nineteenth century and accelerating in the latter half of the twentieth, and by then biomedicalization in the twenty-first century, is best thought of as a historically contingent shift constituted by economic and technological transformations, rather than some unchallengeable truth.<sup>11</sup>

Nonetheless, today, health is generally conceptualized in highly technical, individualistic terms in Western societies, and in turn, the functioning of health systems is largely exiled from democratic deliberation to insulated islands of professional expertise, whether economic calculations of costs and benefits or clinical medicine. As a result, health and health systems are more complex to theorize in terms of democracy than civil rights, or even other social rights such as education,<sup>12</sup> notwithstanding that more than half of the countries in the world have recognized the right to health in domestic constitutional law, through incorporation of international law, or both.<sup>13</sup>

Moreover, scholarship and advocacy around the international right to health or “human rights-based approaches to health” often focus on programming regarding a specific area of health, such as reproductive, maternal, and child health;<sup>14</sup> while critically important, this does not engage with necessary discussions of priorities and trade-offs in a democracy. Likewise, the growing international human rights literature on “global health governance” has tended to focus on how globalization has “upended national human rights implementation, shifting the protection and promotion of human rights from national governments to global institutions.”<sup>15</sup> In turn, many scholars have proposed a bureaucratic, top-down version of “human rights implementation,”<sup>16</sup> which takes a formal and

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10. See generally Vicente Navarro, *Production and the Welfare State: The Political Context of Reforms*, 21 INT’L J. HEALTH SERV. 585 (1991).

11. See generally BIOMEDICALIZATION: TECHNOSCIENCE, HEALTH, AND ILLNESS IN THE U.S. (Adele E. Clarke et al. eds., 2010); Viviane Quirke & Jean-Paul Gaudillière, *The Era of Biomedicine: Science, Medicine, and Public Health in Britain and France After the Second World War*, 52 MED. HIST. 441 (2008).

12. See Comm. on Econ., Soc. & Cultural Rights, *General Comment No. 13: The Right to Education (Article 13 of the Covenant)*, U.N. Doc. E/C.12/1999/10 (1999).

13. See *A Constitutional Right to Health Care: Many Countries Have It, but Not the U.S.*, SCIENCE DAILY (July 19, 2013), <https://www.sciencedaily.com/releases/2013/07/130719104927.htm> [<https://perma.cc/EC66-H627>].

14. Flavia Bustreo & Curtis Doebbler, *Universal Health Coverage: Are We Losing Our Way on Women’s and Children’s Health?* 21 J. HEALTH & HUM. RTS. 229 (2019).

15. Benjamin Mason Meier & Lawrence O. Gostin, *Introduction to HUMAN RIGHTS IN GLOBAL HEALTH: RIGHTS-BASED GOVERNANCE FOR A GLOBALIZING WORLD*, at xxiii (Benjamin Mason Meier & Lawrence O. Gostin eds., 2018); cf. JENNIFER PRAH RUGER, *GLOBAL HEALTH JUSTICE AND GOVERNANCE* (2018).

16. For a broader critique of international human rights law as antidemocratic, see generally John O. McGinnis & Ilya Somin, *Democracy and International Human Rights Law*, 84 NOTRE DAME L. REV. 1739 (2009).

positivistic approach to international human rights law, and fails to illuminate the connections between the right to health and democratic contestation.

In suggesting an alternative socio-legal narrative, the Article proceeds as follows. First, in Part I, beginning with the idea that the central challenge in a plural democracy is the negotiation of difference among subjects of equal dignity,<sup>17</sup> we conceptualize health as a moral and legal right, and argue that this conceptualization challenges conventional thinking in biomedicine and public health.<sup>18</sup> Drawing on examples relating to disability rights, women's sexual and reproductive health rights, and trans people's rights in health, we note the ways in which understanding health as a democratic right deepens our understanding of heterogeneity in a plural democracy.

In Part II, we examine the implications of treating health as a right for the primary institution responsible for preventive and curative health care: the health system. The way health systems are currently conceived in much of the world obscures how health is largely a product of social structures and relations, not just individual behaviors or biological pathogens. There is no reason for health systems not to be analyzed and interrogated in the same ways as other core social institutions—such as justice and educational systems—which mediate between different interests in society, and reinforce (or fail to do so) normative commitments such as dignity and equality. For example, just as the U.S. criminal justice system reinforces racial injustice, the gaping disparities in maternal mortality ratios between white and African American women (approximately one-to-four)<sup>19</sup> in the United States can be understood not just as lapses in quality of care but as the health system inscribing racial subordination on the bodies of women of color. We examine what it means to treat health systems as fundamental to shaping democratic norms, in terms of financing, priority-setting, the organization and delivery of services, information, and oversight.

In Part III, we address the cosmopolitan implications for health rights of today's globalized world where neither people nor determinants of health are contained within borders. Rather than shift the locus of attention in standard-setting and policymaking to global bureaucracies, we suggest that nascent initiatives relating to extraterritorial obligations (ETOs) of states can be used to extend social contracts and strengthen regulations that have implications for global equity in health and beyond. We conclude by asserting that making explicit the links between health and deliberative democracy has the potential to re-focus

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17. Seyla Benhabib, *Toward a Deliberative Model of Democratic Legitimacy*, in *DEMOCRACY AND DIFFERENCE: CONTESTING THE BOUNDARIES OF THE POLITICAL* 68 (Seyla Benhabib ed., 1996).

18. NANCY KRIEGER, *EPIDEMIOLOGY AND THE PEOPLE'S HEALTH: THEORY AND CONTEXT* 126 (2011).

19. Mary Beth Flanders-Stepans, *Alarming Racial Differences in Maternal Mortality*, 9 *J. PERINATAL EDUC.* 50 (2000).

struggles for health and social equality in ways that should not only inform efforts to reform health systems, but also reshape our understanding of health rights more broadly.<sup>20</sup>

## I. CONCEPTUALIZING HEALTH IN TERMS OF MORAL AND LEGAL RIGHTS WITHIN A DEMOCRACY

### *A. Grounding the Moral Right to Health*

John Rawls argued that justice requires the arrangement of major political and social institutions in such a way as to maximize the equality of primary goods because this is essential to enabling terms of fair cooperation and equality of diversely situated people.<sup>21</sup> Primary social goods include civil liberties and political rights, income and wealth, and the social bases of self-respect, which are self-evidently affected by the legal and institutional frameworks in a society.

In his initial work, Rawls considered health not as a social good, but rather as a “natural” good, more akin to intelligence.<sup>22</sup> However, an abundance of empirical evidence has emerged in recent decades that demonstrates that the distributions of health and ill-health are deeply influenced by “social determinants”—the “conditions in which people are born, grow, live, work, and age”<sup>23</sup>—which are invariably shaped by the arrangements of institutions in a society. Further, the health system itself, responsible for preventive measures, such as vaccinations, as well as curative treatment, is itself a social determinant of health. In extending Rawls’ theory of justice to health, Norman Daniels has noted the extent to which patterns of health and ill-health are shaped by structural and institutional factors.<sup>24</sup> Daniels in turn argues that health should be subject to the demands of justice because it is essential to enabling people to preserve a normal range of opportunities in life.

Similarly, Amartya Sen has argued that we can claim a moral right to health because (1) health is essential for people to have the capability to exercise the functionings they value in life, and (2) health is subject to a considerable degree of social influence.<sup>25</sup> Further, in both cases, these opportunities and capabilities are

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20. For a detailed discussion of construction of these linkages, *see generally* ALICIA E. YAMIN, *WHEN MISFORTUNE BECOMES INJUSTICE: EVOLVING HUMAN RIGHTS STRUGGLES FOR HEALTH AND SOCIAL EQUALITY* (2020) [hereinafter *MISFORTUNE*].

21. *See generally* JOHN RAWLS, *A Theory of Justice* 58–59 (1971).

22. *Id.* at 60–142.

23. WHO COMM’N ON SOC. DETERMINANTS OF HEALTH, *CLOSING THE GAP IN A GENERATION: HEALTH EQUITY THROUGH ACTION ON THE SOCIAL DETERMINANTS OF HEALTH* 26 (2008).

24. *See* NORMAN DANIELS, *Three Questions of Justice*, in *JUST HEALTH: MEETING HEALTH NEEDS FAIRLY* 11 (2007).

25. *See generally* Amartya Sen, *Elements of a Theory of Human Rights*, 32 *PHIL. & PUB. AFF.* 315 (2004).

not exercised in a vacuum; health enables people to participate as full and equal members of their polities. Both theories depend on the understanding that: (1) health has special moral value that sets it apart from an ordinary commodity (which could be allocated purely by the market); and (2) health is not merely a “natural” gift, nor a stochastic individual biological state, but rather is deeply influenced by the social and institutional arrangements in society.

Further, both theories are consistent with broader theories of distributive justice that call for deliberative processes to specify how to meet the health needs of diverse groups of people fairly when all health needs invariably cannot be met in rich or poor societies alike. Indeed, health may be the quintessential illustration of the most pressing challenge to plural democracy, which is the legitimate negotiation of difference. As Seyla Benhabib argues, democracy is better thought of not as a rigid form of government but rather “a model for organizing the collective and public exercise of power in the major institutions of society on the basis of the principle that decisions affecting the well-being of a collectivity can be viewed as the outcome of a procedure of free and reasoned deliberation among individuals considered as moral and political equals.”<sup>26</sup>

It is important to underscore that this view of health as inextricably connected to dignity, justice, and the arrangement of institutions in a democracy, which underpins understanding health as both a moral and legal right, contrasts dramatically with how health is construed in biomedical research, clinical practice, and public health programming. When a physician evaluates one’s health using laboratory testing, health is defined as being within the “normal” range for a complete blood count, a liver function test, or a metabolic panel—i.e., the absence of disease or infirmity, or more broadly, the absence of pathology. This “negative” definition of health within biomedicine is simultaneously (1) abstracted from social context (and therefore permits standardization in research and classification of disease); and (2) susceptible to determination only through a specialized scientific expertise.<sup>27</sup> Further, as Nancy Krieger, a leading social epidemiologist, has noted, the biomedical model focuses on determinants of disease amenable to intervention through medical care in individual patients; it “considers social determinants of disease to be at best secondary (if not irrelevant), and views populations simply as the sum of individuals and population patterns of disease as simply reflective of individual cases.”<sup>28</sup> Conventional public health, in turn, operates through an inexorably utilitarian calculus that aggregates individual conditions to arrive at population burdens of disease, and compares cost-effectiveness among different interventions.

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26. Benhabib, *supra* note 17, at 68.

27. See generally MISFORTUNE, *supra* note 20.

28. KRIEGER, *supra* note 18, at 137.

*B. Definition and Scope of a Legal Right to Health in International Law*

The special moral importance of health, as with all *rights*, is fundamentally connected to dignity and self-governance in the modern human rights canon.<sup>29</sup> Every country in the world, including the United States, has recognized at least some dimension of rights regarding health under international law.<sup>30</sup> Further, sometimes the domestic legal recognition of health-related rights is achieved through non-discrimination, protections of bodily integrity, or an increasingly expanded conception of the right to life in international law and in domestic jurisprudence.<sup>31</sup> Moreover, international law functions not merely through domestication of ratified treaties, but also through more diffuse standard-setting and moral persuasion created when sovereign heads of nation states relinquish some of their powers to join with the commonwealth of nations in recognizing common standards of conduct.<sup>32</sup> These common supranational standards of conduct, as well as the obligations that they entail, evolve over time in recursive relation with the particularities of specific national contexts and constitutional orders.

In 1946, the preamble to the World Health Organization (WHO) Constitution was the first mention of a right to health in international law, explicitly rejecting the idea that health is “merely the absence of disease or infirmity.”<sup>33</sup> The core formulation of the right to health in international human rights treaty law was set forth in Article 12(1) of the International Covenant on Economic, Social and Cultural Rights (ICESCR), which identifies the “right of everyone to the enjoyment of the highest attainable standard of physical and mental health.”<sup>34</sup> Under this formulation, the right to health encompasses both underlying public health conditions (e.g., water and sanitation) and “*conditions which would assure to all medical service and medical attention*” and is subject to progressive achievement in accordance with resource availability.<sup>35</sup> In keeping with the notion that it enables us to preserve a range of opportunities, the right to health is not

29. See UDHR, *supra* note 4, art. 1.

30. OFFICE OF THE UN HIGH COMM’R FOR HUMAN RIGHTS & WORLD HEALTH ORG., FACT SHEET No. 31: THE RIGHT TO HEALTH 1 (2008).

31. See, e.g., Convention for the Protection of Human Rights and Fundamental Freedoms art. 2, 14, *opened for signature* Nov. 11, 1950, E.T.S. 5; Ctr. for Legal Res. *ex rel* Câmpeanu v. Romania, 2014-V Eur. Ct. H.R. 1; Human Rights Comm., *General Comment No. 36 (2018) on Article 6 of the International Covenant on Civil and Political Rights, on the Right to Life*, U.N. Doc. CCPR/C/GC/36 (2018); Comm. on the Elimination of Discrimination Against Women, *Elisabeth de Blok et al. v. the Netherlands*, U.N. Doc. CEDAW/C/57/D/36/2012 (Mar. 24, 2014).

32. Robin West, *Reconsidering Legalism*, 88 MINN. L. REV. 154 (2003).

33. Constitution of the World Health Organization, pmb., *opened for signature* July 22, 1946, 62 Stat. 2679, 14 U.N.T.S. 186.

34. ICESCR, *supra* note 6, art. 12.

35. *Id.* art. 12(2)(d); see generally *General Comment No. 14, supra* note 6.

merely a package of good and services; under international law, the right to health includes both freedoms (e.g. informed consent and freedom from coercion) and entitlements to goods, facilities and services.<sup>36</sup>

Equal protection of the law is perhaps the foundational principle in a plural democracy, and non-discrimination is understood as a cross-cutting principle underlying the right to health, as well as other economic, social and cultural (ESC) rights under international law.<sup>37</sup> The Convention on the Elimination of Racial Discrimination, which the United States has ratified, raises the need to eradicate discrimination in relation to rights to “public health, medical care, social security and social services.”<sup>38</sup> The Convention on the Elimination of Discrimination Against Women (CEDAW) mandates that states “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.”<sup>39</sup> CEDAW also places a particular focus on rural women, acknowledging that categories of protected groups often mask intra-group differences.<sup>40</sup>

The overarching importance of non-discrimination in health is two-fold. First, formal non-discrimination requires similarly situated people to be treated similarly under the law, implying that services accessible to one person should not be denied to another with the same condition based on race, gender, caste, etc.<sup>41</sup> Second, international law goes beyond much U.S. constitutional law in that substantive non-discrimination requires treating differently situated people in ways that enable their equal effective enjoyment of rights, including the right to health.<sup>42</sup> Conceptualizing health rights in terms of the distributional consequences that legal rules have upon diverse populations has been extremely important in building the normative scaffolding of the right to health under much constitutional and international law. Laws and policies that arbitrarily distinguish between groups, or alternatively formalistically fail to identify real differences between groups, can be—and have been—reformulated to afford equal effective enjoyment.

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36. *General Comment No. 14, supra* note 6.

37. Non-discrimination is considered a principle in the ICESCR and is a substantive right in the International Covenant on Civil and Political Rights. *See* ICESCR, *supra* note 6, art. 2; International Covenant on Civil and Political Rights art. 2, *opened for signature* Dec. 16, 1966, T.I.A.S. No. 92-908, 999 U.N.T.S. 171.

38. International Convention on the Elimination of All Forms of Racial Discrimination art. 5(e)(IV), *opened for signature* Dec. 21, 1965, T.I.A.S. No. 94-1120, 660 U.N.T.S. 195.

39. Convention on the Elimination of All Forms of Discrimination against Women art. 12, ¶ 1, *opened for signature* Dec. 18, 1979, 1249 U.N.T.S. 13 [hereinafter CEDAW].

40. *Id.* art. 14(2)(b).

41. Comm. on Econ., Soc. & Cultural Rights, *General Comment No. 20 (2009) on Non-discrimination in Economic, Social and Cultural Rights (art. 2, para. 2. of the International Covenant on Economic, Social and Cultural Rights)*, ¶¶ 8–9, U.N. Doc. E/C.12/GC/20 (2009).

