

# Health and Human Rights Journal

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## SPECIAL SECTION

### ECONOMIC INEQUALITY AND THE RIGHT TO HEALTH

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## EDITORIAL

# Realizing the Right to Health: A Long and Winding Road

JOSEPH J. AMON

### Introduction

Where are we, in this moment, in our efforts to realize a right to health for all? As I take on the role of editor-in-chief of *Health and Human Rights Journal*, this question preoccupies me. I began thinking about it while reflecting on the legacies of the editors who preceded me—Jonathan Mann, Sofia Gruskin, and Paul Farmer—towering figures, pioneering scholars, and passionate advocates.

The work of each of these former editors still very much resonates. In the third issue of the journal, Mann talked about how the dialogue between public health and human rights can define more clearly the challenges and perspectives of a new approach to public health; however, he presciently warned that this dialogue would not be met with universal acceptance. Resistance to adopting rights as the foundation of public health would come from within the field, he wrote, because addressing root causes requires societal transformation—an approach too radical for most working in public health.<sup>1</sup>

Gruskin, in an editorial in 2003, wrote about the need to bring health and human rights together to address violence prevention, highlighting the issue as one that, although a core focus of criminal law, humanitarian law, and human rights law, has only slowly been examined at the intersection of public health and human rights despite complementary values, ideals, and practical applications.<sup>2</sup>

In his 2008 paper “Challenging Orthodoxies,” Farmer questioned the “priority often assigned to civil and political rights over economic and social rights” and exhorted readers to “move beyond crude notions of cost-effectiveness and sustainability and to return to the concept of social justice, which once inspired public health but now seems to embarrass us.”<sup>3</sup> Farmer also wrote that he hoped that the journal would focus on “human rights in the doing,” writing that conceptual analysis “must be nourished by contact with communities’ real needs.”

Reflecting on the contributions of Mann, Gruskin, and Farmer is particularly appropriate as we approach the journal’s 30th anniversary and consider the progress and the obstacles that face us. For example, public health as a discipline remains more comfortable talking about ethics than rights, and concerns about the boundary between public health and politics abound. When rights are referenced in

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public health journals, they are often referred to in passing, vaguely.<sup>4</sup> At the same time, social (and political) determinants of health have been widely accepted as an analytical framework, and the use of law—and paralegals—to claim health rights is common.<sup>5</sup> Gruskin’s focus in 2003 on violence prevention could not be more relevant today, as are “the inextricable linkages” she described between the positive and negative impacts of health policies and programs on human rights across areas such as reproductive health, tobacco control, and humanitarian crises.<sup>6</sup> Farmer’s observation of the priority of civil and political rights remains largely true, but more attention is being paid, including in this issue of the journal, to economic inequality.<sup>7</sup>

Furthering this theme of reflecting on “where are we now,” Carmel Williams (the journal’s executive editor) and I have asked authors of some of the first papers published in the journal to look back—and forward—on the meaning and significance of the issues they raised at the journal’s founding and where we are today. From my vantage point, I see many challenges and some hope. But as a human rights activist, I am perhaps predictably drawn to the “glass is half empty” perspective: Why can’t more be done?

## Finding human rights

My own engagement in health and human rights came about gradually. In college I read *And the Band Played On* by Randy Shilts.<sup>8</sup> The book is a combination of detective story—featuring the physicians and epidemiologists struggling to figure out the cause of a new “gay plague”—and the very personal stories of activists and individuals living, and dying, with the disease. It is also a scathing review of the ways in which the US government, media, and others failed to take basic steps to recognize the epidemic and to respond to it.

Shilts writes, “The bitter truth was that AIDS did not just happen to America—it was allowed to

happen.” The book left me outraged and with a deep and lasting interest in public health. It also gave me a profound respect for the voices of individuals—hearing what they have to say and learning from it.

After completing a master’s program in public health, I went to Togo as a Peace Corps volunteer. One of the first lessons I learned was the dedication and commitment of my Togolese colleagues. At the time, Togo was undergoing significant political strife, including a workers’ strike throughout the southern part of the country, but my colleagues found ways to persevere and to maintain critical public health campaigns. While there, I saw the first wave of HIV cases emerge in the country.

When I returned to the United States, I worked for a large US-based international health organization helping Ministries of Health and nongovernmental organizations (NGOs) design monitoring and evaluation systems and conduct research to better understand the HIV/AIDS epidemic and the impact of their programs. After four years of doing that, and then four more getting a PhD in parasitology, I joined the Centers for Disease Control and Prevention’s (CDC) Epidemic Intelligence Service—the same program of “disease detectives” mentioned in the book *And the Band Played On* and the same postdoctoral program where Mann began his career in public health.

I enjoyed working at the CDC. But I was also aware of the limitations of the organization to engage directly in communities and in the advocacy necessary for transformative change. I became frustrated that the underlying causes of the disease outbreaks I investigated were often considered beyond the mandate of the organization. The reasons that people were getting sick—the poor quality of or lack of access to health care, the social marginalization, the desperate poverty, the lack of available and accessible treatment for people who use drugs—were often left out of the epidemiologic analysis or were thought to be too political to include in our recommendations. I didn’t feel like we were listen-

ing enough to the people and communities we were trying to help.

My next stop was at Human Rights Watch (HRW). I stayed for a decade, working on health and human rights and starting new programs on the environment and disability rights. I enjoyed being an epidemiologist amidst human rights lawyers and deepening my understanding of how human rights violations impact health.

Although HRW had occasionally worked on economic, social, and cultural rights, the organization's real focus on health and human rights began with the creation of an HIV program in 2000. The program, led by Joanne Csete, partnered with legal and advocacy organizations and produced research reports related to AIDS orphans in Kenya, the harassment of HIV outreach workers in India, women's property rights, and abuses against people who use drugs in Kazakhstan and Russia, among others.<sup>9</sup> As the work advanced, HRW's executive director, seeking to present a vision for the work more broadly, wrote and published an article in *Human Rights Quarterly* presenting a strategy of "naming and shaming" and asserting that international human rights organizations should limit their work on economic, social, and cultural rights to cases (1) where there is a clear violation, violator, and remedy; (2) where the violation is a result of arbitrary or discriminatory action; and (3) where remedies do not require redistributing resources.<sup>10</sup> There was considerable pushback against this narrow vision, from both inside the organization and outside of it.<sup>11</sup>

When I arrived, in 2005, HIV continued to be a major focus within the organization, with research focused on the impact of the criminalization of sex work and drug use on HIV in Ukraine (2006), political repression, user fees, and access to HIV care in Zimbabwe (2006), police violence and access to HIV treatment for people who use drugs in Thailand (2007), access to HIV care for immigrants in detention in the United States (2007), and

more. Later reports included a focus on access to prevention and care for prisoners in Zambia (2010), Uganda (2011), and the United States (2016), and among people living with disabilities in Zambia (2014).<sup>12</sup>

Another major area of work examined harsh, and ineffective, approaches to drug use, including reports focused on the United States, Russia, Thailand, Vietnam, China, Cambodia, and Lao People's Democratic Republic, led by my HRW colleagues Megan McLemore, Jane Cohen, Rebecca Schleifer, and Richard Pearshouse.<sup>13</sup>

In 2008, HRW began to frame the plight of people with advanced or serious illness, most of whom lacked access to palliative care, as a human rights issue.<sup>14</sup> Through a series of reports, led by Diederick Lohman, the organization documented how millions of patients with cancer and other conditions were suffering moderate and severe pain due to a lack of access to inexpensive and effective analgesics. Many patients with cancer pain described their suffering in similar terms as victims of police torture: they said that the suffering was unbearable and that they would do anything to make it stop.

Part of the human rights argument made in these reports was aligned with the approach outlined by HRW's director. Restrictions on the use of morphine were analyzed using an arbitrariness or discrimination test. For example, reports argued that Indian regulations that required hospitals and pharmacies to obtain four or five different licenses from different government departments in order to procure morphine were not reasonable and were therefore arbitrary. But these reports also went far beyond the proposed approach, arguing that governments had an obligation to ensure the adequate availability and accessibility of morphine as part of minimum core obligations under the International Covenant on Economic, Social and Cultural Rights; to ensure that health care workers received training in palliative care; and to ensure that national health strategies, policies, and budgets addressed the need

of patients requiring palliative care.