42. *Id.*

For example, in a 2019 decision from the First Chamber, the Mexican Supreme Court held that a woman's right to health under the Mexican Constitution and international law was violated when she was denied a medically necessary abortion due to severe threats to her health.<sup>43</sup> The Court phrased this violation in specifically gendered terms—that the plaintiff “was prevented from having prompt and timely access to a health service that only women need with the consequent impairment of her right to the highest possible level of health and wellbeing.”<sup>44</sup> The Court reinforced that ensuring women's right to health necessarily requires both individual and systemic action “to avoid the historical disadvantage due to sex or gender from adversely affecting legitimate claims of justice.”<sup>45</sup>

The integral nature of non-discrimination to a right to health calls into question the ways in which health systems foster discriminatory norms that differentiate between and hierarchize subgroups within society.<sup>46</sup> Indeed, what is most potentially transformative about addressing health as a right is that it forces us to re-evaluate the multiple layers of heterogeneity in our democratic institutions and broader democracies.<sup>47</sup> This is particularly true for those who are not white, able-bodied, cisgender men—the assumed subject upon which both medical knowledge and many laws are premised,<sup>48</sup> as described below in relation to disability, women's reproductive health and obstetric care, and trans persons' rights in health.

### *C. Transformative Implications of Navigating Democratic Difference through*

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43. Suprema Corte de Justicia de la Nación, Primera Sala [Supreme Court of Justice of the Nation, First House] 2019, Amparo en Revisión 1388/2015 ¶¶ 96–109, 150 (May 15, 2019) (Mex.), <https://www2.scjn.gob.mx/ConsultaTematica/PaginasPub/DetallePub.aspx?AsuntoID=190811> [<https://perma.cc/N52C-AZ3R>], translated in *Motion for Constitutional Relief Under Amparo Proceedings in Review 1388/2015*, PETRIE-FLOM CENTER FOR HEALTH LAW POLICY, BIOTECHNOLOGY AND BIOETHICS ¶¶ 51–64, 105, [https://petrieflom.law.harvard.edu/assets/publications/AR\\_1388-2015\\_Tradux\\_FINAL.pdf](https://petrieflom.law.harvard.edu/assets/publications/AR_1388-2015_Tradux_FINAL.pdf) [<https://perma.cc/V792-292X>] [hereinafter Amparo en Revisión 1388/2015].

44. *Id.* ¶ 137 (¶ 92 in the translation).

45. *Id.* ¶ 62 (¶ 22 in the translation).

46. See Didier Fassin, *Another Politics of Life is Possible*, 26 THEORY CULTURE & SOC'Y 44 (2009).

47. Cf. Bustreo & Doebbler, *supra* note 14.

48. Indeed, only in 1993 was the National Institutes of Health Revitalization Act passed, which mandated that National Institutes of Health-funded clinical trials include women and minorities. Since then, progress in centering these groups in medical research has been slow. See MARY HERRIGAN CONNORS CTR. FOR WOMEN'S HEALTH & GENDER BIOLOGY AT BRIGHAM & WOMEN'S HOSP., SEX-SPECIFIC MEDICAL RESEARCH: WHY WOMEN'S HEALTH CAN'T WAIT 3 (2014).

*Health**1. Disability*

The Convention on the Rights of Persons with Disabilities (CRPD) defines disability as a person's "long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others."<sup>49</sup> Further, Article 9 of the CRPD requires states to engage in "identification and elimination of obstacles and barriers to accessibility."<sup>50</sup> This definition of disability moves away from a focus on an individual's biological health state, by conceptualizing disability as the interaction between an individual, their long-term impairment, and their surroundings. Article 25 of the CRPD provides "that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability" and "that States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation."<sup>51</sup> This duty may include the provision of special measures to ensure effective enjoyment of health rights in practice.<sup>52</sup>

The CRPD forces us to consider how the prevailing utilitarian public health paradigm of "species-typical functioning" evident in public health metrics such as Disability-Adjusted Life Years (DALYs) are predicated on devaluing the lives of disabled persons.<sup>53</sup> Under a DALY framework, health interventions for disabled people are calculated as having less impact on alleviating overall disease burden, based on the initial assumption that a disabled person is less functioning than an

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49. Convention on the Rights of Persons with Disabilities art. 1, *opened for signature* Mar. 30, 2007, 2515 U.N.T.S. 3 [hereinafter CRPD].

50. *Id.* art. 9.

51. *Id.* art. 25.

52. In *Eldridge v. British Columbia (AG)*, Canada's Supreme Court held that the province had violated two patients' right to freedom from discrimination on the basis of disability under the Canadian Charter of Rights and Freedoms when they were treated during childbirth despite the communication barrier between themselves and the medical professionals, leading to them receiving "medical services that are inferior to those received by the hearing population." The Court wrote, "Given the central place of good health in the quality of life of all persons in our society, the provision of substandard medical services to the deaf necessarily diminishes the overall quality of their lives." *Eldridge v. British Columbia (AG)*, [1997] 3 S.C.R. 624 ¶ 94. In that case, which was decided before the CRPD entered into force, the Court created an entitlement for deaf patients to have access to a sign language interpreter during hospital care that enables them to communicate with healthcare providers and thus meaningfully participate in decisions relating to their health care.

53. Michael Ashley Stein, Janet E. Lord & Dorothy Weiss Tolchin, *Equal Access to Health Care Under UN Disability Rights Convention*, in *MEDICINE AND SOCIAL JUSTICE: ESSAYS ON THE DISTRIBUTION ON HEALTH CARE* 246–247 (Rosamond Rhodes, Margaret Battin, & Anita Silvers eds., 2012).

able-bodied/minded person, and therefore cannot be restored to full functionality even if they receive a health intervention for other conditions that the disabled person may be experiencing. Using this model to calculate the cost-effectiveness of introducing different health interventions leads to the unjust outcome that a disabled or chronically ill person who is already “disadvantaged in general . . . receives less medical attention for other ailments.” This model also implies that this disabled person may very well not merit other efforts to diminish the impacts of impairments (e.g., changing sidewalks and bathrooms to allow for wheelchairs or providing equal access to learning materials for visually and hearing impaired persons).<sup>54</sup> As Sudhir Anand and Kara Hanson have written, “[a] more appropriate measure of burden of disease must take account of the way in which individual and social resources can compensate for the level of disability experienced.”<sup>55</sup>

The CRPD challenges us to focus on the complex interplay between a person with impairments of some kind and her environment in determining her ability to participate fully in her society.<sup>56</sup> To be clear: this does not mean that highly costly health-related interventions for persons with disabilities always take priority over more cost-effective measures that would impact a broader segment of society. However, a right to health does imply the need to accord diverse groups of people equal moral consideration through a deliberative process, giving due regard to the values of those most impacted as well as the broader democratic polity, rather than automatically opting for the “biggest bang for the buck.”

Moreover, the CRPD’s transformative implications also highlight the ways in which we understand informed consent and dignity in health systems. Article 3(4) mandates “[r]espect for difference and acceptance of persons with disabilities as part of human diversity and humanity,”<sup>57</sup> which makes clear that the goal of the CRPD is not to equalize individualized health states, but to challenge liberal democracies to adapt to different forms of otherness in order to ensure persons with disabilities can participate fully and equally in their societies regardless of their health state. That is, their “defects” need not be fixed in order for them to participate on an equal basis in their communities and societies.

Indeed, Article 12 of the CRPD on legal capacity, as interpreted in General Comment 1 of the CRPD Committee, suggests a new model of “supported decision-making” as opposed to “substitute decision-making” for people with mental disabilities.<sup>58</sup> As the CRPD Committee elaborates, a regime of supported

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54. Amartya Sen, *Why Health Equity?* 11 J. HEALTH ECON. 659, 662 (2002).

55. Sudhir Anand & Kara Hanson, *Disability-Adjusted Life Years: A Critical Review*, 16 J. HEALTH ECON. 685, 694 (1997).

56. Sophie Mitra, *The Human Development Model of Disability, Health, and Wellbeing*, in DISABILITY, HEALTH AND HUMAN DEVELOPMENT 9 (2018).

57. CRPD art. 3(4).

58. CRPD, *supra* note 49, *See generally* Comm. on the Rights of Persons with Disabilities, *General Comment No. 1 (2014) on Article 12: Equal Recognition Before the Law*, U.N. Doc.

decision-making “comprises various support options which give primacy to a person’s will and preferences and respect human rights norms” and avoids overregulation of the lives of persons with disabilities.<sup>59</sup> In many existing legal regimes, once a medical expert deems a person to be incapable of making their own decisions, a legal guardian is appointed who is able to overrule the incapacitated person’s will and preferences with what is “perceived as being in his or her objective best interests.”<sup>60</sup>

The supported decision-making framework of consent thus presents a fundamental challenge to the specialized knowledge of psychiatrists and other clinicians.<sup>61</sup> The CRPD Committee notes: “Mental capacity is not, as is commonly presented, an objective, scientific and naturally occurring phenomenon. Mental capacity is contingent on social and political contexts, as are the disciplines, professions and practices which play a dominant role in assessing mental capacity.”<sup>62</sup> Given that assessments of mental capacity are generally performed according to psychiatric “methods” that are inaccessible to laypersons (and carers who are not trained in scientifically accepted models of mental healthcare), supported decision-making and the broader disability rights paradigm behind the CRPD imply a tectonic shift in the ways in which a health system legitimately exercises power over human beings. Involuntary treatment of persons with psycho-social disabilities would require a different process of justification beyond the proverbial “second opinion” if supported decision-making were effectuated in practice. Further, the “effectiveness” of supported decision-making cannot be evaluated in short-term health outcomes alone, but also by whether persons with psycho-social disabilities are able to exercise agency without having to be re-hospitalized, incarcerated, or otherwise subjected to state confinement and control during a certain period.<sup>63</sup>

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CRPD/C/GC/1 (2014). [hereinafter *CRPD General Comment No. 1*].

59. *CRPD General Comment No. 1*, *supra* note 58, ¶ 29.

60. *Id.*

61. See P. Gooding, *Supported Decision-Making: A Rights-Based Disability Concept and Its Implications for Mental Health Law*, 20 *PSYCHIATRY PSYCHOL. & L.* 431 (2013); cf. M. Scholten & J. Gather, *Adverse Consequences of Article 12 of the UN Convention on the Rights of Persons with Disabilities for Persons with Mental Disabilities and an Alternative Way Forward*, 44 *J. MED. ETHICS* 226 (2018).

62. *CRPD General Comment No. 1*, *supra* note 58, ¶¶ 14-15.

63. For example, one indicator could be the rate and demographics of people who are involuntarily committed. See Jeffrey Swanson et al., *Racial Disparities in Involuntary Outpatient Commitment: Are They Real?* 28 *HEALTH AFF.* 816, 816 (2009) (“Overall, African Americans are more likely than whites to be involuntarily committed for outpatient psychiatric care in New York.”); see also Florian Hotzy et al., *Cross-Cultural Notions of Risk and Liberty: A Comparison of Involuntary Psychiatric Hospitalization and Outpatient Treatment in New York, United States and Zurich, Switzerland*, 9 *FRONTIERS PSYCHIATRY* 1 (2018) (discussing how New York and Zurich have different cultures with regard to involuntary hospitalization and concluding that New York’s culture focuses more on the “danger” of untreated mentally ill persons).

## 2. Women's Sexual and Reproductive Health

All persons who can become pregnant need to be able to make active choices in regard to their sexual and reproductive choices and health, not just to passively receive reproductive health care services. As a result of their socially constructed roles in reproduction, women's control over their reproductive choices and processes is a fundamental part of being able to participate as equal members of society. As recognized in the Committee on Economic, Social and Cultural Rights' (CESCR) General Comment 22, "[t]he right of women to sexual and reproductive health is indispensable to their autonomy and their right to make meaningful decisions about their lives and health."<sup>64</sup> Women require equal access to health facilities, goods, and services, and as recognized by the CEDAW Committee and CESCR, equal enjoyment of the right to health sometimes entails access to "additional" services, such as essential obstetric care.<sup>65</sup>

Deciding the number and spacing of children is a fundamental part of women's self-governance,<sup>66</sup> laws and policies that curtail that agency in the name of demographic imperatives enshrine political discourses that women are less than fully equal subjects of rights. This principle of women's inherent dignity to make sexual and reproductive health choices undergirds the decisions by many national and supranational courts that have found that involuntary sterilization violates not only women's right to health, but also dignity and bodily integrity.<sup>67</sup> Involuntary sterilization is often systematically conducted on women from marginalized groups—such as women with disabilities or HIV, or certain ethnicities or social groups—yet they are frequently cloaked in medical justifications and health systems that structure medical judgments as unchallengeable.<sup>68</sup> While the health effects resulting from these injustices may be the same, health rights advocates and courts fail to highlight issues of democratic inequality and exclusion when they frame these issues narrowly as violations of individual bodily integrity, disconnected from the effects on the agency of women within a plural social

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64. See Comm. on Econ., Soc. & Cultural Rights, *General Comment No. 22 (2016) on the Right to Sexual and Reproductive Health (Article 12 of the International Covenant on Economic, Social and Cultural Rights)*, ¶ 25, U.N. Doc. E/C.12/GC/22 (2016).

65. *Id.*; *General Comment No. 14, supra* note 6; Rep. of the Comm. on the Elimination of Discrimination Against Women, 20th and 21st Sessions, at 3, U.N. Doc. A/54/38/Rev.1 (1999).

66. And persons of all genders who gestate.

67. See, e.g., *Government of the Republic of Namibia v. LM and Others (SA 49/2012)*, 2014 NASC 19 (Nov. 3, 2014) (Namib.); *I.V. v. Bolivia, Preliminary Objections, Merits, Reparations, and Costs, Judgement, Inter-Am. Ct. H.R. (ser. C) No. 329 (Nov. 30, 2016), request for interpretation of judgement denied, Inter-Am. Ct. H.R. (ser. C) No. 336 (May 25, 2017)*; *V.C. v. Slovakia*, 2011-V Eur. Ct. H.R. 381.

68. Alicia Ely Yamin & Corey Prachniak-Rincón, *Compounded Injustice and Cautionary Notes for "Progress" in the Sustainable Development Era: Considering the Case of Sterilization of Women Living with HIV*, 41. HARV. J.L. & GENDER 396 (2018).

context. For example, in *Government of the Republic of Namibia v. LM and Others*, the Supreme Court of Namibia condemned the attitude of medical paternalism that led to the involuntary sterilization in the case, but failed to appreciate that this abuse is disproportionately rendered upon women who are marginalized in Namibian society by their HIV status.<sup>69</sup> “Intersectional discrimination,” as coined originally by Kimberlé Crenshaw, requires us to recognize how different and overlapping forms of difference inhibit women’s exercise of their health rights—and all democratic rights—in complex ways that require us to (1) pay attention to the lived experiences of diverse women; and (2) understand the contextually contingent ways in which the health system reinforces patterns of exclusion of particular groups that exist in the overall society.<sup>70</sup>

Sexual and reproductive health and rights scholars and activists in Latin America have further challenged the prevalent ways that health systems, by being structured around the biomedical paradigm, constrain the agency of women (and other pregnant persons). Activists have argued that women are not only entitled to protection against lack of informed consent and obvious “disrespect and abuse” in receiving reproductive healthcare.<sup>71</sup> Rather, they call for a recognition of “obstetric violence,” a concept now codified in legislation in a number of countries in Latin America,<sup>72</sup> which constitutes an epistemic change that draws into question medical practices from episiotomies to unnecessary caesarean sections.<sup>73</sup> Rachele Chadwick has identified how the concept of obstetric violence gains its “disruptive and radical edge” from its willingness to name forms of violence that have historically been “hidden and unacknowledged,” such as emotional and structural violence.<sup>74</sup> The struggles against obstetric violence are not about health states per se, such as reducing maternal mortality and morbidity. Obstetric violence

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69. *Government of the Republic of Namibia*, ¶¶ 104-106.

70. Yamin & Prachniak-Rincón, *supra* note 68, at 410 (citing Kimberlé Crenshaw, *Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Color*, 43 STAN. L. REV. 1241 (1991) (introducing the theory of intersectionality of race, gender, and other forms of discrimination)).

71. *Prevention and Elimination of Disrespect and Abuse During Childbirth*, WORLD HEALTH ORG. (2019), [https://www.who.int/reproductivehealth/topics/maternal\\_perinatal/statement-childbirth-data/en](https://www.who.int/reproductivehealth/topics/maternal_perinatal/statement-childbirth-data/en) [https://perma.cc/DL97-BCCE].

72. C.R. Williams, C. Jerez, K. Klein, M. Correa, J.J. Belizán & G. Cormick, *Obstetric Violence: a Latin American Legal Response to Mistreatment During Childbirth*, 125 BJOG: INT’L J. OF OBSTETRICS & GYNAECOLOGY 1208 (2018). For example, Argentina’s Comprehensive Law for the Sanction, Prevention, and Eradication of Violence against Women defines reproductive processes broadly, as including as pregnancy, labor work, childbirth, and post-partum periods. Law No. 26485, Apr. 14, 2009, BOLETÍN OFICIAL [B.O.] [OFFICIAL GAZETTE] no. 31632, at 1, 3 (citing Law No. 25929, Sept. 21, 2004, B.O. no. 30489, at 1, 1).

73. Carlos Herrera Vacaflor, *Obstetric Violence: A New Framework for Identifying Challenges to Maternal Healthcare in Argentina*, 24 REPRODUCTIVE HEALTH MATTERS, May 2016, at 65.

74. Rachele Chadwick, *Ambiguous Subjects: Obstetric Violence, Assemblage and South African Birth Narratives*, 27 FEMINISM & PSYCHOL. 489, 492 (2017).

encapsulates the more subtle—yet still damaging—regulation of women as embodied social beings in a democracy. By pathologizing women’s natural reproductive processes, pregnancy is treated as a “disease” and women’s bodies are reduced to objects on which “expert” medical interventions are deployed.

In *Killing the Black Body*, Dorothy Roberts has described the historical and present use of obstetric violence to police Black women’s reproduction in the United States. While Black women’s bodies were literally the mechanisms to reproduce white property under slavery, obstetric violence against Black women has more recently also been funneled through progressive medical advances such as oral and vaccine contraceptives.<sup>75</sup> For example, although birth control in the twentieth century was being disproportionately pushed onto Black women with the intention of reducing their birthrate based on racist and even eugenic narratives, services such as affordable and quality prenatal care were not similarly made widely available to Black women.<sup>76</sup> As Roberts argues, such obstetric violence is not only harmful because it leads to different reproductive outcomes for Black women, but also because these narratives serve the ideological function of making “racial inequality appear to be the product of nature rather than power.”<sup>77</sup> Obstetric violence “thus acts as a mode of discipline that is inextricably intertwined with multiple axes of social marginalization.”<sup>78</sup> In contrast, when diverse women’s lived experiences of their sexuality and bodies are taken into account through the naming of obstetric violence and the demand for redress, the univocal authority of the medical establishment to act upon the Black female body is challenged, and the ways in which racial inequality is constructed become visible. The end result is a challenge to the way in which the power to categorize people, construct difference, and establish social hierarchies is exercised through health systems and refracted throughout society.

### 3. *Trans People’s Rights in Health*

Yet another example of how conceiving of the right to health as having the goal of enabling people to live with dignity in a plural society—as opposed to attaining a specific individual health state—is acutely illustrated in situations faced by trans and gender-nonconforming people. In the biomedical paradigm, these persons have generally been treated as having disorders, such as “gender dysphoria.”<sup>79</sup> Yet in a ground-breaking case, *National Legal Services Authority v.*

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75. DOROTHY ROBERTS, *KILLING THE BLACK BODY: RACE, REPRODUCTION, AND THE MEANING OF LIBERTY* 113–57 (1997).

76. *Id.*

77. *Id.* at 111.

78. Chadwick, *supra* note 74, at 493.

79. Jules Morgan, *Trans\* Health: “Diversity, not Pathology,”* 2 *LANCET* 124 (2015); Zowie Davy & Michael Toze, *What is Gender Dysphoria? A Critical Systematic Narrative Review*, 3

*Union of India*, the Supreme Court of India recognized that there are divergences between dignity and medically-accepted health statuses.<sup>80</sup> The Court held that legal recognition of trans identity as a third category of gender identity is central to upholding the human rights and dignity of trans people in India. Moreover, the Court emphasized that legal recognition of this gender identity is based on the person's own gender expression, and is not contingent on gender reassignment surgery, hormones, or other medical procedures.<sup>81</sup> Further, it called for local governments to take steps to provide gender-sensitive medical care as well as separate bathroom facilities for trans persons.<sup>82</sup> In other countries, such legal reforms have been undertaken through public deliberation and legislation. In Argentina, the 2012 Gender Identity Law allowed for people to choose the name and gender listed on their identity documents without the need for a psychological or medical evaluation, and included sex reassignment treatment in the national health program.<sup>83</sup> Similarly, in 2013, the Dutch legislature voted to pass a bill allowing trans people to change their gender on identity documents without having to undergo hormones and surgery.<sup>84</sup> Thus, dignity and participation in society need not be predicated on access to procedures to attain a specific biomedically-defined outcome.

Just as in disability, the right to health does not automatically mean that trans persons should obtain all treatments they seek; it requires that their concerns be treated with equal concern and respect in the decision-making process. In *AC v. Berkshire West Primary Care Trust*, a case arising in the United Kingdom, the non-statutory citizens' committee reviewing petitions for care rejected a trans woman's request to fund a breast enlargement surgery to supplement her hormone treatment.<sup>85</sup> The National Health Service rejected her request on the basis that cis women would not be entitled to funding for a procedure that was classified as "cosmetic" and not medically necessary.<sup>86</sup> This decision was upheld by the citizens' committee, and later by a court. The court decision adopts a biomedical

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TRANSGENDER HEALTH 159 (2018).

80. Nat'l Legal Serv. Auth. v Union of India, (2014) 5 SCC 438 (India).

81. *Id.* ¶ 129(2).

82. *Id.* ¶ 129(6).

83. Law No. 26743, May 24, 2012, B.O. no. 32404, at 2; *Breaking Down Barriers to Healthcare Access for Transgender People in Argentina*, ORGANISATION PANAMÉRICAINNE DE LA SANTE, [https://www.paho.org/hq/index.php?option=com\\_content&view=article&id=14259:breaking-down-barriers-healthcare-access-transgender-people-argentina&Itemid=135](https://www.paho.org/hq/index.php?option=com_content&view=article&id=14259:breaking-down-barriers-healthcare-access-transgender-people-argentina&Itemid=135) [https://perma.cc/76TM-DQPD].

84. Wet van 18 december 2013, Stb. 2014, no. 1; *The Netherlands: Victory for Transgender Rights*, HUM. RTS. WATCH (Dec. 19, 2013), <https://www.hrw.org/news/2013/12/19/netherlands-victory-transgender-rights> [https://perma.cc/LV7H-CGF7].

85. *AC v. Berkshire West Primary Care Trust* [2010] EWHC 1162 (Admin), *aff'd*, [2011] EWCA Civ 247.

86. *Id.* ¶¶ 13-14.

view of “gender identity disorder” and relies heavily on “expert” medical opinion, largely ignoring the strong dignity and security interests at play for trans women seeking to change their appearance to conform with their gender identity. On the other hand, a contrary ruling granting the breast enhancement surgery at government expense may have reinforced stereotyped views of how women’s bodies should appear and suggested that dignity is contingent upon conforming to a stereotyped conception of femaleness.<sup>87</sup> As discussed in Part II, it is precisely because arguments about substantive equality and dignity in relation to health are invariably deeply contested, in law as well as the financing of health systems, that it is essential that these arguments be subjected to public scrutiny and deliberative practices, such as through both the citizens’ committee and the court.

In short, asserting health as a legal right changes the causal factors that we consider in relation to health states, from purely biological pathogens to social contexts and the legal rules that shape those social contexts. In turn, it must change the way we evaluate programs and progress. That is, we are concerned not merely with the number of deliveries or psychiatric treatments. If human rights are to be used effectively to foster democratic institutions and practices with respect to health, we are interested in the dynamic interaction between embodied social beings and their environment, including democratic institutions and socio-political discourses. We understand intuitively that the right to food requires access to adequate nutrition, but is not violated by individual choices to fast, nor captured by disaggregated calorie or protein measures. Similarly, promoting health rights in ways that strengthen democratic practices cannot be reduced to pasting equity indicators onto standard health outcomes. Understanding the application of human rights in health in this narrow way invariably consigns it to palliative measures, which disregard the connections to broader dignity and equality concerns of differently situated people. Rather, advancing health rights requires engaging with the far more complex arguments regarding what is required in a democracy for human beings with diverse socioeconomic, racial, ethnic, gender, and other identities—and widely divergent health needs and conditions—to receive equal moral consideration both within health systems and the larger society.

## II. THE IMPLICATIONS OF ORGANIZING HEALTH SYSTEMS AROUND HEALTH RIGHTS

There is overwhelming evidence that social determinants of health are

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87. For scholarship discussing the politics of passing within the trans community, see, for example, Katrina Roen, “*Either/Or*” and “*Both/Neither*”: *Discursive Tensions in Transgender Politics*, 27 *SIGNS* 501 (2001); C. Riley Snorton, “*A New Hope*”: *The Psychic Life of Passing*, 24 *HYPATIA* 77 (2009); Sandy Stone, *The Empire Strikes Back: A Posttranssexual Manifesto*, in *THE TRANSGENDER STUDIES READER* 221 (Susan Stryker & Stephen Whittle eds., 2006).

responsible for a far larger portion of the unequal distribution of morbidity and mortality than medical care.<sup>88</sup> However, the health system itself is a social determinant, and acts in synergy with other social determinants. The WHO defines a health system as “all organizations, people and actions whose *primary intent* is to promote, restore or maintain health. This includes efforts to influence determinants of health as well as more direct health-improving activities.”<sup>89</sup> As COVID-19 has unfolded, for example, it has become increasingly clear how the patchwork structure of the United States medical care system, and lack of public health systems, reinforces marginalization and risk among the most vulnerable.<sup>90</sup> As Wendy Parmet has written, “health law has helped to fashion a health care system that lacks the redundancy and resiliency that will be critical in a pandemic.”<sup>91</sup> A “crisis” approach to pandemics will never be as effective as a health and legal system that “recognizes that health care itself is a public health issue.”<sup>92</sup> In the United States, health insurance is far from universal—in 2018, 8.5% of U.S. residents (27.5 million people) had no health insurance at any point that year.<sup>93</sup> The overall result in the midst of this pandemic has been that low-income people, designated as “essential workers,” continue to go to work at jobs that often involve high levels of public contact or alternatively risk economic ruin, due to how the economy writ large and the health system are structured.<sup>94</sup> That is,

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88. See, e.g., Paul Braveman, Susan Egerter & David R. Williams, 32 *The Social Determinants of Health: Coming of Age*, 32 ANN. REV. PUB. HEALTH 381 (2011); Nancy Krieger, *Methods for the Scientific Study of Discrimination and Health: An Ecosocial Approach*, 102 AM. J. PUB. HEALTH 936 (2012); Leslie London, Chuma Himonga, Nicole Fick & Maria Stuttaford, *Social Solidarity and the Right to Health: Essential Elements for People-Centered Health Systems*, 30 HEALTH POL’Y & PLAN. 938 (2015); Michael Marmot, *Social Determinants of Health Inequalities*, 365 LANCET 1099 (2005); Michael Marmot & Jessica J. Allen, *Social Determinants of Health Equity*, 104 AM. J. PUB. HEALTH S517 (2014); David Sanders, *A Global Perspective on Health Promotion and the Social Determinants of Health*, HEALTH PROMOTION J. AUSTL. 165 (2006).

89. WORLD HEALTH ORG., EVERYBODY’S BUSINESS: STRENGTHENING HEALTH SYSTEMS TO IMPROVE HEALTH OUTCOMES—WHO’S FRAMEWORK FOR ACTION 2 (2007).

90. See Max Fisher & Emma Bubola, *As Coronavirus Deepens Inequality, Inequality Worsens Its Spread*, N.Y. TIMES (Mar. 15, 2020), <https://www.nytimes.com/2020/03/15/world/europe/coronavirus-inequality.html> [<https://perma.cc/K3LV-N4DW>]; Michael T. Osterholm & Mark Olshaker, *Why We Are So Ill-Prepared for a Possible Pandemic Like Coronavirus*, TIME (Feb. 4, 2020), <https://time.com/5777923/america-prepared-pandemic-coronavirus> [<https://perma.cc/H3XV-ZYM3>]; *The United States Leads in Coronavirus Cases, but Not Pandemic Response*, SCIENCE (April 1, 2020), <https://www.sciencemag.org/news/2020/04/united-states-leads-coronavirus-cases-not-pandemic-response> [<https://perma.cc/SL7U-Z78F>].

91. Wendy Parmet, *Unprepared: Why Health Law Fails to Prepare Us for a Pandemic*, 2 J. HEALTH & BIOMEDICAL L. 157, 160 (2006).

92. *Id.*

93. EDWARD R. BERCHICK, JESSICA C. BARNETT & RACHEL D. UPTON, U.S. CENSUS BUREAU, P60-267 (RV), HEALTH INSURANCE COVERAGE IN THE UNITED STATES: 2018, at 2 (2019), <https://www.census.gov/content/dam/Census/library/publications/2019/demo/p60-267.pdf> [<https://perma.cc/V4KX-5JLC>].

94. Of course, this reality is not limited to the United States. Revisiting the 2010 Marmot

rather than mitigating the social inequalities in U.S. society, the patchwork and marketized health system is amplifying the marginalization of already disadvantaged groups in this pandemic.

Yet, in “normal” times, we reflect too little on the ways in which health systems reflect on democratic commitments, including through the regulation of diverse populations’ rates of birth, death, illness, fertility, and more.<sup>95</sup> As noted above, the stark disparities in maternal mortality ratios between white and African American women in the United States<sup>96</sup> have received heightened attention in the mainstream media in recent years.<sup>97</sup> One response would be to treat this disparity solely as a quality of care issue to be fixed by technical checklists and protocols.<sup>98</sup> Another would be to underscore the truth that women of color still face the damaging health effects of the toxic interactions of racial, gender and class discrimination from the moment they are born in the United States.<sup>99</sup> But it is

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Review on Health Equity in England in a new review in 2020, Michael Marmot and his coauthors sought to interrogate why after a century of increasing life expectancy in England, these increases had slowed dramatically, and why life expectancy in fact decreased among the most deprived populations in the country. While they could not conclusively attribute the drop to austerity, they wrote that any and all of the following factors were likely contributing:

From rising child poverty and the closure of children’s centres, to declines in education funding, an increase in precarious work and zero hours contracts, to a housing affordability crisis and a rise in homelessness, to people with insufficient money to lead a healthy life and resorting to foodbanks in large numbers, to ignored communities with poor conditions and little reason for hope. And these outcomes, on the whole, are even worse for minority ethnic population groups and people with disabilities.

MICHAEL MARMOT ET AL., HEALTH EQUITY IN ENGLAND: THE MARMOT REVIEW 10 YEARS ON 5 (2020). Moreover, most of the concluding recommendations in the review were not focused narrowly on the health system, but advocated for increased social spending to improve employment, housing, and environmental conditions. *Id.* at 151.

95. See LYNN P. FREEDMAN ET AL., MILLENNIUM PROJECT TASK FORCE ON CHILD & MATERNAL HEALTH, WHO’S GOT THE POWER? TRANSFORMING HEALTH SYSTEMS FOR WOMEN AND CHILDREN (2005); Gunilla Backman et al., *Health Systems and the Right to Health: an Assessment of 194 Countries*, 372 LANCET 2047 (2008); Lynn Freedman, *Achieving the MDGs: Health Systems as Core Social Institutions*, 48 DEVELOPMENT 19 (2005) [hereinafter Freedman, *Achieving the MDGs*]; Paul Hunt, *The Human Right to the Highest Attainable Standard of Health: New Opportunities and Challenges*, 100 TRANSACTIONS ROYAL SOC’Y TROPICAL MED. & HYGIENE 603 (2006).

96. Flanders-Stepans, *supra* note 19.

97. Allyson Chiu, *Beyoncé, Serena Williams Open up About Potentially Fatal Childbirths, a Problem Especially for Black Mothers*, WASH. POST (Aug. 7, 2018), <https://www.washingtonpost.com/news/morning-mix/wp/2018/08/07/beyonce-serena-williams-open-up-about-potentially-fatal-childbirths-a-problem-especially-for-black-mothers> [<https://perma.cc/96D7-DGBJ>].

98. ATUL GAWANDE, THE CHECKLIST MANIFESTO: HOW TO GET THINGS RIGHT (2009); *cf.* Kelly Grant, *Surgical Checklists Have Little Effect on Patient Outcomes, Study Finds*, GLOBE & MAIL (March 12, 2014), <https://www.theglobeandmail.com/news/national/surgical-checklists-have-little-effect-on-patient-outcomes-study-finds/article17473716> [<https://perma.cc/B989-6FNQ>].