The advocacy also went well beyond what was outlined.<sup>15</sup> Certainly, naming and shaming was an important part of the advocacy strategy—news coverage often contributed to governments recognizing the need to take steps to address palliative care gaps—but it was not the only or often even the main component of the advocacy approach, which incorporated a combination of public pressure, constructive engagement, capacity building, and epidemiologic research.<sup>16</sup>

Throughout my decade at the organization, and under the leadership of Lohman following my departure, there were many other significant impacts stemming from rights documentation and advocacy—on issues such as the detention of hospital patients; drug-resistant tuberculosis; lead and mercury poisoning; the response to cholera, typhoid, SARS, and Ebola outbreaks; and more.<sup>17</sup>

Yet in 2018, three years after I left the organization, and not long before the arrival of COVID-19, HRW shut down the division. The explanation given to staff was that health issues could be “mainstreamed” throughout the organization. As with most “mainstreaming” efforts, the result was a sharp drop-off in work. The situation is not much different at Amnesty International, where the organization’s website has no mention of health among 20 themes that are presented as defining “what we do.”<sup>18</sup> Similarly, the once mighty brain trust and funder of health and human rights work, Open Society Foundations, has largely shuttered its innovative and essential public health program and scattered its expertise to the wind.

## Coopting rights

For some organizations, rights are a rallying cry. For others, they are a legal framework or an operational approach. At times the invocation of rights seems to be perfunctory or disingenuous. Certain rights are emphasized while others are ignored or

even denied. In this complex arena of competing human rights claims, how does one evaluate the relevance, force, and effect of these claims? What evidence is marshaled to support claims to rights, and how does this evidence differ from that used by other actors in efforts to shape global health policies?

In 2001, the World Health Organization (WHO) introduced a campaign focused on your “right to know.” The campaign promoted the idea that every person has a right to know their HIV serostatus.<sup>19</sup> However, the campaign, coming from an organization that only selectively invoked human rights, was constructed, in part, to counter HIV and human rights activists who advocated for the rights of individuals to informed consent, privacy, and voluntary counseling and testing—advocacy that officials at WHO felt was slowing the acceptance of routine HIV testing services.

Not long after WHO’s campaign was launched, UNICEF introduced a “your right to know” campaign as well. In contrast to WHO’s campaign, UNICEF’s effort focused on the right of adolescents to comprehensive information about HIV prevention. This version of a “right to know” was also contested, this time by governments that sought to limit or deny information about HIV treatment or prevention—either broadly or to specific populations—to promote “abstinence only” approaches or to suppress information for LGBTI communities.

Amidst these battles to define and lay claim to a “right to know,” individuals living with HIV campaigned for expanded HIV prevention programs and greater access to affordable antiretroviral drugs. These campaigns sometimes included a rallying cry calling for people living with HIV to “know your rights,” emphasizing not only a right to HIV prevention and treatment but also rights to be free from violence and discrimination.

WHO’s emphasis on the “right to know” one’s serostatus was grounded in the view that individuals vulnerable to HIV infection, or already living

with HIV, are able to realize behavior change unrestricted by structural barriers or factors such as inequality, power, or gender-based violence. The campaign was a part of an effort calling for a return to “traditional” public health methods of case identification and treatment, using a language of rights to mask a return to paternalistic models of medical care.<sup>20</sup> Pitting a “rights-based” approach against a “public health” approach, Kevin DeCock, Dorothy Mbori-Ngacha, and Elizabeth Marum claimed in 2002 that the emphasis on human rights in HIV prevention obscured the “essential” nature of public health and social justice. They argued that the emphasis by human rights activists on “Western” approaches, such as anonymous testing with informed consent and pre- and post-test counseling, was discouraging the acceptance of HIV testing.<sup>21</sup>

This argument echoed long-standing criticisms of human rights: that rather than being universal, they are reflective of “Western” values; in other words, too expansive. In Eswatini, one of the countries hardest hit by the HIV epidemic, UNICEF’s representative argued that the “Western preoccupation” with the need for informed consent prior to HIV testing and with preserving the confidentiality of test results caused “the ignorance and stigma that grew up around AIDS in the West to make its leap to Africa.”<sup>22</sup>

Blaming consent and confidentiality around HIV testing for the slow response to the epidemic ignored the kingdom’s massive under-investment in health and its severely restricted rights for women. Until constitutional reforms were passed in 2005, women in Eswatini assumed the legal status of a child upon marriage and were not allowed to register property. There were no specific laws criminalizing domestic violence. Rape laws excluded marital rape, and one in three women reported suffering sexual abuse as a child. More fundamentally, the argument that “Western preoccupation” was to blame for the slow response to the HIV epidemic in the country ignored the fact that HIV testing was

not widely available in the country until after HIV prevalence exploded.

## Evidence

Whether as a CDC epidemiologist or doing research at HRW, I have always thought a lot about the issue of evidence, how it is defined, what type of evidence is valued (and devalued), the amount of evidence needed for policymaking, and, importantly, how policymaking is done when evidence is sparse.

Frequently, I have found that despite epidemiological treatises about what constitutes high-quality evidence, in practice the amount of evidence required and what constitutes strong evidence is often highly subjective—and reflective of explicit or implicit values conveyed in the different types of training of health workers and in the values—and power—of institutions that are seeking a change in the status quo.<sup>23</sup>

One example of two very different approaches to evidence and values arose toward the end of my tenure at the CDC in 2004, when I attended a meeting on HIV. The meeting had two panel discussions, the first on HIV treatment and the second on prevention. During the first, there were a lot of comments by panelists about how “we do not have enough understanding of how to roll out HIV treatment in low-income settings.” But the overall message was *We have to do something and learn as we go*.

By contrast, the second panel discussion on prevention was rife with hesitancy and fear that approaches such as peer education were ineffective. The message was *We need large-scale randomized trials to understand what works in HIV prevention, and we should not waste money until we have a better understanding of what works*.

The debate betrayed a sense of frustration among the epidemiologists in the room with the complexity of human behavior and a desire for an imagined simplicity of biomedical approaches.

Confident in their ability to prescribe medicines, the absence of evidence was a small barrier. Unconfident in their understanding of behaviors and the determinants of behavior, a desire for evidence far outweighed any consideration of urgency in addressing the clear vulnerability of those at risk.

I saw the same dynamic play out at WHO as it promoted an approach to expanding access to HIV treatment through expanded testing, under the slogan of “test and treat.” The intentions were undoubtedly good, but the approach was simplistic, imagining a world where getting an HIV test result would be met with equanimity, with immediate access to care, and without fear, discrimination, or any negative consequences whatsoever.

The promotion of such an overly simplistic approach, because it was coming from the world’s public health policymaking organization, could be interpreted in simplistic ways as well. For example, in 2011 a group of researchers led by Lorraine Yap, conducted a study, funded by the Chinese and Australian governments, in three reeducation-through-labor camps for persons who use drugs in China.<sup>24</sup> While HIV testing in detention centers was mandatory, the authors found that pre-test education and disclosure was not. Of those testing positive, only 25% received HIV antiretroviral therapy. In a separate paper, the authors reported that nearly half of the male and female detainees over 45 years of age experienced “severe psychological distress,” and about 30% said that their health status was “poor.” Rather than examining the clear rights violations faced by those detained, the authors concluded that “labor camps provide another opportunity to implement universal treatment (‘Test and Treat’) to prevent the spread of HIV” and that “forensic mental health services” are needed.<sup>25</sup>

Four years before the study above was conducted, HRW also conducted research on reeducation-through-labor centers in China. We found a wide range of severe human rights abuses,

including the use of HIV tests, according to one guard, “to know which female inmates they could sleep with without using a condom.”<sup>26</sup> One former detainee told us, “I started taking antiretroviral drugs before I was put into detox. Then when I was in [detox] I had to stop. I was really worried about my health but there was nothing I could do.”<sup>27</sup> Another told us, “Lots of people inside drug detention centers have TB [tuberculosis], and lots of people get TB while in detention. There is no treatment and everyone is all together all the time.”<sup>28</sup> Even the head of the United Nations Office of Drugs and Crime (UNODC) in China agreed that the centers were not a solution, telling the Associated Press that “being detained in these centers not only does not help drug users to recover, as evidenced by the high rates of relapse, but also increases the likelihood that an individual will become infected with HIV.”<sup>29</sup> UNODC’s statement was not in isolation—in 2012, 12 United Nations agencies called for compulsory drug detention centers such as China’s reeducation-through-labor camps to be closed down “without delay.”<sup>30</sup>