99. See generally Arline T. Geronimus et al., *Do US Black Women Experience Stress-Related Accelerated Biological Aging?* 21 HUM. NATURE 19 (2010); Arline T. Geronimus et al., *Race-*

equally true, as Elizabeth Dawes Gay of Black Mamas Matter writes, that:

Racial discrimination within the health-care setting is a modern problem built on the legacy of slavery, reproductive oppression, and control of medicine and black bodies . . . . Today racial discrimination in clinical care presents in a variety of ways. Research has shown that implicit racial bias may cause doctors to spend less time with black patients and that black people receive less-effective care. Doctors are also more likely to underestimate the pain of their black patients. And anecdotes of disrespect and mistreatment abound.<sup>100</sup>

As has been underscored in the COVID-19 pandemic, the U.S. health system reinforces societal racism not just in the treatment individual Black patients may receive by practitioners at the micro-level, but through macro-level issues (e.g. financing) and meso-level issues (e.g. inadequacy of primary care). As these issues disproportionately affect people of color, the design and functioning of the health system treats racial difference in ways that undermine the equal concern and respect that is owed to diverse members of a democracy.

Yet, in human rights scholarship and practice there has been little examination of the role of the health system—whether in the United States or elsewhere—in upholding or violating fundamental normative commitments in the same ways as, for example, the justice system. As Lynn Freedman writes, “Human rights activists have long understood the political arms of the state—prisons, judicial systems and police forces—to have the power to exclude, abuse and silence. But rarely are . . . the social institutions on which [health rights] depend approached with the same understanding.”<sup>101</sup>

Here we aim to contribute to that understanding of the requirements for health systems to be organized around respecting, protecting and fulfilling the right to health within a democracy. Specifically, we consider implications for: (1) financing, (2) priority-setting, (3) information, and (4) judicial as well as other oversight of health systems.

#### *A. Fairness in Financing*

The right to health is subject to progressive achievement in accordance with

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*Ethnicity, Poverty, Urban Stressors, and Telomere Length in a Detroit Community-Based Sample*, 56 J. HEALTH & SOC. BEHAV. 199 (2015).

100. Elizabeth Dawes Gay, *Serena Williams Could Insist that Doctors Listen to Her. Most Black Women Can't*, NATION (Jan. 18, 2018), <https://www.thenation.com/article/serena-williams-could-insist-that-doctors-listen-to-her-most-black-women-cant> [<https://perma.cc/4F6M-NPXL>].

101. Freedman, *Achieving the MDGs*, *supra* note 95, at 20.

maximum available resources, as are all social rights under international law.<sup>102</sup> Under constitutional frameworks that recognize the right to health, it is also subject to constraints of resource availability. In reality, all rights require resources, including those conventionally thought of in the liberal state as “negative shields” against the incursion of the government. For example, consider the freedom from arbitrary detention, which requires appropriately allocated funding for justice institutions as well as regulatory oversight. Moreover, civil rights vary with resource availability across contexts; think of due process in Canada versus Cameroon. However, civil and political rights are generally funded through general taxation which both reflects their status as fundamental pillars of democracy and makes them less susceptible to marketization and outsourcing to non-governmental provision.

Health goods and services, by contrast, are generally funded through combinations of general taxation, payroll taxes, and social and private insurance schemes, as well as by direct out-of-pocket payments. For health systems to function in ways that reaffirm democratic values of inclusion, solidarity, and equality, they require fair financing, including sufficient pooled resources to cover social and legal citizens.<sup>103</sup> Just as it should be unacceptable in any democracy in the twenty-first century to allocate basic education by a price mechanism, so too is it undemocratic for essential health goods and services to be treated as mere commodities with no special moral value nor inextricable connection to dignity.

Nonetheless, neoliberal policies that privilege market solutions encourage health systems to do exactly this across much of the world today. In David Sanders and Mickey Chopra’s case study of South Africa, they wrote, “The dominant global and national policy environment that prioritizes the market and the private sector discourages state spending on ‘unproductive’ social investment,” such as health. This policy environment “accounts largely for the continuing health and [well-being] inequities” in the country—and many other middle-income countries as well.<sup>104</sup> As Ronald Dworkin aptly noted, a laissez-faire political economy “does not show equal concern for everyone. Anyone impoverished through that system is entitled to ask: ‘There are other, more regulatory and redistributive, sets of laws that would put me in a better position. How can [the] government claim that this system shows equal concern for me?’”<sup>105</sup>

The extreme of an approach that treats health—and health care—as a

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102. ICESCR, *supra* note 6, art. 2.

103. ALICIA ELY YAMIN, POWER, SUFFERING, AND THE STRUGGLE FOR DIGNITY: HUMAN RIGHTS FRAMEWORKS FOR HEALTH AND WHY THEY MATTER 99-127 (2016).

104. David Sanders & Mickey Chopra, *Key Challenges to Achieving Health for All in an Inequitable Society: The Case of South Africa*, 96 AM. J. PUB. HEALTH 73 (2006). For another case study example, see Fran Baum et al., *Comprehensive Primary Health Care Under Neo-Liberalism in Australia*, 168 SOC. SCI. & MED. 43 (2016).

105. RONALD DWORKIN, JUSTICE FOR HEDGEHOGS 3 (2011).

commodity without sufficient oversight has led to egregious health and other human rights violations in Kenya, where the High Court recently found that the right to life and dignity of two women had been violated when they were detained by a hospital immediately after giving birth for being unable to pay medical fees.<sup>106</sup> But the inequities of market allocation of health care are not limited to poor or middle-income countries. For instance, in the United States, ostensibly “non-profit” hospitals have brought hundreds of thousands of lawsuits to garnish the wages of uninsured, low-income patients for unpaid medical bills.<sup>107</sup> Vicente Navarro argues that “the enormous power of corporate interests in both the media and the political process” has been a key contributing factor to the United States being the only developed country without guaranteed health care regardless of ability to pay.<sup>108</sup> Indeed, even in the lead-up to the Affordable Care Act in 2008, lobbying by key healthcare industry players—such as pharmaceutical and insurance companies—constrained political debate on this option,<sup>109</sup> notwithstanding the high levels of popular support for single-payer healthcare at the time.<sup>110</sup> In 2018, U.S. health spending absorbed 17.7% of GDP,<sup>111</sup> and is expected to reach 19.9% of GDP by 2025.<sup>112</sup> It is more per capita than comparable countries like Canada and Sweden.<sup>113</sup> Moreover, as discussed above, this system involves starkly disparate access and outcomes along racial and income lines. Yet, as of this writing, significant reform in the financing of the largely private, market-

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106. *M.A.O. v. Attorney General*, [2015] eKLR (H.C.K. Sept. 17, 2015), <http://kenyalaw.org/caselaw/cases/view/131104> [<https://perma.cc/4YVU-XG9V>].

107. Maya Miller & Beena Raghavendran, *Thousands of Poor Patients Face Lawsuits from Nonprofit Hospitals that Trap Them in Debt*, PROPUBLICA (Sept. 13, 2019), <https://www.propublica.org/article/thousands-of-poor-patients-face-lawsuits-from-nonprofit-hospitals-that-trap-them-in-debt> [<https://perma.cc/V67F-TASP>].

108. Vincent Navarro, *Policy Without Politics: The Limits of Social Engineering*, 93 AM. J. PUB. HEALTH 64 (2003).

109. See *Examining the Single-Payer Health Care Option: Hearing Before Subcomm. on Health, Emp't, Labor & Pensions of the H. Comm. on Educ. & Labor*, 111th Cong. (2009); *High Health Care Costs: A State Perspective: Hearing Before the S. Comm. on Fin.*, 110th Cong. (2008).

110. *American Public Opinion: Today vs. 30 Years Ago*, CBS NEWS (Feb. 1, 2009), [www.cbsnews.com/htdocs/pdf/SunMo\\_poll\\_0209.pdf](http://www.cbsnews.com/htdocs/pdf/SunMo_poll_0209.pdf) [<https://perma.cc/4YVB-YAKW>] (finding in a 2009 public opinion poll that 49% of those surveyed would prefer government-provided health insurance over private insurance for “all problems”).

111. U.S. CENTERS FOR MEDICARE & MEDICAID SERVICES, NATIONAL HEALTH EXPENDITURE DATA (2019).

112. Press Release, U.S. Centers for Medicare & Medicaid Services, 2016-2025 Projections of National Health Expenditure Data Released (Feb. 15, 2017), <https://www.cms.gov/newsroom/press-releases/2016-2025-projections-national-health-expenditures-data-released> [<https://perma.cc/KUU4-K24N>].

113. Niall McCarthy, *How U.S. Healthcare Spending Per Capita Compares with Other Countries*, FORBES (Aug. 8, 2019), <https://www.forbes.com/sites/niallmccarthy/2019/08/08/how-us-healthcare-spending-per-capita-compares-with-other-countries-infographic> [<https://perma.cc/EX8V-VKYJ>].

based healthcare system seems a remote possibility.

Fairness in financing relates to universal coverage across different sub-populations in a democracy; it also relates to the way coverage is financed across multiple levels of administration in federalist systems of government. For example, since Canada shifted the financing for its healthcare system to the equivalent of “block grants” to the provinces, inequities between provinces in access to and quality of care have expanded, as well as dissatisfaction among populations within provinces.<sup>114</sup> In November 2019, the Supreme Court of the province of British Columbia heard closing arguments of a years-long case in which private medical clinics challenged a provincial law that disallows charging patients for necessary medical care.<sup>115</sup> If plaintiffs prevail, wealthier patients will be able to pay for faster access to essential services, which has the potential to lure healthcare professionals into private clinics, worsen wait times in the public system and set off a landslide of privatization.<sup>116</sup>

It should be noted that this is not the first time that a plaintiff has—successfully—challenged a prohibition on private health care provision in a Canadian province. In *Chaoulli v Quebec (AG)*,<sup>117</sup> the Supreme Court of Canada struck down Quebec’s law banning private insurance and held that the Quebec Charter of Rights and Freedoms allows for private insurance when the province fails to “provide public health care of a reasonable standard within a reasonable time”, which was directed at the extensive wait times for certain procedures in Quebec’s public healthcare system.<sup>118</sup> The Court held that the ban on private insurance was not justified by the government’s desire to protect the public healthcare system, and listed examples of other countries, such as Germany, Sweden, and the United Kingdom, where it claimed that the availability of private insurance had not eroded the universal healthcare system.<sup>119</sup>

Despite the *Chaoulli* decision, Quebec’s public healthcare system has thus far remained intact without devolving into a two-tiered system, and if we are concerned with decision-making about health and the health system as part of democracy, it is instructive to understand why. Quebec’s provincial legislature produced a moderate response to the ruling, Bill 33, which cabined the impact of

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114. TOBA BRYANT, AN INTRODUCTION TO HEALTH POLICY 151-152 (2009); see also Christel A. Woodward & Catharine A. Charles, *The Changing Faces of Health Care in Canada*, in HEALTH CARE REFORM AROUND THE WORLD 78, 81 (Andrew C. Twaddle ed., 2002).

115. Kelly Grant, *Universal Health Care on Trial: What You Need to Know About a Historic Charter Challenge in B.C.*, GLOBE & MAIL (Nov. 12, 2019), <https://www.theglobeandmail.com/canada/article-universal-health-care-on-trial-what-you-need-to-know-about-a-historic/> [<https://perma.cc/727S-VSXU>].

116. *Id.*

117. *Chaoulli v. Quebec (AG)* [2005] 1 S.C.R. 791 (Can.).

118. *Id.* ¶ 105, 162.

119. *Id.* ¶¶ 142-146.

*Chaoulli* by allowing private insurance to cover only specified “specialized medical treatments” that had the longest wait times in the public system, such as hip replacements and cataract surgeries.<sup>120</sup> However, the provincial government did not allow private insurance for other forms of care available in the public system.<sup>121</sup> Thus, the court decision triggered a democratic dialogue about the relationship between publicly-funded interventions, and the effects on people’s dignity and equality under the Quebec Charter, which resulted in a nuanced solution that allowed for reasonable realization of various dignity and equality interests. In short, organizing a health system around a right to health does not dictate a specific modality of administering health care or precise level of health financing; however, if we understand health to be part of the texture of democracy, financing the health system must reflect equal concern and respect for diverse groups and members of society.

### *B. Fair and Democratic Priority-Setting*

The criteria for considering that an electoral process or due process of law meets constitutional standards in a democracy have been well-established. In health systems, these rules and processes must be related to and justified in terms of dignity and consent, as described in Part I. They also relate to priority-setting processes among competing interests to define entitlements that should be available on a basis of non-discrimination. Just as a right to health is not a right to be healthy, a right to health cannot mean all treatments for everyone. To be clear, as described above, the legitimacy of any given health budget and system financing structure must be adequately justified. Decisions regarding a wide array of issues, from pharmaceutical regulation to reliance on specialist care as opposed to general practitioners, have enormous budgetary consequences, which call for democratic scrutiny. However, failure to acknowledge the need for rationing in much human rights advocacy is actually anti-democratic and unjust; it is akin to accepting that those with power, money, privilege and other sources of status will be the ones who get access to health entitlements. As Norman Daniels argues, because health needs are potentially bottomless, the question for democratic health systems is always, “how can we meet health needs fairly when we cannot meet them all?”<sup>122</sup> That is, there will always be new pathogens, such as COVID-19, as well as new treatments and biotechnologies, together with demographic changes that alter population health needs and priorities.

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120. *See generally* An Act to Amend the Act Respecting Health Services and Social Services and Other Legislative Provisions, S.Q. 2006, c. 43.

121. Yu-Sung Soh, *Shooting from the Hip: The Health of Universal Health Care Following Chaoulli v. Quebec*, THECOURT.CA (Mar. 8, 2007), <http://www.thecourt.ca/shooting-from-the-hip-the-health-of-universal-health-care-following-chaoulli> [<https://perma.cc/Q6X7-3NYB>].

122. NORMAN DANIELS, *JUST HEALTH: MEETING HEALTH NEEDS FAIRLY* 103 (2007).

It is fallacious to act as though progressive achievement of the right to health under international law follows some kind of linear path that can be dictated in the abstract. Indeed, as Daniels notes, unlike in a trial or an election, where the “rules of the game” are widely agreed upon, in health:

[t]here will be reasonable disagreements about how resources can most effectively be used and about what kinds of partial improvements—for example, in access to care—should be emphasized. Decisions about these issues will create winners and losers. Consequently, it is important to establish that all are being treated fairly and that the outcome of the negotiation is perceived as legitimate.<sup>123</sup>

In extending Rawlsian principles of procedural justice as the result of a fair and legitimate process, Daniels argues that accountability for reasonableness in priority-setting requires four conditions: (1) publicity/transparency (which precludes implicit priority-setting based on wait lists and price); (2) decisions made upon relevant reasons (as opposed to ideology, rent-seeking, etc.); (3) revisability in light of new information; and (4) regulation and enforcement of the first three conditions.<sup>124</sup> Here it is important to underscore that procedural fairness can coexist with protected rights. For example, the denial of a life-saving procedure required by women, such as therapeutic abortion, cannot be excluded based upon religious or ideological reasons (“comprehensive moral doctrines” in political philosophy) even if such denials are accepted by a majority of electors.<sup>125</sup>

Consider the most extreme example of rationing ventilators, ICU beds, or dialysis machines during the COVID-19 pandemic. As argued above, not acknowledging the need for rationing is morally and democratically unacceptable. However, the general rule of maximizing the health benefit of a treatment—which accepts that all people have equal dignity—must be done in ways that treat diverse people with equal concern and respect. A democratic health system cannot permit discrimination in information, testing and treatment for COVID-19 on the basis of gender, religion, sexual orientation, disability, race, ethnicity, or—importantly—income or socioeconomic status. Equal concern is also violated if a COVID-19 patient gets care by displacing others with similarly grave or more serious conditions who could benefit more. Moreover, rationing should not be done behind closed doors by “experts.” Taking openly about rationing with people who are affected, including persons who may have pre-existing conditions or certain

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123. *Id.* at 319.

124. *Id.* at 103–39.

125. See generally Seyla Benhabib, *The Embattled Public Sphere: Hannah Arendt, Jürgen Habermas and Beyond*, 44 *THEORIA* 1 (1997).

disabilities, may produce important revisions of policy based on these considerations, such as giving extra priority to the worst off.<sup>126</sup> Indeed, in Massachusetts there was backlash when the public (including disproportionately affected minority populations and persons with disabilities) was not consulted. Revised crisis guidelines were then issued, which at least ensured that priority for critical equipment would only take into account immediate survival probabilities, and not long-term quality or disability-adjusted life measures that could lead to invidious discrimination against persons with certain disabilities.<sup>127</sup>

In crisis situations and “normal” times alike, if we take seriously the connections between health and democracy, the criteria by which health entitlements are defined and ranked cannot be decided exclusively by technocrats behind closed doors.<sup>128</sup> Of course, health professionals (epidemiologists, clinicians and health economists, among others) play a critical role in compiling evidence regarding clinical- and cost-effectiveness; appraising the strength of that evidence; and ensuring health benefit packages are “data driven and evidence-based.”<sup>129</sup> Governments are ultimately responsible for ensuring the legitimacy of the decisions and process. Nonetheless, it is increasingly acknowledged that values and norms are inescapably embedded in every level and aspect of health systems, just as they are in other fundamental social institutions—such as education and justice systems. In a democracy, it would be unacceptable for curricula to be defined or trial outcomes decided without transparency and public input in one way or another. For priority-setting processes to be democratically legitimate as well as scientifically sound, meaningful consultation with those who will have to live by the priorities that are set is essential, as demonstrated even in the most extreme example of crisis triage guidelines during the COVID-19 pandemic.

Indeed, the WHO’s multi-disciplinary Technical Advisory Group on

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126. See Alicia Ely Yamin & Ole F. Norheim, *3 Human Rights Imperatives for Rationing Care in the Time of Coronavirus*, BILL OF HEALTH (March 27, 2020), <https://blog.petrieflom.law.harvard.edu/2020/03/27/rationing-health-care-coronavirus-human-rights> [<https://perma.cc/5F4E-UE9R>]. See also Ole F. Norheim, *Ethical Priority Setting for Universal Health Coverage: Challenges in Deciding upon Fair Distribution of Health Services*, 14 BMC MED., May 11, 2016; Govind Persad, *Why Disability Law Permits Evidence-Based Triage in a Pandemic*, 130 Yale L.J.F. 26 (2020), [https://www.yalelawjournal.org/pdf/PersadForumEssay\\_qk77t52y.pdf](https://www.yalelawjournal.org/pdf/PersadForumEssay_qk77t52y.pdf) [<https://perma.cc/X2RR-73Z8>].

127. See Martha Bebinger, *After Uproar, Mass. Revises Guidelines on Who Gets an ICU Bed or Ventilator Amid COVID-19 Surge*, WBUR (April 22, 2020), <https://www.wbur.org/commonhealth/2020/04/20/mass-guidelines-ventilator-covid-coronavirus> [<https://perma.cc/W83C-UUCF>].

128. For further discussion of democratically legitimate priority-setting, see, for example, WHO CONSULTATIVE GROUP ON EQUITY & UNIVERSAL HEALTH COVERAGE, *MAKING FAIR CHOICES ON THE PATH TO UNIVERSAL HEALTH COVERAGE* (2014); and Maarten P.M. Jansen, Rob Baltussen & Kristine Bævre, *Stakeholder Participation for Legitimate Priority Setting: A Checklist*, 7 INT’L J. HEALTH POL’Y MGMT. 973 (2018).

129. WORLD HEALTH ORG., *PRINCIPLES OF HEALTH BENEFIT PACKAGE DESIGN* (2020).

Principles of Health Benefit Package Design argues that “[a] sound principle is that *all affected parties, all stakeholders and their interests*, should be represented in the process and able to make their voices heard on conditions of rough background equality.”<sup>130</sup> This opportunity for broad and equitable stakeholder input does not only apply to the design and selection of package benefits themselves, but also to the necessarily preceding discussion of what norms and values will shape the criteria that guide the inclusion and exclusion of certain benefits. Indeed, the Advisory Group expressly identifies that “social values play an important role in the selection of benefits” and a “legitimate, fair decision-making process will begin with a transparent and inclusive identification of the criteria in the local setting, with all appropriate stakeholders included in the criteria selection process.”<sup>131</sup>

Concrete examples of processes that increase participatory decision-making include exercises in deliberative polling, which Jane Mansbridge argues has knock-on benefits to democratic engagement in electoral and consultative processes.<sup>132</sup> Further, the National Health Service in Britain makes use of a non-statutory Priorities Committee that “includes NHS clinicians and managers as well as a lay chair, legal advisor, and [lay] ethical advisor, and reviews treatments that local stakeholders submit for consideration.”<sup>133</sup> Health systems can also draw inspiration from structured citizen participation on public issues that are similarly complex. For example, in Toronto, Canada two panels comprised of randomly selected citizens meet every two months over a two-year period to “provide informed inputs on planning or transportation issues.”<sup>134</sup> Finally, democratic engagement with priority-setting in health should not be limited to “official” channels. As the society-wide debates on the issue of abortion in Argentina and Ireland have made clear, social movements play an important role in creating spaces in which social values can be clarified and health policies can be shaped.<sup>135</sup> This activism can have profound results, as in Ireland’s successful referendum to

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130. *Id.* at 4. See also ALL. FOR HEALTH POLICY & SYS. RESEARCH, STRENGTHENING HEALTH SYSTEMS: THE ROLE AND PROMISE OF POLICY AND HEALTH SYSTEMS RESEARCH (2004); Jalil Safaei, *Deliberative Democracy in Health Care: Current Challenges and Future Prospects*, 7 J. HEALTHCARE LEADERSHIP 123 (2015).

131. PRINCIPLES OF HEALTH BENEFIT PACKAGE DESIGN, *supra* note 129, at 4.

132. Jane Mansbridge, *Deliberative Polling as the Gold Standard*, 19 GOOD SOC’Y 55 (2010).

133. MISFORTUNE, *supra* note 20 (quoting Christopher Newdick, *Can Judges Ration with Compassion?—A Priority Setting Matrix*, 20 HEALTH & HUM. RTS. J., June 2018, at 107, 111).

134. See Claudia Chwalisz, *A New Wave of Deliberative Democracy*, CARNEGIE EUROPE (Nov. 26, 2019), [https://carnegieendowment.org/files/10-17-19\\_Chwalisz\\_Deliberative.pdf](https://carnegieendowment.org/files/10-17-19_Chwalisz_Deliberative.pdf) [<https://perma.cc/8ASU-Y9GW>].

135. See *Argentina Abortion: Crowds Gather to Back Pro-Choice Bill*, BBC (May 29, 2019), <https://www.bbc.com/news/world-latin-america-48444884> [<https://perma.cc/8Y52-RRUA>]; *Timeline: Ireland and Abortion*, BBC (May 26, 2018), <https://www.bbc.com/news/world-europe-43962738> [<https://perma.cc/CM8P-RNS4>].

repeal the Constitutional subsection prohibiting most abortions and replacing it with a provision that allowed the legislature to start regulating legal abortion.<sup>136</sup>

Some courts have acknowledged the importance of user participation in a constitutionally legitimate process for designing health benefit packages. Responding to systematic regulatory failure in the health system in the famous T-760/08 decision, the Colombian Constitutional Court ordered the government to comply with its legislated responsibility to conduct a yearly “systematic review” of the obligatory health benefits scheme “with regard to: (1) changes in demographic structure, (2) the national epidemiological profile, (3) appropriate technology available in the country, and (4) the financial conditions of the system.”<sup>137</sup> The Court held the government accountable by setting standards and deadlines for compliance, but left most decisions about priority-setting and resource allocation to the government—albeit with mandated meaningful opportunities for public participation by the scientific community and affected groups.<sup>138</sup>

As discussed further in Section II.E. below, this “dialogical approach” to judicial oversight is consistent with democratic experimentalism, understanding the limits of the Court’s democratic legitimacy in dictating the content of a right to health. As Mark Tushnet has described, “[a] democratic experimentalist court begins with a constitutional principle stated at a reasonably high level of abstraction” and “offer[s] an incomplete specification of the principle’s meaning in a particular context” before asking “legislators and executive officials to develop and begin to implement plans that have a reasonable prospect of fulfilling the incompletely specified constitutional requirement.”<sup>139</sup> Once legislative and executive actors have acted, or at least attempted, to meet constitutional demands, courts engage with the results of that experiment and assess whether the constitutional minimum has been met, and if not, what else is required.<sup>140</sup> This iterative process, a form of weak judicial review, “places into question the assumption that judicial review must involve coercive orders” and can be used

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136. See Ivana Bacik, *Ireland Has Changed Utterly: the Cruel Eighth Amendment is History*, GUARDIAN (May 26, 2018), <https://www.theguardian.com/commentisfree/2018/may/26/ireland-has-changed-utterly-the-cruel-eighth-amendment-is-history> [<https://perma.cc/S4KL-PBL8>]; *History of Abortion in Ireland*, IRISH FAMILY PLANNING ASS’N, <https://www.ifpa.ie/advocacy/abortion-in-ireland-legal-timeline> [<https://perma.cc/2WTU-6SR3>].

137. *English Summary, Judgment T-760/08*, ESCR-NET, [https://www.escri-net.org/sites/default/files/English\\_summary\\_T-760.pdf](https://www.escri-net.org/sites/default/files/English_summary_T-760.pdf) [<https://perma.cc/9AN8-BF5Q>] (quoting Corte Constitucional [C.C.] [Constitutional Court], julio 31, 2008, Sentencia T-760/08 § 6.1.1.1.1, <https://www.corteconstitucional.gov.co/relatoria/2008/t-760-08.htm> [<https://perma.cc/5WR4-NLMD>] [hereinafter T-760/08]).

138. *Id.* (quoting T-760/08, §§ 3.3.9, 4.1.3, 4.4.2, 6.1.3, 6.1.2.2).

139. Mark Tushnet, *New Forms of Judicial Review and the Persistence of Rights – And Democracy-Based Worries*, 38 WAKE FOREST L. REV. 813, 822-23 (2003).

140. *Id.*

effectively to enforce social and economic rights through courts in a way that is still democratically legitimate.<sup>141</sup> Indeed, in practice, the T-760/08 decision fostered a process of structured participation in decision-making in relation to Colombia's health system, which was crucial to a reawakened political debate and the country's adoption of a Statutory Framework Law on Health based explicitly on the right to health in 2015.<sup>142</sup> As discussed below, this form of judicial oversight offers particular promise in the realm of health, where the rules set out by any decision have multifaceted impacts on different stakeholders.

### *C. Health Service Organization and Delivery*

Just as with the organization of electoral and judicial systems, the organization and delivery of services is equally important to the democratic function of a health system. Indeed, they function in synergy. Consider again the example of rationing ventilators, ICU beds, or dialysis machines during the global COVID-19 pandemic.<sup>143</sup> Rationing of patients' access to intensive care at the micro-level is deeply affected by prior decisions and policies regarding health system capacity and function, including allocations of scarce health resources among sub-national areas.

Further, containing transmission rates is inextricably related to testing, contact tracing, and isolation, which depends upon public health and systems that have invested in primary care capacities. Likewise, systems that invest in strengthening primary care capacities are critical for ensuring availability and accessibility of a wide swath of interventions in "normal" times, which cannot be met by systems that focus on specialty and tertiary care.

Under the formulation of the right to health set out by CESCR, the organization of a health system must ensure that health care services are not only available and accessible, but also acceptable and of adequate quality.<sup>144</sup> The organization of a health system affects all of these inter-related elements. For example, accessibility has been interpreted as having several dimensions, including non-discrimination, affordability, accessibility of information concerning health issues, and physical accessibility.<sup>145</sup> Physical accessibility can be further broken down into safe geographic accessibility, especially for

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141. MARK TUSHNET, *WEAK COURTS, STRONG RIGHTS* 228, 249 (2008).

142. *Id.* at 16. *See also* L. 1751, febrero 16, 2015, DIARIO OFICIAL [D.O.] (Colom.); OFFICE OF THE UN HIGH COMM'R FOR HUMAN RIGHTS, *GUIDE FOR THE JUDICIARY ON APPLYING A HUMAN RIGHTS-BASED APPROACH TO HEALTH* 11-12 (2010).

143. *See* James Hamblin, *The Curve is not Flat Enough*, ATLANTIC (Mar. 28, 2020), <https://www.theatlantic.com/health/archive/2020/03/coronavirus-forcing-american-hospitals-ration-care/609004> [<https://perma.cc/QFV7-WW2R>].

144. *General Comment No. 14, supra* note 6, ¶ 12.

145. *Id.* ¶ 12(b).

marginalized populations, as well as physical accessibility of buildings for disabled persons.<sup>146</sup> One local initiative that has worked to foster accessibility in health care is the establishment of Mohalla Clinics in Delhi, which were an integral part of the Aam Aadmi Party’s vision for local democracy. In response to constituents’ public demands, they designed the Mohalla Clinics to increase underserved urban populations’ access to basic health services, without having to travel long distances or pay fees.<sup>147</sup> The results have been stunning: on average, these clinics increased their patients’ average number of healthcare visits per year to 5.6; the average across India is just 1 per year.<sup>148</sup>

In addition to accounting for the rights of diverse patients, the organization of a democratic healthcare system should account for the rights of workers as well. Workers are not cogs in a technical apparatus designed to achieve specific outcomes. Rather, in the same way that due process and equal justice suffer when overworked public defenders cannot provide quality representation to indigent defendants,<sup>149</sup> the healthcare system functions less democratically—and less effectively—when healthcare workers are set up to fail by long hours, low pay, a lack of adequate facilities, and other poor working conditions.<sup>150</sup> We have witnessed this acutely during the COVID-19 crisis, as overworked health workers have faced inadequate safety protections in a number of countries.

In some instances, “human rights-based approaches” to health have not paid

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146. *Id.*

147. Chandrakant Lahariya, *Mohalla Clinics of Delhi, India: Could These Become Platform to Strengthen Primary Healthcare?* 6 J. FAMILY MED. & PRIMARY CARE 1 (2017); Subir Roy, *Mohalla Clinics, A Viable Primary-Care Model*, HINDU BUSINESSLINE (Nov. 28, 2019), <https://www.thehindubusinessline.com/opinion/columns/mohalla-clinics-a-viable-primary-care-model/article30099666.ece> [<https://perma.cc/YL9J-UY9E>]; Sadhika Tiwari, *How the Aam Aadmi Party’s Mohalla Clinics Changed Public Healthcare in Delhi*, SCROLL.IN (Feb. 7, 2020), <https://scroll.in/article/952440/how-the-aam-aadmi-party-s-mohalla-clinics-changed-public-healthcare-in-delhi> [<https://perma.cc/439B-2HFZ>].

148. Tiwari, *supra* note 147.

149. See, e.g., Matt Ford, *A ‘Constitutional Crisis’ in Missouri*, ATLANTIC (Mar. 14, 2017), <https://www.theatlantic.com/politics/archive/2017/03/missouri-public-defender-crisis/519444> [<https://perma.cc/4SCF-FJ4P>]; Oliver Laughland, *The Human Toll of America’s Public Defender Crisis*, GUARDIAN (Sept. 7, 2016), <https://www.theguardian.com/us-news/2016/sep/07/public-defender-us-criminal-justice-system> [<https://perma.cc/59MH-L7NB>]; Pamela Melzger, *Equal Justice Depends on Properly Funding Public Defenders*, HILL (May 22, 2019), <https://thehill.com/opinion/criminal-justice/444588-equal-justice-depends-on-properly-funding-public-defenders> [<https://perma.cc/DJT3-2P7R>].

150. See, e.g., Ryan Cronk & Jamie Bartram, *Environmental Conditions in Health Care Facilities in Low- and Middle-Income Countries: Coverage and Inequities*, 221 INTL. J. HYGIENE & ENVTL. HEALTH 409 (2018); Jack Needleman et al. *Nurse-Staffing Levels and the Quality of Care in Hospitals*, 22 NEW ENGL. J. MED. 1715 (2002); Roni Jacobson, *Widespread Understaffing of Nurses Increases Risk to Patients*, SCI. AM. (July 14, 2015), <https://www.scientificamerican.com/article/widespread-understaffing-of-nurses-increases-risk-to-patients> [<https://perma.cc/38JJ-U7ET>].

sufficient attention to the rights of health workers, or to systemic issues. For example, maternal death reviews—which have been touted as a “human rights-based approach” to accountability for maternal deaths<sup>151</sup>—more likely than not scapegoat health workers with little control over the circumstances of a woman’s death, while systemic issues, such as supply chain problems, are left unaddressed. Punitive treatment of health workers invariably affects the treatment of patients as well. Indeed, it is simply impossible to create and sustain democratic health systems without recognizing health workers’ rights to safe and respectful work environments and adequate compensation. In a positive development, in December 2019, Uruguay became the first country in the world to ratify ILO Convention 190 on Violence and Harassment,<sup>152</sup> which recognizes that in addition to impacting women’s health in myriad ways, sexual harassment also “affects the quality of public and private services.”<sup>153</sup> A potential effect of the current pandemic could be to raise much needed consciousness of how the health rights of patients are interdependent on the rights of healthcare providers and other nonclinical workers in healthcare settings.