Yap and colleagues’ recommendations for universal testing and treatment were intended, no doubt, to protect the health and well-being of those detained. Yet their research failed to ask the right questions and consequently prescribed the wrong medicine. Expanded HIV treatment and mental health counseling would aid some concerns of some detainees. Closing these centers down and expanding voluntary, community-based substance abuse treatment would advance both public health and human rights.<sup>31</sup>

How can public health researchers narrow their vision so significantly that they fail to see obvious abuses in pursuit of inappropriate solutions? Sadly, I found that this was common. In Cambodia, a detention center for children was funded by UNICEF. Children we interviewed spoke of being given electrical shocks, being beaten, and being forced to dance naked. In Vietnam, our research

on drug rehabilitation centers found that drug users were detained for up to four years without ever being charged or tried, and were routinely beaten, shocked with electric batons, and locked in isolation cells or punishment rooms when they were not being forced to work. Project staff from aid agencies and NGOs visited on a regular basis. The World Bank described its funding of the centers as a humanitarian necessity.<sup>32</sup>

If you know nothing about human rights, and you don't ask the right questions, I guess it is easy to believe that what you see is vocational training and rehabilitation. Less charitably, if your focus is on diseases and prevention strategies, it is apparently quite easy to never see the individuals in front of you, who, in addition to being someone you want tested and treated for HIV, may have other pressing needs.

Public health practitioners sometimes render individuals invisible by focusing on "HIV hot spots" or by referring to "hard to reach" populations. Ironically, "hard to reach" populations are often found in "HIV hot spots." So how exactly does one become hard to reach, and why are we blaming them for the failure of our health programs to meet their needs?

When public health practitioners refer to "hard to reach" populations, they are often referring to prisoners, drug users, men who have sex with men, and sex workers. Prisoners by definition are pretty easy to reach. They usually can't go very far. But they can disappear. A colleague of mine at HRW, Kate Todrys, wrote a series of reports on prison health in Africa. During research for one report, she visited the Muinanina Farm Prison in Uganda. Seeing her, 10 prisoners banded together and passed her a letter. It described years behind bars without trial or contact with a magistrate, endless work, and brutal beatings. It concluded, "We feel we are invisible prisoners. If we are invisible, tell us."<sup>33</sup>

With or without "hot spot" maps, police don't

have any problem finding people who use drugs, men who have sex with men, or sex workers. And such maps can unintentionally cause backlash, such as police raids, arrests, and sensationalistic media coverage.<sup>34</sup> Yet in a deft example of evading liability, the funders and researchers of one hot spot mapping project of "most-at-risk populations" cautioned:

*neither Neilsen nor the supporting partners—World Bank, UNAIDS, UNDP [United Nations Development Program], UNODC and USAID [United States Agency for International Development]—conducting or supporting the study on mapping and size estimation ... is liable or can be held responsible or accountable for the misuse of data and information in the reports ... Any legal responsibility resulting through the use of any data or information contained in this report is withdrawn.*<sup>35</sup>

Mapping "hot spots" is ultimately a crude effort to identify risk. More compelling would be mapping human rights violations. For example, public health and human rights professionals could map where HIV peer educators are being arrested for distributing condoms and information on HIV prevention in Senegal.<sup>36</sup> HIV donors could commission a mapping of funding levels—identifying inequities by province or district within a country or by key population. They could map stockouts of HIV medicines or the quality of health centers. They could map stigma and sexual violence—including in police stations—and the confiscation of condoms from sex workers.<sup>37</sup> In other words, they could map the drivers of HIV transmission.

In my experience, it is often not the individuals at risk of, or living with, HIV infection who are hard to reach. It's the politicians and policy makers who are unavailable. But HIV researchers, too, seem to be hard to reach at times, failing to investigate political determinants of health and the impact of laws, policies, and enforcement on HIV vulnerability and access to care.<sup>38</sup>

## Rights-based interventions

Within the HIV response, attention to human rights and to rights-based interventions has waxed and waned. Currently, organizations such as UNAIDS are more likely to talk about equity or equality than rights.<sup>39</sup> But where do inequalities come from? A number of years ago, I spoke with a senior program officer at a major foundation working on HIV globally who told me, “We don’t take a rights-based approach, we take an equity approach.” After a bit of back and forth, it became clear that the foundation was uncomfortable with the idea of accountability, a key component of human rights.

Similarly, a keynote address at the American Public Health Association annual meeting, presented by the president and CEO of a large international development agency, spoke about her organization’s approach to fighting poverty, emphasizing three core strategies: “embracing a rights-based approach, forging partnerships, and empowering women.” She said, “Putting rights at the heart of our work means giving people the tools to create positive change in their lives and to hold themselves and others accountable for making that change happen.” Accountability can be framed in a lot of different ways, but I’m pretty sure it’s not meant to be about holding marginalized and vulnerable populations accountable for making change happen. The speech said nothing about gender-based violence. Or property and inheritance rights abuses. Or state obligations or those of NGOs.

In contrast, the Global Fund’s “Breaking Down Barriers” initiative has funded interventions in 20 countries that seek to ensure that key and vulnerable populations can get access to HIV prevention and treatment. In recent trips to Jamaica and Benin to see these programs in action, I found integrated teams of peer educators, paralegals, social workers, psychologists, lawyers, and HIV specialists working together to ensure that individuals coming to health centers for HIV testing were

able to navigate all of the potential human rights issues they faced—from fears of discrimination and uncertainty about disclosure to the need for protection from domestic abuse or the provision of sexual and reproductive health care. Unlike many HIV programs that engage in a kind of magical thinking that slogans can change deep prejudice, the programs I saw were based on close listening and support—an approach that Farmer championed as “accompaniment,” but on steroids.

A recent review found evidence of the impact of these types of human rights programs (singly and combined) on HIV-related outcomes for people living with HIV and key and vulnerable populations, ranging from decreased HIV risk behaviors to increased HIV testing to reduced incidence.<sup>40</sup> Yet adequately funded human rights programs addressing discrimination and operating at national scale are rare. More often, “stigma and discrimination” programs emphasize stigma but ignore discriminatory laws, policies, and practices.<sup>41</sup> They rely on messaging that calls on everyone to act together to end stigma, while ignoring mechanisms, such as the judiciary, that can identify and hold responsible those who discriminate against others. Making everyone responsible usually means that no one is accountable.

## Challenging rights frameworks

In his 2016 report to the Human Rights Council, Philip Alston, the United Nations Special Rapporteur on extreme poverty and human rights, painted a pessimistic portrait of respect for economic and social rights, saying that their acceptance both by states and by “many of the most prominent civil society groups focusing on human rights” remained marginal.<sup>42</sup>

In 2020, Jonathan Cohen, then at the Open Society Foundations, raised the issue in these pages of whether human rights work is political enough for a moment like this: “By appealing to evidence,

facts, and universal norms, does human rights exempt itself from political struggle and underestimate the reality of power in shaping decisions?”<sup>43</sup>

Legal scholar Samuel Moyn has argued that “even perfectly realized human rights are compatible with radical inequality.”<sup>44</sup> Moyn describes the system of laws and programs to enforce economic and social rights as “a helpless bystander of market fundamentalism”—if not to blame for the neoliberal world order that emerged after the Cold War, then certainly ineffectual in addressing it.

In an article I wrote with my colleague João Biehl, we replied to some of these criticisms, writing that

*peoples (let's keep them multiple) live in exhausted worlds. Worlds on the edge of autocracy, of financial collapse, of infrastructural breakdown and environmental tipping points—mediated by extreme populism and state and corporate efforts to dismantle piecemeal, though meaningful, agendas of socioeconomic rights. Violence and deadly health disparities are persistent realities that, time and again, are couched by experts in a rhetoric of recovery even as conditions stagnate or worsen.*<sup>45</sup>

Undoubtedly, it's important to engage—indeed, to invite—critiques to how we think and practice health and human rights and to examine questions about whether we are acting forcefully enough to challenge neoliberal policies and ensure that practicing human rights remains a radical praxis and not a comfortable profession.

I am especially thankful for critiques that ask what a more urgent and progressive human rights movement looks like, across all of the spaces and topics on which we work, especially when those critiques come—as Amy Kapczynski in her article “Right to Medicines in an Age of Neoliberalism” highlights—from “marginal places” at the periphery.<sup>46</sup> In these places, even in the absence of health rights being fulfilled and despite weak mechanisms of redress, there is power in claiming rights, mobi-

lizing, making demands in the courts and on the streets or online, and finding commonalities across rights, communities, health concerns, and government failures.

Human rights paradigms and frameworks can be argued at the global level, but they must never lose their focus on justice locally, on accountability, and on the need to fight within existing political and economic systems to advance, and sustain, rights protections. This is part of the struggle for “decolonization”—of means, priorities, resources, and epistemologies.<sup>47</sup>

## Conflict

Threats to the right to health—and the full realization of all rights—are acute whenever countries face, or create, conflict. To highlight just three: Since its invasion of Ukraine in 2022, Russia has committed indiscriminate attacks and the war crimes of torture, rape, and other sexual violence—all resulting in severe and long-term consequences for the physical and mental health of the victims.<sup>48</sup> The United Nations Office for the Coordination of Humanitarian Affairs has estimated that some 10,000 civilians have been killed since the start of the invasion and that “people's lives are dominated by the constant sound of air raid sirens, as unrelenting air strikes rain down and destroy civilian objects.”<sup>49</sup>

The Chinese government's mass arbitrary detention (in so-called vocational education and training centers) of Uyghurs and other Turkic Muslims in Xinjiang—including acts of torture, enforced disappearances, mass surveillance, cultural and religious persecution, separation of families, forced labor, sexual violence, and violations of reproductive rights—was finally recognized by the Office of the United Nations High Commissioner for Human Rights in 2022. The institution said the rights violations “may constitute ... crimes against humanity.”<sup>50</sup>

In October 2023, in response to a terrorist attack by Hamas, which included targeted killings and kidnapping of civilians—clear war crimes—Israel has laid siege to Gaza, with devastating consequences for its civilian population. On November 8, the United Nations Special Rapporteur on the right to adequate housing highlighted Israel’s targeting of housing and infrastructure in Gaza—rendering an entire city uninhabitable—as a war crime as well.<sup>51</sup> As I write, a tentative cease-fire holds.

In each of these crises, there are both public health and human rights activists engaging—documenting abuses, providing medical and public health care, and challenging intolerance and hate. For example, in Ukraine, the invasion had a major impact on Ukraine’s HIV and tuberculosis responses, as health services were diverted to deal with caring for wounded soldiers and civilians. Health care workers faced the difficult choice of staying or fleeing. Hospitals and clinics came under attack. Medical supplies were disrupted, leaving clinics without essential commodities. Patients were afraid to seek care while there was fighting in the streets and the threat of air attacks in the skies. Many were displaced and did not know where to go to get back into care. Thousands of people on antiretroviral and tuberculosis medications were cut off from their treatment. People on opioid substitution treatment, which is banned in Russia, feared that their treatment programs could be discontinued. In occupied territories, Ukrainian health care services ceased altogether.<sup>52</sup> After a few weeks, though, HIV and tuberculosis programs came back—public health programs adapted, finding and linking people who needed care to services, and finding ways to keep prevention interventions and medicine supply chains running and to continue providing care.

Human rights documentation is critical in crisis settings, whether by international human rights organizations such as HRW and Amnesty International, by local rights groups, or by groups

such as Insecurity Insight and the Safeguarding Health in Conflict Coalition (representing nearly 50 NGOs, academic institutions, medical student and health care provider groups, and human rights organizations). The challenge is not only documenting attacks on health workers, facilities, and transport amidst the “fog” of war, but conducting advocacy with governments, including Ministries of Health and Defense, to ensure that humanitarian actors are not harassed.<sup>53</sup> Similarly, pressure by medical organizations, such as the International Council of Nurses and the World Medical Association, can amplify and challenge governments that target health providers—or health professionals who participate in rights violations.<sup>54</sup>

This frontline work is not easy, and it is never finished. Humanitarian and human rights organizations sometimes struggle to balance access with their obligation to bear witness. Governments use divisiveness and hatred to suppress dissent. Discrimination, in forms less extreme than arbitrary detention or conflict, is widespread and directly impacts realization of the right to health.<sup>55</sup> At the beginning of this editorial, I mentioned my “glass is half empty” approach. But when I am asked how I can sustain work on health and human rights despite all of the challenges and abuses, I reply that I am inspired by those working as rights defenders around the world, in difficult, and almost impossible, settings, doggedly seeking to bring about respect for human rights for all.

## Conclusion

This year marks the 75th anniversary of the Universal Declaration of Human Rights, a document that imagined a world vastly different from the one that existed at the time, a world where those most vulnerable among us would be *free and equal in dignity and rights*. This claim, found in the very first article of the declaration, was the subject of Mann’s last paper, published in this journal after his untimely

death in 1998, at the age of 51 years. Mann wrote that “from a health and human rights perspective, the possible connections between dignity and health are simultaneously complex, intuitively powerful and difficult to assess.”<sup>6</sup> This call to action is still relevant today, and one that needs to be carried into our work on climate change, emerging pathogens, chronic diseases, violence, and on and on.

Amidst all the upheavals of the world today, I am confident that when the public health field focuses on dignity and human rights, we will be better able to restore trust with the communities we serve. But embracing rights as a foundation for public health work will require public health professionals to listen more closely. That will be the easy part. Harder will be the need for public health professionals to understand their work differently.

I am thrilled to take on the job of editor-in-chief, delighted with the role the journal has played in fostering discussion about health and human rights and advancing the field, and excited about working to ensure that the journal remains a robust home for scholars and advocates, public health professionals and human rights activists, to continue the journey of imagining and reimagining, as well as building a world where the right to health is realized for all. Our work is far from complete. I welcome your engagement with the journal in its next chapter.

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# Assisted Regulation: Argentine Courts Address Regulatory Gaps on Surrogacy

PATRICIO LÓPEZ TURCONI

## Abstract

Surrogacy operates in a regulatory void in Argentina. Despite attempts to legislate this practice, Argentine law contains no univocal rules governing the legality and enforceability of surrogacy agreements. Unsurprisingly, this has not stopped intended parents from pursuing surrogacy; quite the contrary, it has steered them into the courts, thrusting the issue into the realm of judicial policy. Through a comprehensive review and qualitative study of 32 court rulings, I address the judicial scenario regarding surrogacy in Argentina. I describe the profile of litigants who are bringing altruistic gestational surrogacy claims, the legal arguments used by courts, and the types of orders issued. I explain how the judiciary, through judicial review of the current legal framework and the application of international human rights law, including the principle of the best interests of the child, is playing a key role in ensuring access to this form of third-party assisted reproductive technology. Finally, I make the case for regulation by critically assessing these rulings to highlight the intricacies, challenges, and complexities that come with the judicial regulation of surrogacy.

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## Introduction

Surrogacy as a form of third-party assisted reproduction continues to be the subject of heated debate. Perhaps because of the ethical, legal, and social concerns that come with this practice, there is a considerable regulatory void in relation to surrogacy arrangements at both the domestic and the international levels.<sup>1</sup> Lawmakers around the globe have abstained from regulating surrogacy in view of the difficulties of reaching agreement on a host of issues, including its legality, questions of parentage, and mechanisms for safeguarding the rights of all parties involved.

This trend of abstentionism is also true for Argentina. Despite many attempts to legislate this practice, Congress has refrained from providing a regulatory framework for gestational or genetic surrogacy, which means that Argentine law contains no univocal rules governing the legality and enforceability of these agreements. Unsurprisingly, the lack of legislation has not stopped intended parents from pursuing this family planning option in the country; quite the contrary, it has driven them to seek legal recourse in courts in the hope of obtaining different forms of assurance. As a result, the distinct and complex legal issues associated with surrogacy in Argentina have now entered the realm of judicial policy.