#### *D. Information to be Active Citizens Regarding Health*

Conceiving of health in terms of rights, and health systems as democratic institutions, immediately makes apparent that people are not just passive patients or targets of health policies and programming; they should be treated as informed and active participants in both personal and policy decisions with respect to health and their health systems. As noted in Section II.C., the availability and accessibility of information is listed as an inter-related element of the right to health in CESCR General Comment 14, including “the right to seek, receive and impart information and ideas concerning health issues.”<sup>154</sup> In Article 14(2)(b), CEDAW mandates that states must ensure that even women in rural areas “have access to adequate health

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151. Paul Hunt, *Rep. of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Health*, Paul Hunt, *Addendum 2: Mission to India*, U.N. Doc. A/HRC/14/20/Add.2 ¶¶ 71-74 (Apr. 15, 2010); Office of the UN High Comm’r for Human Rights, *Technical Guidance on the Application of a Human Rights-Based Approach to the Implementation of Policies and Programmes to Reduce Preventable Maternal Morbidity and Mortality*, U.N. Doc. A/HRC/21/22 ¶ 75(c) (July 2, 2012).

152. *Uruguay is the First Country in the World to Ratify ILO Convention 190*, PUB. SERV. INT’L (Dec. 18, 2019), <https://publicservices.international/resources/news/uruguay-is-the-first-country-in-the-world-to-ratify-ilo-convention-190?id=10498&lang=en> [<https://perma.cc/9UV9-5DSP>]. Following the second ratification by Fiji on June 25, 2020, the convention will enter into force in 2021. *ILO Violence and Harassment Convention Will Enter into Force in June 2021*, INT’L LABOR ORG. (June 25, 2020), [https://www.ilo.org/global/about-the-ilo/newsroom/news/WCMS\\_749148/lang--en/index.htm](https://www.ilo.org/global/about-the-ilo/newsroom/news/WCMS_749148/lang--en/index.htm) [<https://perma.cc/Y4PP-QLUT>].

153. Convention Concerning the Elimination of Violence and Harassment in the World of Work, *adopted by the International Labor Organization June 21, 2019*, 58 I.L.M. 1170 pmb1.

154. *General Comment No. 14*, *supra* note 6, ¶ 12(b).

care facilities, including information, counselling and services in family planning.”<sup>155</sup> Elaborating on this duty to ensure that health information is accessible, in General Recommendation 34 on the Rights of Rural Women, the CEDAW Committee specifies that states parties should ensure:

[t]hat health-care information is widely disseminated in local languages and dialects through various media, including in writing, through illustrations and orally, and that it includes information on, inter alia: hygiene; preventing communicable, non-communicable and sexually transmitted diseases; healthy lifestyles and nutrition; family planning and the benefits of delayed childbearing; health during pregnancy; breastfeeding and its impact on child and maternal health; and the need to eliminate violence against women, including sexual and domestic violence and harmful practices.<sup>156</sup>

Ensuring the right to health requires broad accessibility and availability of information, in terms of both form and content.

Courts have consistently played a role in ensuring protection against insufficient and misleading information about health. For example, the European Court of Human Rights has recognized the importance of having sufficiently clear—medical and legal—information to effectively challenge a healthcare decision. In *Tysiac v. Poland*, Ms. Tysiac was denied a legal abortion by her doctor, despite evidence that pregnancy could cause irreparable damage to her vision.<sup>157</sup> The Court found that Poland had violated Ms. Tysiac’s right to privacy under article 8 of the European Convention on Human Rights by providing no clear legal mechanism by which she could challenge her doctor’s denial of a medically necessary abortion, and no requirement for doctors to provide accessible, documented reasons upon which the challenge could be based.<sup>158</sup> The Court emphasized that a proper framework needs to “ensure clarity of the pregnant woman’s legal position” with regard to the abortion she is seeking.<sup>159</sup> In a later case, the European Committee on Social Rights recognized that the requirement of accessible and accurate information does not only apply in the context of individual health decisions, but also more broadly, in its holding that sexual health education including discriminatory and incorrect information about LGBTIQI

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155. CEDAW, *supra* note 39.

156. Comm. on the Elimination of Discrimination Against Women, *General Recommendation No. 34 (2016) on the Rights of Rural Women* ¶ 39(f), U.N. Doc. CEDAW/C/GC/34 (2016).

157. *See generally* *Tysiac v. Poland*, 2007-I Eur. Ct. H.R. 219.

158. *Id.* ¶¶ 114-135.

159. *Id.* ¶ 116.

sexual health violates the right to health under the European Social Charter.<sup>160</sup> If health and health systems are democratic social institutions, the right to information must then be understood not in a narrow instrumental way but broadly, as fundamental to the legitimate authority of a democratic government.

For health to be treated as a matter of democracy, people need to be enabled to participate meaningfully not just in decisions that affect their own health, and in priority-setting, as discussed above. In a pandemic and in normal times, diversely situated people also need to be able to see how government policies are rationally related to, and justifiable in terms of, protecting public health. Such policies also include the regulation of private actors. For example, a United States Court of Appeals decision found that Philip Morris USA, a cigarette manufacturer, engaged for decades “in a scheme to defraud smokers and potential smokers” by denying various adverse health effects of smoking and second-hand smoke.<sup>161</sup> While this case was not framed in terms of the right to health, many of the remedies were fashioned to provide consumers with health information they should have had all along, including providing corrective statements, disclosing marketing data, and publishing all previously withheld health research on the company website.<sup>162</sup>

Similarly, the use of algorithms to govern our lives has been increasingly questioned as highly undemocratic.<sup>163</sup> Nowhere is this more evident than in the potential effects on population health, where algorithms are now deployed to make distributive decisions within domestic welfare systems and public health interventions. If the value of democracy lies in establishing a “republic of reasons,”<sup>164</sup> it requires more than the black box assessments that algorithms offer. Rather, it requires some mechanism for providing those affected by algorithm-informed choices with a meaningful opportunity to shape the normative framing of the issue, values, and assumptions that are inherently built into the algorithm. For example, in terms of framing, Philip Alston has written about how the digitization of welfare, while presented as a benign and efficient update to existing systems, broadly facilitates “a move towards a detached bureaucratic process” that puts the onus on the citizen to meet technical eligibility requirements.<sup>165</sup> This

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160. *Interights v Croatia*, Complaint No. 45/2007, ¶¶ 60–61 (Eur. Comm. Soc. Rights Apr. 9, 2009), <http://hudoc.esc.coe.int/eng/?i=cc-45-2007-dmerits-en> [<https://perma.cc/2BNL-Q3KZ>].

161. *United States v. Philip Morris USA, Inc.*, 449 F. Supp. 2d 1, 852 (D.D.C. 2006), *aff'd on this issue*, 566 F.3d 1095 (D.C. Cir. 2009).

162. *Id.*

163. See, e.g., Ben Green, *The Responsible City: Avoiding Technology's Undemocratic Social Contracts*, in *THE SMART ENOUGH CITY* (2019), available at <https://smartenoughcity.mitpress.mit.edu/pub/yvyv9j2i/release/1>; Henry A. Giroux, *Totalitarian Paranoia in the Post-Orwellian Surveillance State*, 29 *CULTURAL STUD.* 108 (2015); David Lyon, *State and Surveillance*, *CTR. FOR INT'L GOVERNANCE INNOVATION*, <https://www.cigionline.org/articles/state-and-surveillance> [<https://perma.cc/FZF8-ZZ7W>].

164. CASS R. SUNSTEIN, *DESIGNING DEMOCRACY: WHAT CONSTITUTIONS DO* 239 (2001).

165. Philip Alston, *What the “Digital Welfare State” Really Means for Human Rights*, *OPEN*

conceptualization of individuals as “applicants” rather than “rights-holders” flips the presumption that undergirds the exercise of human rights, as “[i]nstead of the State being accountable to the citizen for ensuring an adequate standard of living for all, the burden of accountability is now on the citizen to demonstrate that he or she is somehow deserving.”<sup>166</sup>

Moreover, algorithmic assessments of who is deserving of assistance can reinforce existing biases and power imbalances. Algorithms may not inherently be biased, but often the end up that way due to the unexamined assumptions of the people and organizations that design and implement them. The exploding use of algorithms in health is particularly dangerous because it invisibly *institutionalizes* these biases and cloaks them in a veneer of scientific legitimacy. One well-publicized example involved a widely used risk-prediction tool in the United States,<sup>167</sup> which was used to identify at-risk patients who need additional healthcare intervention.<sup>168</sup> The tool used cost of care as a proxy for the patient’s need, despite the fact that “unequal access to care means that we spend less money caring for Black patients than for White patients.”<sup>169</sup> The result of this imbalance was that the algorithm failed to identify nearly 30% of cases where extra intervention was warranted for Black patients—therefore not only failing these individual patients, but reinforcing a cycle in which Black patients systemically receive less care.<sup>170</sup> In short, a democratic health system’s determination regarding the contours of health entitlements should not only be able to justify the decisions, but also the reasons for those decisions.

#### *E. Oversight: Regulation and Remedies*

As suggested throughout this Article, if we understand health systems to embed normative values, then in order to meet democratic standards, health system standards and procedures require not just technical oversight but also regulatory and judicial oversight, to ensure they are consistent with normative commitments set out in legal frameworks. In all of the cases mentioned above, whether financing a sexual reassignment surgery or allowing private providers to offer certain non-essential health services, courts can play important roles in subjecting decisions in

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GLOB. RIGHTS (Jan. 8, 2020), <https://www.openglobalrights.org/digital-welfare-state-and-what-it-means-for-human-rights> [<https://perma.cc/NH87-CCGE>].

166. *Id.*

167. This tool was applied to approximately 200 million patients annually. See Ziad Obermeyer, Brian Powers, Christine Vogeli & Sendhil Mullainathan, *Dissecting Racial Bias in an Algorithm Used to Manage the Health of Populations*, 366 SCI. 447, 448 (2019).

168. *Id.*

169. *Id.*

170. See *id.*; see also Milena A. Gianfrancesco, Suzanne Tamang, Jinoos Yazdany & Gabriela Schmajuk, *Potential Biases in Machine Learning Algorithms Using Electronic Health Record Data*, 178 JAMA INTERNAL MED. 1544 (2018).

health to scrutiny in line with constitutional or international human rights commitments.

In addition to protecting democratically justified decisions, courts can spur public learning regarding constitutional and human rights commitments by taking normative arguments seriously and making visible concerns of often marginalized groups.<sup>171</sup> According to Keith Syrett, courts' decisions have the ability to strengthen the public legitimacy of necessary rationing in the health system:<sup>172</sup>

The provision of reasons for decisions therefore enables judges to offer an explanation to (and thus to educate) both the losing side and the wider public in terms which meet the conditions of reciprocity: that is, those which "fair-minded people" seeking social co-operation can recognise as valid and germane in the light of principles and ideals which they endorse as rational, even if they may disagree on the conclusion reached in the instant case. In this manner, the practice of judicial reason-giving may contribute to legitimacy either through acceptance of the validity of the reasons offered or, more indirectly, through its impact as a stimulus for a further process of public deliberation which can provide the conditions through which such legitimacy may be secured.<sup>173</sup>

Thus, court intervention into health systems need not be seen as a threat to those systems—rather, courts can play an "instrumental" or "facilitative" role, by "channeling and guiding decision-making processes" and "diagnosing and addressing institutional and/or systemic problems and weaknesses."<sup>174</sup> For example, as in the case in Kenya discussed above in which women were detained postpartum at the hospital because they could not pay their medical bills, a court holding that their human rights were violated provides a signal to the legislature that healthcare cannot be left entirely to market forces. Rather, it must be organized in a more principled way to meet human rights requirements. Indeed, as the right to health is inherently complex—due both to the "spiderweb-like effects" of health decisions, as Lon Fuller described,<sup>175</sup> and to the uncertainty regarding what the

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171. Roberto Gargarella, *Dialogic Justice in the Enforcement of Social Rights: Some Initial Arguments*, in *LITIGATING HEALTH RIGHTS: CAN COURTS BRING MORE JUSTICE TO HEALTH?* 232, 242 (Alicia Ely Yamin & Siri Gloppen eds., 2011).

172. KEITH SYRETT, *LAW, LEGITIMACY AND THE RATIONING OF HEALTH CARE: A CONTEXTUAL AND COMPARATIVE PERSPECTIVE* 136 (2007).

173. *Id.* at 156.

174. *Id.* at 127, 135, 157.

175. See Lon L. Fuller, *The Forms and Limits of Adjudication*, 92 *HARV. L. REV.* 353, 395 (1978).

right to health entails—this facilitative role is essential.

Further, if we are concerned with strengthening links between democracy and health, even individual protection writ remedies (e.g., *amparos* and *tutelas* in Latin America) should seek to catalyze and reinforce legitimate priority-setting and regulation, rather than substitute judicial judgment in *ad hoc* ways. In such mixed common and civil law jurisdictions, the accumulation of protection writ cases regarding clusters of complaints allows courts to address regulatory and compliance gaps, and to ensure the priority-setting processes conform to democratic principles.

Likewise, in structural matters, courts can supplement rather than supplant political discussion regarding health by “set[ting] the boundaries of a political decision, or provid[ing] politicians with criteria about basic constitutional demands—criteria to be taken into account by the legislators in their decisions.”<sup>176</sup> As Robin West has written, “[t]he pinnacle moment of ordinary legalism is not the trial . . . it is the legislative process” through which a shared commitment to certain legal ends is made.<sup>177</sup> Courts can thus also intervene to address structural problems that legislators systematically fail to address, such as environmental issues and the health rights of marginalized minorities.<sup>178</sup> Indeed, this is what occurred in the Mexican Supreme Court’s abortion decision—after holding that the denial of abortion services discriminatorily deprived only women of an essential health service, the court instructed Mexican sub-national states to take up an issue that had previously been ignored, and to design and implement “policies aimed at providing women with access to a full range of high-quality and affordable health care, including sexual and reproductive healthcare services.”<sup>179</sup>

Courts can also play this democratically legitimate role with public health conditions beyond care, which tend to be equally polycentric and spiderweb-like. For example, in *Beatriz Silvia Mendoza y Otros c. Estado Nacional y Otros*, the Argentine Supreme Court addressed extreme the environmental pollution of the Matanza/Riachuelo River and the ensuing health impacts, and presided over a resulting mega “Clean-Up Plan” undertaken by the government defendants.<sup>180</sup> The Court set forth three goals: (1) improving the river basin inhabitants’ quality of life; (2) restoring the environment; and (3) preventing reasonably foreseeable harm, including to health. In its follow-up, the Court established highly complex reporting and compliance requirements on a variety of issues, including public

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176. Gargarella, *supra* note 171, at 239.

177. Robin West, *Reconsidering Legalism*, 88 MINN. L. REV. 119, 154 (2003).

178. *Id.*

179. Amparo en Revisión 1388/2015, *supra* note 43, ¶ 104 (¶ 59 in the translation).

180. Corte Suprema de Justicia de la Nación [CSJN] [National Supreme Court of Justice], 8/7/2008, “Beatriz Silvia Mendoza y Otros c. Estado Nacional y Otros / daños y perjuicios,” Fallos de la Corte Suprema de Justicia de la Nación [Fallos] (2008-331-1622).

information, industrial pollution, landfill clean-up, sanitation, and emergency health plans. In the process, the Court engaged technical experts and emphasized the importance of strengthening citizen participation in the monitoring, but like that in T-760/08, it left the exact methods for compliance to the government's discretion. Notwithstanding the unwieldy challenge of overseeing government compliance, ten years later there were notable, if slow, improvements, including the removal of 1,500 tons of solid waste from the river, the construction of 14 health centers, the development of sewage plans, and relocation of 122 families out of high-risk zones near the river.<sup>181</sup> It also led to the establishment of a new oversight mechanism, ACUMAR, and to sustained citizen engagement in a structured participation process for making decisions that affect residents' lives and well-being.<sup>182</sup> The *Mendoza* case, as others, demonstrates that courts can play a catalytic role in spurring democratic action regarding health issues, rather than instituting top-down solutions: "if the law is to bind [the people] as free men and women, they must also be its makers."<sup>183</sup>

Needless to say, in health, just as in other fields, complex structural remedies do not catalyze democratic deliberation automatically—they call for participatory follow-up, together with significant independent authority and a robust mandate for the court. A 2001 case from the African Commission on Human and Peoples' Rights reveals the outcome when ongoing oversight processes are absent. The case alleged severe environmental degradation and resulting health harms in the Ogoniland area of Nigeria from the activities of oil corporations.<sup>184</sup> The Commission called on Nigeria to provide "meaningful access to regulatory and decision-making bodies [for] communities likely to be affected by oil operations" but had no ability to meaningfully monitor state implementation of and compliance with the decision.<sup>185</sup> As a result of the lack of a compliance structure, as well as

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181. Fabiana Frayssinet, *It Takes More than Two to Tango — or to Clean up Argentina's Riachuelo River*, IPS NEWS (Aug. 13, 2014), <http://www.ipsnews.net/2014/08/it-takes-more-than-two-to-tango-or-to-clean-up-argentinias-riachuelo-river> [<https://perma.cc/5QPH-QNZH>].