In this paper, I address how surrogacy arrangements are playing out in Argentine courts by presenting the findings of a comprehensive review of rulings covering this practice. My study reviewed 32 decisions pertaining to surrogacy agreements carried out entirely in Argentine territory, excluding cases of cross-border surrogacy. My sample consisted of decisions published between August 2015 (when the Civil and Commercial Code entered into force) and December 2021 containing the search terms “subrogación,” “maternidad subrogada,” or “gestación por sustitución.” All decisions were downloaded from Thomson Reuters’ online legal research service for Argentina; no

unpublished decisions were included in the sample.

Based on my findings, I describe the pivotal role of Argentine judges in facilitating access to certain forms of surrogacy in the face of insufficient regulation. At the same time, I highlight the main shortcomings of judicial policy in this field, which speak to the importance of establishing a regulatory framework for addressing the ongoing practice of surrogacy in Argentina.

My analysis is structured as follows. I first provide a succinct overview of the legal instruments that can be understood as applicable to surrogacy arrangements under Argentine law. I then delve into the judicial scenario regarding surrogacy by presenting a qualitative analysis of the opinions included in the sample, emphasizing the legal reasoning used by judges. Finally, I critically assess the case law included in my sample, highlighting the challenges that persist due to both the regulatory vacuum and the ad hoc judicial handling of surrogacy.

## Overview of the Argentine legal system

Surrogacy in Argentina is not expressly regulated by law. A provision covering gestational surrogacy was included in the Draft Civil and Commercial Code (*Anteproyecto*) but did not make it through the legislative process. As a result, these agreements are governed by rules contained in three legal instruments of different hierarchy: the Argentine Constitution (as amended in 1994), the Civil and Commercial Code (2014), and Law 26,862 on Medically Assisted Reproduction (2013). All three instruments are uniformly applicable to the entire Argentine territory and must be relied on by all judges in the resolution of disputes.<sup>2</sup>

### *The legal framework governing surrogacy agreements in Argentina*

The Constitution contains two rules that are of special relevance for the debate on surrogacy. Article

19 sets out the *reserva de ley* principle, according to which no individual “shall be obliged to perform what the law does not demand nor deprived of what it does not prohibit.”<sup>3</sup> Article 75.22 accords express constitutional hierarchy to the core international human rights treaties ratified by Argentina. The rights contained therein, including the rights to health and to form a family, are considered constitutional rights that complement, and do not repeal, previously enumerated rights.<sup>4</sup>

The Civil and Commercial Code (Law 26,994) codifies the rules of private law pertaining to contracts and family. Articles 1 and 2 of the code stipulate that its provisions must be applied and interpreted in accordance with the Constitution and the human rights treaties to which Argentina is a party.<sup>5</sup> Because of their constitutional status, these treaties have the power to invalidate the rules of private law. In practice, this means that courts must abstain from applying an article of the code to a given case if that would contradict a constitutional or treaty provision.<sup>6</sup>

The Civil and Commercial Code does not explicitly regulate or mention surrogacy; however, several of its provisions could be construed as applying to this practice. On the surface, certain rules could be interpreted as impeding commercial surrogacy arrangements: article 17 indicates that the “rights over the human body” cannot have a commercial value, while articles 56, 279, 344, 386, 958, 1004, and 1014 prohibit, in different ways, acts that may be deemed contrary to public order or morality (*orden público, moral y buenas costumbres*).<sup>7</sup> Articles 560 to 564, containing the rules on parentage by assisted reproductive technology (ART), might also be understood as predetermining the parentage of children born through surrogacy. In particular, article 562 on “procreational will” stipulates that “those born by assisted human reproduction techniques are children of the person who gave birth and of the man or woman who has

also given their prior, informed and free consent.”<sup>8</sup> As a result, this article codifies the principle that motherhood is determined by birth (*mater semper certa est* principle), even in the context of ART.

Finally, Law 26,862 on Access to Medically Assisted Reproduction is also relevant. At its core, this law seeks to guarantee access to ART by setting out a coverage mandate for certain techniques. The National Executive and the Ministry of Health have clarified and restricted the mandate’s scope of application through subsequent resolutions.<sup>9</sup> While none of these instruments reference surrogacy, the law’s broad definition of “medically assisted reproduction” might accommodate this practice, as it encompasses all “procedures and techniques performed with medical assistance to achieve a pregnancy.”<sup>10</sup>

### *The failed attempt to include surrogacy in the Civil and Commercial Code*

The enactment of the Civil and Commercial Code was a protracted political process that involved different stakeholders. The legal scholars charged with drafting the rules of family law had originally pushed for regulating certain aspects of surrogacy, introducing a draft article on the matter in the *Anteproyecto*. Article 562 of the *Anteproyecto* would have authorized only altruistic gestational surrogacy agreements, provided that certain procedural safeguards were met. These requirements included (1) prior judicial authorization of the agreement; (2) a documented inability to conceive or carry a pregnancy to term through other methods; (3) a limit on the number of times a woman could be a surrogate; and (4) that the surrogate candidate have had at least one child of her own.<sup>11</sup> Additionally, article 561 of the *Anteproyecto* (current article 562 of the code) avoided any reference to *mater semper certa est* in the context of ART.<sup>12</sup>

All these rules were ultimately rejected when the *Anteproyecto* was reviewed by the Senate, which

argued that the time was not right for regulating surrogacy since the issue warranted a profound legal, ethical, and interdisciplinary debate.<sup>13</sup>

## Surrogacy in courts: Review of judicial decisions

My study reviewed a total of 32 judicial decisions (published from August 2015 to December 2021) covering surrogacy arrangements carried out entirely on Argentine territory. The full list of decisions analyzed can be found in the Annex. At first sight, the sheer number of rulings published in such a short time frame hints to a high prevalence of this practice, despite the fact that it is not expressly regulated. It also suggests that the regulatory void has steered people into family courts, which, by interpreting the current legal framework, have essentially become the gatekeepers of this form of assisted reproduction in the country.

To gain a deeper understanding of this judicial phenomenon, I analyzed all decisions using Siri Gloppen's analytical framework for health rights litigation. Gloppen argues that merely examining court judgments is insufficient for grasping how litigation can have a positive or negative impact on a certain health issue—in this case, surrogacy. Rather, it is crucial to conceptualize the litigation process as consisting of four interconnected stages (claims formation, adjudication, implementation, and social outcomes) and to conduct a detailed analysis of each stage. This involves taking a close look at the type of litigants, their claims and legal basis, the different courts involved, and how the cases differ in their “outputs,” among other things.<sup>14</sup>

Focusing on the first two stages of Gloppen's analytical framework, I present the results of a qualitative analysis of all 32 decisions, highlighting the type of litigants who are bringing surrogacy-related claims to courts, the legal justifications used by judges to solve these cases, and the types of orders issued.

## *Litigants, claims, and orders*

Most applicants were heterosexual couples confronting infertility or similar medical conditions that prevented the woman from carrying a pregnancy to term (e.g., hysterectomy), while only a few cases were brought by LGBTI couples. No cases dealt with single parents. In the case of heterosexual couples, the surrogate was generally a family member or immediate relative; for LGBTI applicants, the surrogate was usually a close friend. Surrogates were always a party to the dispute and were usually subjected to home visits and extended interviews by judges.

All claims concerned altruistic gestational surrogacy agreements. Intuitively, and from a legal standpoint, this could be attributed to the influence of the rules of the Civil and Commercial Code and the *Anteproyecto*. As noted, several articles of the code prohibit agreements that may be deemed contrary to morality. In particular, article 17 categorically stipulates that the rights over the human body or its parts “do not have a commercial value, but an affective ... or social value and can only be made available by their owner provided that one of these values is respected.”<sup>15</sup> Additionally, the *Anteproyecto* made room only for gestational surrogacy. In the absence of explicit regulation or *lex specialis* to the contrary, litigants could have reasonably believed that altruistic gestational surrogacy had a greater likelihood of being authorized by the judiciary.

Litigants turned to the courts at different stages of the medical process: the great majority filed claims before implantation occurred, some did so after implantation but before birth, and a few filed claims after the child had already been born. These differences are a direct result of the regulatory vacuum and have concrete implications for the type of claims made. In the claims filed before implantation, applicants typically sought judicial authorization of the practice or the agreement itself, as well as an assurance that the child would not be registered following the *mater semper certa*

*est* principle. In the claims filed after implantation, litigants mostly pursued the proper registration of the child, either through a provisional measure to that effect or by rectifying certificates that followed the exact wording of article 562 of the Civil and Commercial Code.