182. *Mendoza Beatriz Silva et al. vs. State of Argentina et al. on damages (damages resulting from environmental pollution of Matanza/Riachuelo river)*. File M. 1569. XL, ESCR-NET (Jan. 2, 2019), <https://www.es-cr-net.org/caselaw/2011/mendoza-beatriz-silva-et-al-vs-state-argentina-et-al-damages-damages-resulting> [<https://perma.cc/T9WH-HBMT>].

183. Michael Walzer, *Philosophy and Democracy* 9 POL. THEORY 379, 383 (1981).

184. Soc. & Econ. Rights Action Ctr. v. Nigeria, Comm'n No. 155/96 (Afr. Comm'n on Human & Peoples' Rights Oct. 27, 2001), <https://www.achpr.org/sessions/descions?id=134> [<https://perma.cc/9FWK-BM65>].

185. *Id.* Estimates by the Centre for Human Rights in Pretoria suggest that "in 2004-2005 approximately 34-35% of the ACHPR's recommendations had been implemented" and that the Commission's limited follow-up procedures stem from a lack of funding. *Follow-Up and Implementation of Decisions by Human Rights Treaty Bodies*, HUMAN RIGHTS IMPLEMENTATION CTR., UNIV. OF BRISTOL LAW SCH. 6-7 (2009), <http://www.bristol.ac.uk/media-library/sites/law/migrated/documents/semrep2009.pdf> [<https://perma.cc/4466-G45N>] [hereinafter *Follow-Up and Implementation*].

the refusal of corporate giant Shell to take any action in relation to its oil-producing activities in Ogoniland, severe environmental and health degradation in the area has continued.<sup>186</sup> Importantly, this lack of an effective compliance structure is not a problem unique to the African human rights system—it is present to some degree in all regional human rights systems, as well as UN treaty-monitoring bodies,<sup>187</sup> suggesting challenges for trying to use supranational bodies to catalyze systemic change.

In short, in this section we have posited that if addressing disagreements among a diverse population is *the principal* challenge of the democratic state, there is no area in which such disagreements have more immediate—indeed, often life-and-death—consequences than in health, and these disagreements are played out in health systems, as well as in the policies that affect health. Understanding the right to health as connected to the negotiation of competing claims and interests through democratically legitimate processes significantly shifts the focus of progressive achievement of the right to health. Progressive realization must entail institutionalizing processes that provide choice situations that both continually evolve in light of changing demographics, technologies, and epidemiology, and also reinforce norms of equality and solidarity. Here we have argued that taking seriously the connection between rights claims and the role of health systems as democratic social institutions has implications for how laws structure health

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186. *Shell and Nigeria Have Failed on Oil Pollution Clean-Up, Amnesty Says*, GUARDIAN (Aug. 4, 2014), <https://www.theguardian.com/environment/2014/aug/04/shell-nigeria-oil-pollution-clean-up-amnesty> [<https://perma.cc/2BF3-6WLA>].

187. In the Inter-American system, “between 2001 and 2006, the [Inter-American] Commission reported full compliance with its decisions in only 5.3% of cases” while the Inter-American Court reported full compliance in only “11.57% of judgments.” *Follow-Up and Implementation*, *supra* note 185, at 9. In contrast, the European Court of Human Rights has a “long-standing, formal and well-documented” follow-up procedure which involves the “Committee of Ministers,” a body which meets four times per year for the sole purpose of documenting state action taken to comply with judgments. The Committee keeps state judgments on its docket and continues to seek state redress until full compliance is achieved, and publishes its findings after each meeting. However, despite this relatively effective follow-up procedure for individual cases, the existence of “repetitive cases” being brought against certain member states indicates that the European Court’s follow-up procedures are not necessarily resolving systemic problems within the offending states. *Id.* at 11–12.

Some treaty-monitoring and supranational bodies also have follow-up procedures to guide state implementation of human rights decisions, but like the regional procedures, tend to be unable to enforce full compliance. The UN Human Rights Committee that oversees compliance with the International Covenant on Civil and Political Rights (ICCPR) uses a “grading” system to determine how well a defendant state has implemented the Committee’s “Communications” (decisions) on individual complaints brought under the First Optional Protocol to the ICCPR. The committees charged with enforcing other UN treaties, including CRPD, CEDAW, ICESCR, and the Convention Against Torture, use similar, yet not identical grading systems. However, not only do the committees lack any actual enforcement power, but the actual grades given to states being monitored are not sufficiently disseminated to human rights advocates and communities. See Vincent Ploton, *The Implementation of UN Treaty Body Recommendations*, 14 SUR: INT’L J. HUM. RTS., Jul. 2017, at 219.

system financing, priority-setting processes, and health service organization and delivery, and guarantee information regarding health. It also makes apparent the need for judicial oversight to catalyze and reinforce democratic commitments to equal moral consideration in health systems.

### III. HEALTH AND DEMOCRACY IN A GLOBALIZED WORLD

It might seem counterintuitive to argue that health is a matter of democracy and at the same time suggest that obligations go beyond borders and transcend the state-citizen dyad. Yet perhaps the most obvious lesson of the COVID-19 pandemic is that diseases do not respect borders, and states' obligations to protect the security of their inhabitants must adjust to that fact. Likewise, diseases do not respect taxonomies of access to entitlements based upon legal citizenship. And beyond the current pandemic, treating the right to health as fundamental to liberal democracies calls for rewriting the narrative of who is entitled to assets of democratic inclusion and reconsidering the nature of shared national-global health governance. As Jennifer Prah Ruger has argued, such a model of shared health governance "differs from the technocratic model in understanding that political legitimacy involves normative reasoning and public deliberation."<sup>188</sup> Shared health governance is "based on a genuine commitment among global health actors to achieve health justice as opposed to pursuing narrow self, group, or state interest alone,"<sup>189</sup> through the sharing of resources, accountability, and most importantly, power.<sup>190</sup> Here we consider how in a global context of massive migration and forced displacement,<sup>191</sup> democracies must account for more liminal forms of citizenship in access to health entitlements and consider the claims of people beyond borders whose health is affected by the actions of a state or by actors under the state's effective control.<sup>192</sup>

#### *A. Migrants*

Patricia Illingworth and Wendy E. Parmet have argued that neither of the two theories of citizenship typically offered by legal scholarship "provides an adequate justification for the denial of health-related rights" to migrants.<sup>193</sup> First, they argue

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188. JENNIFER PRAH RUGER, *GLOBAL HEALTH JUSTICE AND GOVERNANCE* 366 (2018).

189. *Id.* at 145.

190. *Id.* at 167–70.

191. Adrian Edwards, *Forced Displacement at Record 68.5 Million*, UNHCR: UN REFUGEE AGENCY (June 19, 2018), <https://www.unhcr.org/news/stories/2018/6/5b222c494/forced-displacement-record-685-million.html> [https://perma.cc/F8XP-G8B6].

192. ETO CONSORTIUM, *MAASTRICHT PRINCIPLES ON EXTRATERRITORIAL OBLIGATIONS OF STATES IN THE AREA OF ECONOMIC, SOCIAL AND CULTURAL RIGHTS* (Sep. 28, 2011) [hereinafter *MAASTRICHT PRINCIPLES*].

193. PATRICIA ILLINGWORTH & WENDY E. PARMET, *THE HEALTH OF NEWCOMERS* 170–71

that the ascriptive, or legal, theory of citizenship—as “something that attaches to people as a result of an innate status, such as birth in a territory or membership in a distinct demographic group”—is tautology, providing no justification for why any particular status that endows citizenship should also automatically determine health rights.<sup>194</sup> The second theory of citizenship, the consent view, is more logically and morally defensible, but still inconsistent with the denial of health rights to non-legal citizens, because social citizens do “demonstrate their consent to membership in the nations to which they have immigrated” in many different ways.<sup>195</sup> These include working (often in “necessary jobs, such as caretaking for the ill, that citizens abjure”); paying taxes; and engaging in volunteer work or political activism.<sup>196</sup> Starkly divergent choices with respect to immigrants’ inclusion in U.S. democracy, as Tiffany Joseph has identified, are illustrated by the express exclusion of many non-legal citizens from the Federal Patient Protection and Affordable Care Act (ACA) versus their inclusion in Massachusetts’ 2006 health care reforms (which ironically served as a model for the ACA).<sup>197</sup> The Massachusetts healthcare system has a larger immigrant population than the national average, yet recognizes a broader category of immigrants that have consented to be part of its “civic community” than the ACA.<sup>198</sup>

Importantly, immigrants’ rights to health can also be indirectly violated even if health care is available but practical barriers inhibit access to services. In *Defence for Children International (DCI) v. Belgium*,<sup>199</sup> the European Committee of Social Rights—charged with interpreting and monitoring compliance with the European Charter of Social Rights—addressed the failure of Belgium to enforce its laws providing for the reception of unaccompanied foreign minors into observation and guidance centres where they could theoretically receive support and material assistance. The committee noted “the total lack—since 2009—of reception facilities for accompanied foreign minors and the partial lack of such facilities for unaccompanied foreign minors, leading some of them to live in the street, makes it difficult for foreign minors unlawfully in the country to access the health system.”<sup>200</sup> The committee connected the state’s failure to ensure that

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(2017).

194. *Id.* at 170–71.

195. *Id.* at 173.

196. *Id.*

197. See Tiffany D. Joseph, *What Health Care Reform Means for Immigrants: Comparing the Affordable Care Act and Massachusetts Health Reforms*, 41 J. HEALTH POL. POL’Y & L. 101 (2016).

198. *Id.* at 104, 111.

199. *Defence for Children International (DCI) v. Belgium*, Complaint No. 69/2011 (Eur. Comm. Soc. Rights Oct. 23, 2012), <http://hudoc.esc.coe.int/eng?i=cc-69-2011-dmerits-en> [<https://perma.cc/9SQE-BB4U>].

200. *Id.* ¶ 116.

migrant children were not living on the street, with poor access to health care. Thus, the committee found a violation of the right of access to health care under Article 11, Section 1 of the European Social Charter, first finding that failing to apply Article 11, Section 1 to unlawfully present minors “would mean not securing their right to the preservation of human dignity and exposing the children and young persons concerned to serious threats to their lives and physical integrity.”<sup>201</sup> In turn, the committee held that “providing foreign minors with housing and foster homes is a minimum prerequisite for attempting to remove the causes of ill health among these minors (including epidemic, endemic or other diseases)” and that Belgium had failed to meet this obligation.<sup>202</sup>

*B. Transnational Drivers of Health, and Extraterritorial Obligations (ETOs)*

It is not just infectious diseases that cross borders and cause ill-health. In today’s world many determinants of health and structures of health systems lie in transnational space. The Lancet–University of Oslo Commission on Global Health Governance dubbed the “norms, policies, and practices that arise from transnational interaction” the “political determinants of health,” which “cause and maintain health inequities.”<sup>203</sup> Transnational obligations relating to health do not relate only to the health of migrants, but can apply extraterritorially as well.<sup>204</sup> Under international human rights law, there are obligations of “assistance and cooperation, especially economic and technical” to facilitate national states progressively realizing the right to health, as well as all other economic and social rights.<sup>205</sup>

A number of scholars have emphasized the importance of the financial aspect of these obligations. Perhaps most notably, Gorik Ooms and Rachel Hammonds have argued in a number of papers to the effect that “[w]ithout international obligations to provide assistance—without global responsibility, that is—the right to health is not a right but a privilege reserved for those who are born outside of the world’s poorest countries.”<sup>206</sup> Ooms and Hammonds further suggest that rich countries could satisfy this obligation of international cooperation and assistance by apportioning no more than 0.1% of their GDP to international health assistance,

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201. *Id.* ¶ 102.

202. *Id.* ¶ 117.

203. Ole P. Ottersen et al., Lancet–Univ. of Oslo Comm’n on Glob. Governance for Health, *The Political Origins of Health Inequity: Prospects for Change*, 383 LANCET 630 (2014).

204. MAASTRICHT PRINCIPLES, *supra* note 192.

205. ICESCR, *supra* note 6, art. 2, ¶ 1.

206. Gorik Ooms & Rachel Hammonds, *Taking up Daniels’ Challenge: The Case for Global Health Justice*, 12 HEALTH & HUM. RTS., June 2010, at 29, 36; *See also* Lawrence O. Gostin & Eric A. Friedman, *Towards a Framework Convention on Global Health: A Transformative Agenda for Global Health Justice*, 13 YALE J. HEALTH POL’Y L. & ETHICS 1 (2013).

to assist lower-income countries to realize the “core content” of the right to health.<sup>207</sup> Obligations of assistance and cooperation are fundamental to support countries with limited resource capacities in achieving functional health capacities, as is the recognition of and support for global public goods in health, such as an eventual vaccine for COVID-19.

However, the linkage that we have been constructing in these pages between health and democracy suggests examining more closely the underlying structural requirements that make the reapportionment of finances in sustainable and needs-based ways dependent on the level of democratic solidarity between governmental units. For example, reapportioning finances is done within the United States, where the federal government routinely apportions tax revenue among states through grants, to entice certain states to fulfill federal objectives with regard to issues like education, social security, and health care.<sup>208</sup> Indeed, the federal matching rate for Medicaid is higher in states with lower per capita income,<sup>209</sup> indicating that richer states’ resources are being redistributed to some degree to pay for the Medicaid needs of poorer states.<sup>210</sup> Currently, West Virginia, Kentucky, and Mississippi have some of the highest federal funding shares for Medicaid—with the federal government paying between 75% and 80% of the cost of the program in each of these states—and are all also among the ten states that consistently have the lowest GDP per capita in the country.<sup>211</sup> Similarly, within the European Union (EU), wealthier countries subsidize public investment in poorer countries mainly through the EU’s Cohesion Policy, which accounts for nearly one-third of the EU’s budget, or €355.1 billion between 2014–2020.<sup>212</sup> As part of that policy, the EU is targeting

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207. Ooms & Hammonds, *supra* note 206, at 41. Here, Ooms and Hammonds suggest that this framework for international assistance would stretch only to “core content,” and after the minimum core content is reached in lower-income countries, richer countries could then revert to prioritizing the domestic obligation to meet the highest attainable standard of health. *Id.* at 36. However, they use the formulation of “core content” in CESCR’s *General Comment No. 14*, which, as discussed above in Section II.C, includes a host of social determinants and may swallow up many other rights. See *General Comment No. 14*, *supra* note 6, ¶ 16.

208. CTR. ON BUDGET & POLICY PRIORITIES, FEDERAL AID TO STATE AND LOCAL GOVERNMENTS (April 19, 2018), <https://www.cbpp.org/sites/default/files/atoms/files/policybasics-federalaid.pdf> [<https://perma.cc/A2XD-7N9B>].

209. Robin Rudowitz, Kendal Orgera & Elizabeth Hinton, *Medicaid Financing: The Basics*, KAISER FAMILY FOUND. (Mar. 21, 2019), <http://files.kff.org/attachment/Issue-Brief-Medicaid-Financing-The-Basics> [<https://perma.cc/6GBH-MLN7>].

210. John Tierney, *Which States Are Givers and Which Are Takers?* ATLANTIC (May 5, 2014), <https://www.theatlantic.com/business/archive/2014/05/which-states-are-givers-and-which-are-takers/361668> [<https://perma.cc/Y7CE-BUA2>].

211. KAISER FAMILY FOUND., FEDERAL AND STATE SHARE OF MEDICAID SPENDING (2018), <https://www.kff.org/medicaid/state-indicator/federalstate-share-of-spending> (*last visited* June 26, 2020); *Per Capita Real GDP by State (Chained 2012 Dollars)*, BUREAU OF ECON. ANALYSIS, <https://www.bea.gov/data/gdp/gdp-state> (*last visited* June 26, 2020).