Orders consistently favored the applicants, authorizing implantation in the surrogate or granting provisional measures to ensure the accurate registration of the child. All favorable decisions had *inter partes* effects, except for one collective *amparo* from the City of Buenos Aires. This particular *amparo* granted the applicant's request to register children born through surrogacy without placing the surrogate as a parent, with collective effects for all births following altruistic gestational surrogacy agreements performed in the country that are registered in the City of Buenos Aires. The effects of this *amparo* are thus limited to that jurisdiction and do not extend to other parts of the country.<sup>16</sup>

Of all decisions reviewed, only one case decided by a court of appeals denied the rectification of the birth certificate of a child who had been born through surrogacy. I will address the court's legal justification for rejecting this claim later, but it is relevant to note that this was one of the few cases involving gay applicants who sought the rectification of the birth certificate in a case of altruistic gestational surrogacy.<sup>17</sup>

### *Legal basis of judgments*

Favorable opinions used a variety of legal and policy arguments to either authorize surrogacy or allow for the intended effects of these agreements. Argumentation varied depending on the time of judicial intervention (i.e., before implantation, before birth, or after birth). However, three arguments were common: (1) the value of the *reserva de ley* principle; (2) the direct applicability of human rights treaties included in article 75.22 of the Constitution; and (3) the inapplicability or unconstitutionality of article 562 of the Civil and Commercial Code to surrogacy cases.

**Surrogacy and Reserva de Ley.** In the absence of regulations on surrogacy, article 19 of the Constitution would suggest that surrogacy must be allowed, as no individual can be "deprived of what [the law] does not prohibit."<sup>18</sup> Nearly all family courts agreed with this statement, concluding that surrogacy had to be authorized because it was not expressly banned by the Civil and Commercial Code or by any other law. Some judges even thought that this practice had "implicit recognition" in the Argentine legal framework by virtue of the code, which recognizes ART as a source of parentage, and Law 26,862's broad definition of "medically assisted reproduction."<sup>19</sup>

One judge went as far as to claim that, per article 19 of the Constitution, there was no basis to justify judicial intervention in cases of surrogacy. The decision argued that if Law 26,862, which regulates access to ART, did not expressly prohibit surrogacy or require prior judicial approval, then there was no need for judges to intervene—at least not before birth. It concluded that surrogacy should be deemed an issue requiring medical (and not judicial) authorization, in conformity with the principles of bioethics.<sup>20</sup>

The only case in the sample that denied the applicant's claim to rectify a birth certificate concluded that there was no regulatory void, arguing that the text of article 562 of the Civil and Commercial Code revealed legislators' clear intention to prohibit this practice. Accordingly, the majority claimed that *reserva de ley* was inapplicable to the case and that parentage could only be "determined by the uterus, regardless of any consent."<sup>21</sup> The minority voted to grant the claim, arguing that the case needed to be decided in light of the *Ante-proyecto* and international human rights law.

**The direct applicability of international human rights law.** The overwhelming majority of opinions turned to international human rights law to authorize altruistic surrogacy arrangements. Most judges

claimed that, per article 75.22 of the Constitution, the regulatory void should be addressed by directly applying human rights treaties.<sup>22</sup> They argued that articles 1 and 2 of the Civil and Commercial Code required judges to interpret and apply rules on parentage, including article 562, in alignment with these treaties.<sup>23</sup>

To authorize surrogacy, courts largely relied on the rights to sexual and reproductive health, to privacy, to form a family, and to enjoy the benefits of scientific progress and its applications. Most opinions used the Inter-American Court of Human Rights' judgment in *Artavia Murillo v. Costa Rica* (2012) to argue the existence of a "human right to procreational will," a "right to access ART to try to procreate," or a "right to become mother through the use of ART."<sup>24</sup> On the basis of *Artavia*, a few decisions held that authorizing surrogacy was the only way to guarantee access to ART to single men, gay couples, and women unable carry a pregnancy to term due to health reasons.<sup>25</sup>

Some opinions further emphasized that courts needed to address surrogacy-related claims from a perspective that considers both gender and human rights, focusing on the rights of the surrogate.<sup>26</sup> Using this rationale, these rulings argued that the surrogate's right to privacy encompassed a right to "make use of their own bodies with a view toward satisfying someone else's reproductive desire."<sup>27</sup>

To order proper registration at birth or shortly thereafter, most courts invoked the provisions of the Convention on the Rights of the Child, including the rights of children to be registered immediately after birth, to preserve their identity, and to judicial protection.<sup>28</sup> Most opinions concluded that departing from the *mater semper certa est* principle was necessary to protect the best interests of the child. Two judges who were asked to intervene before implantation claimed that they were under an obligation to consider the best interests of the "child to be gestated" pursuant to article 3 of the Convention

on the Rights of the Child, even if that child was not granted legal personhood under the Civil and Commercial Code.<sup>29</sup>

### **On article 562 of the Civil and Commercial Code.**

By incorporating the principle of *mater semper certa est* in the context of ART, article 562 of the code interferes with the typical objective sought by parties to a surrogacy arrangement: ensuring that only the intended parents will be accorded the rights and responsibilities of parentage.

Faced with this obstacle, courts adopted one of three approaches: (1) to ignore the issue of article 562 of the code altogether and focus on the direct applicability of international human rights law; (2) to declare the article inapplicable to the case; or (3) to declare the article unconstitutional on the grounds of contravening the human rights treaties contained in article 75.22 of the Constitution.

At first sight, the difference between approaches (2) and (3) lies in a mere doctrinal debate. Under Argentine constitutional law, before declaring the unconstitutionality of a rule, judges must ascertain whether the provision in question applies to the case. Under this line of reasoning, some opinions argued that judicial review was unwarranted since article 562 was inapplicable to surrogacy scenarios. They asserted that the rule had not been designed to "regulate this type of ART, but only those techniques in which the person who gestates and the person who has expressed their procreational will are the same."<sup>30</sup> Because surrogacy had been removed from the final text of the code, Congress had no reason to deviate from the *mater semper certa est* principle insofar as it had not "envisioned the possibility of separating gestation from motherhood" at the time.<sup>31</sup>

In contrast, those who decided to perform a judicial review of article 562 argued that the rule applied to all children "born by assisted human reproduction techniques" but that applying *mater*

*certa semper est* to surrogacy cases would be contrary to the effective enjoyment of the “human right to procreational will,” the right to form a family, and other entitlements protected in the treaties to which Argentina is a party.<sup>32</sup>

As applied, the differences between these two approaches could be explained by the judiciary’s general reluctance to interfere with legislative matters. As pointed out by one judge, “[judicial review], no matter how much it refers to the specific case, has a social impact and undermines the validity of the norm. Equity, for its part, as a general principle of law, merely corrects it and readjusts [the norm] to its purpose in the specific case.”<sup>33</sup>

## Challenges

While judicial policy may be paving the way for surrogacy agreements in Argentina, this ad hoc, patchwork approach is failing to provide the legal certainty and safeguards that the surrogacy process demands. Certainly, a qualitative analysis of the opinions included in this study reveals that there are some critical issues that courts are either still unable to address through judicial review or that may have to be repeatedly litigated by future applicants. As expressed by one court:

*There are several challenging situations that can arise and that require regulated solutions: from cases in which the pregnant woman refuses to comply with the agreement and to hand over the child, to the regrettable cases in which the parents intentionally refuse to take care of the child born with some kind of disability ... It is neither desirable nor prudent to leave it entirely up to the judge to establish the content of [Argentine law] in such cases, which are becoming increasingly frequent.*<sup>34</sup>

This section will review some of the challenges that are evident from the decisions encompassed in this study, including (1) questions on coverage; (2) the problem on enforcing agreements; and (3) lingering concerns around the exploitation of surrogates.

## Concerns with medical coverage

Even if surrogacy might fall under the broad definition of “medically assisted reproduction,” it is still missing from Law 26,862 itself and from its implementing resolutions.<sup>35</sup> In this sense, coverage of the various medical procedures involved in surrogacy is likely to be disputed by insurance companies until this practice is addressed by way of legislation and regulation.