212. *The EU’s Main Investment Policy*, EUROPEAN COMMISSION, [https://ec.europa.eu/regional\\_policy/en/funding/cohesion-fund](https://ec.europa.eu/regional_policy/en/funding/cohesion-fund) [<https://perma.cc/SLY9-PHGZ>].

€63.4 billion over that same time period to member states with per capita GNIs less than 90% of the EU average through the Cohesion Fund, in order to reduce economic and social disparities and promote development.<sup>213</sup> Beneficiaries include Poland, Hungary, Greece, Romania, Bulgaria, and Portugal.<sup>214</sup>

These may be radically insufficient in practice. But what is crucial to recognize is that the above examples of transfers between locations do not occur merely due to coincidentally proximate geographic boundaries; they are unions tied together by some version of a social contract. States within the United States, or to a lesser extent members of the European Union, do not tend to frame their contributions as obligations of charitable assistance; these exchanges are mutually beneficial and are in fact constitutive of the political and economic communities to which the states belong. Indeed, the current “assistance” framing of the international legal obligation of rich countries to assist poor countries in realizing the right to health (and other ESC rights) constrains development of such a social contract in at least two ways. First, wealthy nations are able to sidestep their first and primary obligation to “do no harm,” and refrain from in any way undermining poorer nations’ efforts to realize the right to health. Second, the framing of these obligations in terms of *foreign affairs* and *aid* tends to remove the substantive issues from the domestic political realm in both donor and recipient states, making governments less accountable to their constituents.<sup>215</sup>

More broadly, a focus on “assistance” and “aid” anneal the structural inequalities in the political economy of global health and beyond. The benefits that wealthier states extract from poor states, and the resulting resource and power asymmetries, are largely obfuscated by the focus on interstate assistance from donor states to aid-dependent states. Importantly, the same commission that defined “political determinants of health” also recognized that “[p]ower asymmetry and global social norms limit the range of choice and constrain action on health inequity” and that “major drivers of ill health lie beyond the control of national governments and, in many instances, also outside of the health sector.”<sup>216</sup> For example, transnational corporations contribute to social and political determinants of health, and result in health inequity, when they aggressively market health-damaging products—such as in the cigarette, sugar, and alcohol industries—onto local populations.<sup>217</sup> Transnational corporations, such as those

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213. *Cohesion Fund*, EUROPEAN COMMISSION, [https://ec.europa.eu/regional\\_policy/en/funding/cohesion-fund](https://ec.europa.eu/regional_policy/en/funding/cohesion-fund) [<https://perma.cc/4TSY-5LFV>].

214. *Id.*

215. Indeed, “aid” now actually more often comes from private donors, such as the Bill and Melinda Gates Foundation, which are not politically accountable in the same way as governments.

216. Ottersen et al., *supra* note 203, at 630–31.

217. *See generally* Philip Morris Brands Sàrl, Philip Morris Products S.A. & Abal Hermanos S.A. v. Oriental Republic of Uruguay, ICSID Case No. ARB/10/7, Award (July 8, 2016), [http://icsidfiles.worldbank.org/icsid/ICSIDBLOBS/OnlineAwards/C1000/DC9012\\_En.pdf](http://icsidfiles.worldbank.org/icsid/ICSIDBLOBS/OnlineAwards/C1000/DC9012_En.pdf)

within the soft drink industry, have also fostered the privatization—and sometimes the contamination—of local water supplies in developing countries, with the support of international financial institutions, including the International Monetary Fund and World Bank.<sup>218</sup>

Perhaps less intuitively, developing nations suffer even more profoundly at the hands of transnational corporations and international financial institutions through extraction of funds that would otherwise go to domestic infrastructure, including health. Despite the typical view of foreign aid as flowing from richer to poorer countries, current estimates indicate that “for every \$1 of aid that developing countries receive, they lose \$24 in net outflows.”<sup>219</sup> These “outflows” occur through poorer states’ interest payments on sovereign debt, uneven trade agreements, illicit flows, and corporate tax evasion. For example, countries in the global South have paid over \$4.2 trillion in interest payments on sovereign debts since 1980.<sup>220</sup> “Illicit flows” comprise an even larger share of the money being drained out of developing nations, by transnational corporations seeking to avoid paying domestic taxes—often the same corporations hawking their corrosive products into the domestic markets. For example, corporations engage in a practice known as “trade misinvoicing” to evade taxes, which involves reporting “false prices on their trade invoices in order to spirit money out of developing countries directly into tax havens and secrecy jurisdictions” in sums that add up to hundreds of billions each year.<sup>221</sup> Similar tactics for avoiding taxation, such as “same-invoice faking” or “transfer pricing,” drain further hundreds of billions in tax dollars that could otherwise go toward the host states’ development of local infrastructure, including health.<sup>222</sup>

The response to these facts then cannot be solely—or even primarily—calls for crumbs of charitable assistance that reify the colonialist global order. On the contrary, the actions of transnational corporations occur under the effective control of governments in the economic North, as do many of the policies instituted by

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[<https://perma.cc/7D6D-MGWR>], *rectified*, Decision on Rectification (Sept. 26, 2016), [http://icsidfiles.worldbank.org/icsid/ICSIDBLOBS/OnlineAwards/C1000/DC9013\\_En.pdf](http://icsidfiles.worldbank.org/icsid/ICSIDBLOBS/OnlineAwards/C1000/DC9013_En.pdf) [<https://perma.cc/6N7P-KMKJ>]; WORLD HEALTH ORG., GLOBAL STATUS REPORT ON ALCOHOL AND HEALTH (2018); Tjidde Tempels, Marcel Verweij & Vincent Blok, *Big Food's Ambivalence: Seeking Profit and Responsibility for Health*, 107 AM. J. PUB. HEALTH 402 (2017).

218 JONATHAN M. HARRIS & BRIAN ROACH, ENVIRONMENTAL AND NATURAL RESOURCE ECONOMICS: A CONTEMPORARY APPROACH 554–555 (4th ed. 2017).

219 Jason Hickel, *Aid in Reverse: How Poor Countries Develop Rich Countries*, GUARDIAN (Jan. 14, 2017), <https://www.theguardian.com/global-development-professionals-network/2017/jan/14/aid-in-reverse-how-poor-countries-develop-rich-countries> [<https://perma.cc/KHD3-WTMW>].

220. *Id.*

221. *Id.* See also GLOBAL FINANCIAL INTEGRITY, FINANCIAL FLOWS AND TAX HAVENS: COMBINING TO LIMIT THE LIVES OF BILLIONS OF PEOPLE 15 (2015).

222. *Id.* at 95; MISFORTUNE, *supra* note 20.

international financial institutions. The response, then, should be to reassert democratic control over decisions, which have fundamental implications for the fiscal space available for health institutions and beyond. As UN Special Rapporteur on Extreme Poverty and Human Rights, Philip Alston called out the World Bank and the International Monetary Fund, challenging longstanding pretensions that their policies and lending do not affect “political” questions.<sup>223</sup> The visibly ravaging effects of decisions regarding sovereign debt burdens and austerity during the COVID-19 pandemic,<sup>224</sup> lend urgency to the imperative of radically democratizing these decisions in the future.

The influential, although non-binding, *Maastricht Principles on the Extraterritorial Obligations of States in the Area of Economic, Social and Cultural Rights* provide that a state has extraterritorial obligations with regard to situations “over which it exercises authority or effective control” in which its “acts or omissions bring about foreseeable effects” on the enjoyment of ESC rights, “whether within or outside its territory.”<sup>225</sup> Since the issuance of the *Maastricht Principles*, UN treaty-monitoring bodies, domestic courts, and supranational tribunals have increasingly begun to examine countries’ extraterritorial obligations (ETOs) that stem from the actions of states or non-state actors and have harmful impacts elsewhere. These situations include those in which “the State, acting separately or jointly, whether through its executive, legislative or judicial branches, is in a position to exercise decisive influence or to take measures to realize” ESC rights.<sup>226</sup>

For example, in issuing an advisory opinion on *State Obligations in Relation to the Environment in the Context of the Protection and Guarantee of the Rights to Life and to Personal Integrity*,<sup>227</sup> the Inter-American Court on Human Rights

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223. Philip Alston (Special Rapporteur on Extreme Poverty and Human Rights), *Extreme Poverty and Human Rights*, U.N. Doc. A/70/274, summary (Aug. 4, 2015) (“The Special Rapporteur concludes that the existing approach taken by the Bank to human rights is incoherent, counterproductive and unsustainable . . . . The biggest single obstacle to moving towards an appropriate approach is the anachronistic and inconsistent interpretation of the ‘political prohibition’ . . . . That inhibits its ability to take adequate account of the social and political economy aspects of its work within countries and contradicts and undermines the consistent recognition by the international community of the integral relationship between human rights and development.”).

224. Juan Pablo Bohoslavsky, *COVID-19 Economy vs Human Rights: A Misleading Dichotomy*, HEALTH & HUM. RTS. J.: VIEWPOINTS. (April 20, 2020), <https://www.hhrjournal.org/2020/04/covid-19-economy-vs-human-rights-a-misleading-dichotomy> [<https://perma.cc/B497-VN4E>] (citing Juan Pablo Bohoslavsky (Independent Expert on the Effects of Foreign Debt and Other Related International Financial Obligations of States on the Full Enjoyment of Human Rights, Particularly Economic, Social and Cultural Rights), *Private Debt and Human Rights*, U.N. Doc. A/HRC/43/45 (Jan. 3, 2020)).

225. MAASTRICHT PRINCIPLES, *supra* note 192, art. 9.

226. *Id.*

227. The Environment and Human Rights (State Obligations in Relation to the Environment in the Context of the Protection and Guarantee of the Rights to Life and to Personal Integrity:

extended states' obligations to respect the right to a healthy environment of those residing outside of a state's territory. The Court clarified that the "concept of jurisdiction under Article 1(1) of the American Convention encompasses any situation in which a State exercises authority or effective control over an individual, either within or outside its territory."<sup>228</sup> Thus, states are responsible for extraterritorial impacts of activities occurring within their jurisdiction, and "must ensure that their territory is not used in such a way as to cause significant damage to the environment of other States or of areas beyond the limits of their territory" if such damage would violate any person's rights.<sup>229</sup>

As tectonic a shift as ETOs might seem to imply, basic legal frameworks and models for addressing ETOs domestically have been generated in the past. For example, in the United States, the amended U.S. Foreign Corrupt Practices Act of 1977 prohibits U.S.-based persons (including corporations) from bribing officials of foreign jurisdictions to obtain business benefits.<sup>230</sup> It is possible to imagine extending this sort of prohibition to persons and corporations whose U.S.-based activities contribute to the many kinds of extraterritorial flows out of foreign countries which can be tied directly to health. Moreover, in recent years there has been bipartisan support for incorporating requirements for improved—yet still tepid—labor and environmental standards for people in other countries under trade agreements such as the United States–Mexico–Canada Agreement,<sup>231</sup> passed by the U.S. Congress in January 2020.<sup>232</sup> In short, social pressures can be generated to hold governments that have effective control over the drivers of ill health accountable by their citizens through democratic institutions, rather than solely invoking the responsibility of countries where impacts are felt.

While groundwork for ETOs has begun to be laid, we fully acknowledge that additional work and legal experimentalism is needed to refine the extent and

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Interpretation and Scope of Articles 4(1) and 5(1) in Relation to Articles 1(1) and 2 of the American Convention on Human Rights), Advisory Opinion OC-23/17, Inter-Am. Ct. H.R. (ser. A) No. 23 (Nov. 15, 2017).

228. *Id.* ¶ 244(1).

229. *Id.* ¶ 104(f).

230. 15 U.S.C. § 78dd-1 to -3.

231. See, e.g., Nicole M. Aschoff, *The New NAFTA Is a Raw Deal for Workers*, JACOBIN (Dec. 14, 2019), <https://jacobinmag.com/2019/12/nafta-deal-usmca-united-states-mexico-canada-agreement> [<https://perma.cc/CZP2-GRL3>]; Beth Baltzan & Jeffrey Kucik, *NAFTA's Replacement Gives Labor Some Shelter from Globalization's Storms*, FOREIGN POL'Y (Jan. 16, 2020), <https://foreignpolicy.com/2020/01/16/usmca-mexico-canada-trump-workers-democrats-naftas-replacement-gives-labor-some-shelter-from-globalizations-storms> [<https://perma.cc/5DUH-L28J>]; David Bacon, *The New NAFTA Won't Protect Workers' Rights*, NATION (Nov. 8, 2019), <https://www.thenation.com/article/archive/nafta-usmca-trade-agreement> [<https://perma.cc/LS7Z-K333>].

232. United States–Mexico–Canada Agreement, Pub. L. No. 116-113 (2020).

content of ETOs under different circumstances.<sup>233</sup> However, the realities of our globalized world and the transnational drivers of health demand subjecting the policy and legal decisions that impact health abroad to greater democratic scrutiny and decision-making. Without doing so, assistance in the current political economy of global health compounds and obscures the legacies of colonialism and neocolonialism that generated the existing economic and political power imbalances in the first place, and displaces accountability to citizens with aid dependent upon donors. Imposing ETOs on states would necessitate that we first reconstitute and enlarge our understanding of the social contract as being inclusive of the transboundary effects of states and transnational corporations in this globalized world.

### CONCLUSION

As underscored by differential governmental responses during the COVID-19 pandemic, we have argued here that it is urgent to advance understanding of the linkage between democracy and health, which is too often considered a technical, “norm-free” subject. In doing so, we have emphasized that health, perhaps more than any other right, calls for a reconsideration of the traditionally isolated way in which human rights realization has generally been theorized. As South African Constitutional Court Justice Albie Sachs noted in his *Soobramoney v. Minister of Health* concurrence:

Health care rights by their very nature have to be considered not only in a traditional legal context structured around the ideas of human autonomy but in a new analytical framework based on the notion of human interdependence . . . . When rights by their very nature are shared and inter-dependent, striking appropriate balances between the equally valid entitlements or expectations of a multitude of claimants should not be seen as imposing limits on those rights . . . but as defining the circumstances in which the rights may most fairly and effectively be enjoyed.<sup>234</sup>

To date, health rights have too often been articulated in the abstract untethered from the institutional arrangements and democratic practices necessary to breathe life into them, as well as the political economy that invariably shapes such arrangements in practice.

That scaffolding for health rights is inadequate because, as Rawls reminds us, “[t]he kind of lives that people can and do lead is importantly affected by the moral conception publicly realized in their society. What sorts of persons we are is shaped by how we think ourselves and this in turn is influenced by the social forms

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233. Human Rights Council Res. 26/9, U.N. Doc. A/HRC/RES/26/9 (July 14, 2014).

234. *Soobramoney v. Minister of Health (Kwazulu-Natal)* 1998 (1) SA 765 (CC) at para. 54 (Sachs, J., concurring).

we live under.”<sup>235</sup> The set of rights the law recognizes as assets of citizenship and the ways health-related rights are defined play a fundamental role in understandings of governmental and private responsibility for patterns of suffering and well-being. COVID-19 struck a world shackled by decades of legal rules embedding privatization in health systems and inequalities in national and global political economies. Today, to move beyond the horrors and massive social trauma of the pandemic, we will need to rebuild our democracies in new ways, and rethinking the role of health and health systems, and the transboundary impacts on health that different structural factors have, should be an integral part of how we do so.

As we have argued here, an understanding of health systems as democratic social institutions has implications, among other things, for (1) financing and delivery of goods, facilities, and services (including public health goods and services); (2) defining the contours of a legally enforceable health entitlement through legitimate processes; (3) oversight and regulation of the preceding conditions; and (4) provision of adequate information that allows decisions affecting health (made by governments and commercial actors alike) to be subjected to democratic scrutiny. As suggested by Justice Sachs in *Soobramoney*, here we have asserted that defining the contours of health rights—the process for determining what is included in guaranteed care and how it is delivered—belies the idea of rights as protections from the state and against one another: rights to be left alone. Rather, health rights require people to come together under conditions of background equality to analyze and make decisions about collective imperatives.

Indeed, at a time when international human rights are increasingly widely perceived as disconnected from broader struggles for social justice and substantive democracy, we would do well to recall that all rights are ultimately “dependent for their normative force on the engagement and commitment of an active citizen body.”<sup>236</sup> Nowhere is this recognition more crucial than in health, which determines so much of our ability to execute life plans and participate as diverse but equal members of our societies in one shared world.

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235. John Rawls, *The Independence of Moral Theory*, 48 PROC. & ADDRESSES OF THE AM. PHIL. ASS'N 5, 20 (1974–75).

236. Benjamin R. Barber, *Foundationalism and Democracy*, in DEMOCRACY AND DIFFERENCE, *supra* note 17, at 348, 354.