Few cases under review pertained to coverage issues. However, one ruling included in the sample vividly illustrates the type of disputes that can arise due to the lack of regulation. The case concerned the denial of coverage for procedures considered essential for gestational surrogacy (in vitro fertilization and the cryopreservation of embryos) for a woman who had undergone a hysterectomy, even though she had not indicated that she intended to enter such an arrangement. According to the insurance company, coverage was unwarranted because the applicant would be able to use those embryos only if she resorted to surrogacy or underwent a uterus transplant, neither of which was expressly authorized by Argentine law.<sup>36</sup> Faced with this challenge, the court noted that judges must not “engage in futurology” but rather stick to the content of the claim: despite the lack of legislation around surrogacy and uterus transplantation, the requested services (i.e., in vitro fertilization and cryopreservation) were expressly included in Law 26,862. That reason alone was enough to mandate coverage.<sup>37</sup>

Even if laudable, this decision suggests that under the patchwork approach to surrogacy, coverage of services that are fundamental to this arrangement not only is left to judicial discretion but might ultimately depend on the way that litigants frame their claims. At the end of the day, the case was successful on its merits because it concerned procedures that were meant to be performed on the applicant and were explicitly provided by law. The results might have been different had the woman

requested coverage of other medical expenses related to surrogacy (e.g., embryo transfer to the surrogate, maternity care of the surrogate, etc.).

### *Questions on the content and enforceability of surrogacy agreements*

The rulings included in this study addressed only a small spectrum of the challenges faced in the surrogacy process, particularly those related to the determination of parentage. Even more, courts were faced only with altruistic gestational surrogacy cases in which all parties were in agreement. This means that even if judges have started to make up for some of the areas that Congress has failed to regulate, most of the ethical and legal risks that come with surrogacy arrangements remain to be addressed.

The content and legal enforceability of the surrogacy agreement itself is one such challenge. In three of the cases studied, litigants specifically asked the courts to validate previously drafted agreements.<sup>38</sup> One of the agreements contained provisions on termination, allocation of costs, posthumous reproduction, and the surrogate's anticipated consent for the correct registration of the child.<sup>39</sup> In these cases, courts only took the agreements as evidence of informed consent but refused to validate their content under the current state of the law. According to one decision, doing the latter would have implied "advancing on personal rights, in fact incoercible, and therefore insusceptible of ... any sanction in case of non-compliance."<sup>40</sup> After authorizing implantation, another decision concluded that the subject of the agreement "would be the delivery of the child, which would be insusceptible of specific performance."<sup>41</sup>

One conclusion can be firmly drawn from these opinions: even if litigants obtain the judicial green light for implantation and an assurance of registration, surrogacy remains largely unenforceable. In particular, these decisions suggest that

judges would probably be unwilling or unable to enforce agreements in the face of disputes that could be characterized as involving "personal rights"—an extremely broad concept that would encompass disagreements around termination, tort liability, and the surrogate's ability to make her own health decisions, among other things. All of these are distinct issues of surrogacy arrangements that judicial policy is still failing to respond to.

In practice, the judiciary's reluctance to tackle the content of agreements also means that until Congress enacts clear legislation on the matter, written altruistic surrogacy agreements—as tailored as they might be—may be accorded little or no value in this field. Certainly, the rulings reviewed suggest that litigation will probably be necessary to resolve most contractual disputes between surrogates and intended parents.

### *Lingering concerns regarding the exploitation or abuse of surrogates*

I have described how the rules of the Civil and Commercial Code might be construed as prohibiting compensated arrangements, which would explain why only altruistic surrogacy cases have been authorized by courts. Still, legal uncertainty around commercial surrogacy does not prevent its occurrence—in fact, it could be driving compensated arrangements underground and failing to provide safeguards against the exploitation of surrogates experiencing poverty or economic distress.<sup>42</sup>

Two judgments included in the study sample, and which were issued by the same court, illustrate how this might be happening in Argentina. The first ruling was issued in 2017, authorizing implantation in "A," a woman who had three children of her own and wanted to become an altruistic surrogate, after finding no evidence of compensation. Four years later, the same judge authorized "A" to become a surrogate for a different couple. This time, an expert witness testimony vividly spelled out how

“A” had lost her job during the pandemic, had no health insurance, and was supporting herself by selling consumer products, making a monthly income that was well below minimum wage.<sup>43</sup> Even in the face of these signs of financial hardship, the judge ruled out a risk of exploitation because there was no proof of retribution, and, thus, “there [was] no economic purpose involved.”<sup>44</sup>

By using compensation as the sole criterion for identifying exploitation, these judgments show that an ad hoc judicial approach to surrogacy possesses limited means to identify and prevent the potential abuses that are associated with this practice. In this sense, the decisions also speak to the need for regulation that goes beyond ex ante judicial review and the usual contractual defenses and that includes permanent “exploitation-avoiding” frameworks (e.g., the informed consent of all parties involved, psychological evaluations, counseling, and even a “fair price” for surrogacy).<sup>45</sup>

## Conclusion

As stated by one of the judgments, “Surrogacy ... does not cease to exist because the law does not want to see it.”<sup>46</sup> Argentine legislators have long ignored surrogacy, perhaps in an effort to discourage its use. However, the number of rulings included in this study paints a different picture. Far from preventing the use of surrogacy, the regulatory void has turned judges into the sole arbitrators of this form of third-party reproduction. Altruistic gestational arrangements appear to be common, particularly among heterosexual couples experiencing infertility; and claimants seem to be experiencing high rates of success, primarily due to the judiciary’s use of international human rights law.

Still, the decisions included in this study may not encompass all the intricacies, difficulties, and challenges of judicial policy in this field. The methodological approach to this study focused on published decisions retrieved from a single search

engine, which means that the reality of surrogacy in Argentina could potentially be broader and more complex. Unpublished decisions from other courts may exist, and there might be surrogacy arrangements that never reached the courts, potentially further reinforcing the issues examined in this study.

Additionally, certain cases included in this study could be subject to review by higher courts at both the local and the federal levels, including the Argentine Supreme Court. Hence, there is a considerable degree of uncertainty around how judges will continue to address this issue, particularly if the regulatory void persists.

Altogether, this paper has sought to describe the judicial scenario concerning surrogacy in Argentina and to make a compelling case for regulation. Even if courts are gradually accommodating surrogacy, they still grapple with a number of unresolved questions, and there is no assurance that the judiciary will be able to adequately address them without the guidance of tailored regulations. While some lawmakers have made efforts to reintroduce the topic in legislative debates, there appears to be minimal political motivation to take decisive action on this matter. The seemingly growing number of intended parents pursuing surrogacy, the ethical and legal challenges that come with this practice, and the need to protect all parties involved underscore the pressing need for a well-defined regulatory framework.

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## Translation

All translations from Spanish to English were performed by the author.

ANNEX: List of judgments included in the study sample

1. Juzgado de Familia Nro. 1 de Mendoza (Family Court No. 1 of Mendoza), *C. M. E. y J. R. M. c. O.S.D.E. s/ medidas cautelares*, September 2, 2015.
2. Tribunal Superior de Justicia de la Ciudad Autónoma de Buenos Aires (Superior Court of Justice of the City of Buenos Aires), *X., T. S y otros s/ información sumaria s/ recurso de inconstitucionalidad concedido*, November 4, 2015.
3. Juzgado de Familia Nro. 1 de Mendoza (Family Court No. 1 of Mendoza), *C. M. E. y J. R. M. s/ inscripción nacimiento*, December 15, 2015.
4. Juzgado de Familia Nro. 9 de Bariloche (Family Court No. 9 of Bariloche), *Dato reservado*, December 29, 2015.
5. Juzgado de Familia Nro. 7 de Lomas de Zamora (Family Court No. 7 of Lomas de Zamora), *H.M. y otro s/ medidas precautorias*, December 30, 2015.
6. Tribunal Colegiado de Familia Nro. 5 de Rosario (Family Court No. 5 of Rosario), *S. G. G. y otros s/ filiación*, May 27, 2016.
7. Juzgado de Familia Nro. 2 de Moreno (Family Court No. 2 of Moreno), *S. P., B. B. c. S. P., R. F. s/ materia a categorizar*, July 4, 2016.
8. Juzgado de Familia Nro. 3 de San Martín (Family Court No. 3 of San Martín), *M., I. M. y otro/a s/ autorización judicial*, August 22, 2016.
9. Juzgado Nacional de 1a Instancia en lo Civil Nro. 8 (Lower Court of First Instance over the District of Buenos Aires), *B., B. M. y otro c. G., Y. A s/ impugnación de filiación*, September 20, 2016.
10. Juzgado de Familia Nro. 7 de Lomas de Zamora (Family Court No. 7 of Lomas de Zamora), *B. J. D. y otros s/ materia a categorizar*, November 30, 2016.
11. Juzgado Nacional de 1a Instancia en lo Civil Nro. 81 (Lower Court of First Instance over the District of Buenos Aires), *S., I. N. y otro c. A., C. L. s/ impugnación de filiación*, June 14, 2017.
12. Juzgado de Familia Nro. 7 de Viedma (Family Court No. 7 of Viedma), *Reservado s/ autorización judicial (f)*, July 6, 2017.
13. Cámara de Apelaciones en lo Contencioso Administrativo y Tributario de la Ciudad Autónoma de Buenos Aires (Court of Appeals in Administrative and Tax Matters of the City of Buenos Aires),

*Defensor del Pueblo de la Ciudad Autónoma de Buenos Aires y otros c. GCBA y otros s/amparo*, August 4, 2017.

14. Juzgado de Familia Nro. 2 de Mendoza (Family Court No. 2 of Mendoza), *M. M. C. y M. G. J. y R. F. N. s/ medidas autosatisfactivas*, September 6, 2017.

15. Tribunal Colegiado de Familia Nro. 7 de Rosario (Family Court No. 7 of Rosario), *H., M.E. y otros s/ Venias y dispensas*, December 5, 2017.

16. Juzgado de Familia Nro. 2 de Mendoza (Family Court No. 2 of Mendoza), *S. M. S.; T. C. J.; B. P. V. s/ medidas autosatisfactivas*, February 15, 2018.

17. Juzgado de Familia Nro. 6 de San Isidro (Family Court No. 6 of San Isidro), *S., M. J. s/ autorización judicial*, March 20, 2018.

18. Juzgado de 1a Instancia en lo Civil, Comercial y de Familia de 2a Nominación de Villa María (Lower Court in Civil, Commercial and Family Matters of Villa María), *R., R. A. y otros s/ autorizaciones*, June 8, 2018.

19. Juzgado en lo Civil en Familia y Sucesiones de 1a Nominación de Tucumán (Lower Court in Civil, Family and Inheritance Law of Tucumán), *P. A. M. y otro s/ autorización judicial*, June 8, 2018.

20. Juzgado Nacional de 1a Instancia en lo Civil Nro. 87 (Lower Court of First Instance over the District of Buenos Aires), *O. F., G. A. y otro s/ Autorización*, April 3, 2019.

21. Juzgado de Familia Nro. 1 de Pergamino (Family Court No. 1 of Pergamino), *C., C. A. y otros s/ materia a categorizar*, April 22, 2019.

22. Juzgado de Familia de 5a Nominación de Córdoba (Family Court of Córdoba), *V. A. B. y otros s/ solicita homologación*, April 25, 2018.

23. Juzgado de Familia Nro. 2 de Zarate (Family Court No. 2 of Zarate), *F., F. M. y otros s/ solicita homologación*, July 1, 2019.

24. Juzgado de Familia de 6a Nominación de Córdoba (Family Court of Córdoba), *F., C. y Otro*, August 13, 2019.

25. Cámara de Apelaciones en lo Civil y Comercial de Salta (Court of Appeals in Civil and Commercial Matters of Salta), *T. C., E. M.; T., J. I. c. Instituto Provincial de Salud de Salta (I.P.S.) s/ Amparo*, November 6, 2019.

26. Juzgado de Familia Nro. 8 de La Plata (Family Court No. 8 of La Plata), *D., J. E. y otro/a s/ autorización judicial*, April 27, 2020.
27. Cámara Nacional de Apelaciones en lo Civil, Sala I (National Court of Civil Appeals over the District of Buenos Aires, Section I), *S., M. D. y otros c. A., S. S. s/ filiación*, August 28, 2020.
28. Cámara Nacional de Apelaciones en lo Civil, Sala K (National Court of Civil Appeals over the District of Buenos Aires, Section K), *F., R. R. y otro c. G. P., M. A. s/ impugnación de filiación*, October 28, 2020.
29. Juzgado de Familia Nro. 7 de Viedma (Family Court No. 7 of Viedma), *Reservado s/ autorización judicial*, March 31, 2021.
30. Juzgado en lo Contencioso Administrativo y Tributario Nro. 6 de la Ciudad Autónoma de Buenos Aires (Court in Administrative and Tax Matters No. 6 of the City of Buenos Aires), *C., V. D. y otros c. OBSBA s/ salud*, June 24, 2021.
31. Cámara Federal de Apelaciones de Córdoba, Sala A (Federal Court of Appeals of Córdoba, Section A), *S., N. A. y otro c. Obra Social del Poder Judicial de la Nación s/ Prestaciones médicas*, July 8, 2021.
32. Tribunal de Familia de Jujuy, Sala III (Family Court of Jujuy, Section III), *B., B. D. R. – B., C. R. – B., Y. F. s/ Autorización Judicial*, October 15, 2021.

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3. Constitution of Argentina (1994), art. 19.
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Civil Nro. 81 (Lower Court of First Instance over the District of Buenos Aires), *S., I. N. y otro c. A., C. L. s/ impugnación de filiación*, June 14, 2017; Juzgado de Familia Nro. 8 de La Plata (Family Court No. 8 of La Plata), *D., J. E. y otro/a s/ autorización judicial*, April 27, 2020; Tribunal Colegiado de Familia Nro. 5 de Rosario (Family Court No. 5 of Rosario), *S. G. G. y otros s/ filiación*, May 27, 2016; Juzgado de Familia Nro. 7 de Viedma (Family Court No. 7 of Viedma), *Reservado s/ autorización judicial (f)*, July 06, 2017; Tribunal Colegiado de Familia Nro. 7 de Rosario (Family Court No. 7 of Rosario), *H., M.E. y otros s/ Venias y dispensas*, December 5, 2017.

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30. *O. F., G. A. y otro s/ Autorización* (see note 22).

31. *H., M.E. y otros s/ Venias y dispensas* (see note 28).

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35. Law 26,862 (see note 10); Decree No. 956/2013 (see note 9); Ministry of Health Resolution No. 1-E/2017 (see note 9); Ministry of Health Resolution No. 1044/2018 (see note 9).

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37. *Ibid.*

38. *F., C. y Otro* (see note 25); *V. A. B. y otros s/ solicita homologación* (see note 24); Juzgado de Familia Nro. 7 de Viedma (Family Court No. 7 of Viedma), *Reservado s/ autorización judicial*, March 31, 2021.

39. *F., C. y Otro* (see note 25).

40. *Ibid.*

41. *Reservado s/ autorización judicial* (see note 38).

42. M. Hevia, “Surrogacy, Privacy, and the American Convention on Human Rights,” *Journal of Law and the Bio-sciences* 5/2 (2018).

43. *Reservado s/ autorización judicial* (see note 38).

44. *Ibid.*

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# Reproduction as Work: Addressing a Gap in Current Economic Rights Discourses

LAUREN DANIELOWSKI

## Abstract

In 2022, the global commercial surrogacy industry was valued at approximately US\$14 billion. This paper explores the issue of surrogacy to reveal how international human rights standards and labor laws treat reproduction as work, building on previous scholarship analyzing similar framing at the grassroots level in Mexico. I argue that the failure to recognize surrogacy as labor is rooted in three lacunae: (1) contemporary policies and practices around surrogacy globally pay little attention to the well-being and rights fulfillment of surrogates themselves, particularly the economic rights of surrogates; (2) the stigma of surrogacy as sexualized care work results in neglect of the labor rights of surrogates in mainstream economic rights discourses; and (3) relevant international rights law has not yet addressed the economic rights of surrogates, nor has it effectively articulated the interdependent relationship between economic rights and reproductive rights. Lastly, I discuss where reproductive rights and economic rights overlap in existing human rights conventions and standards and what possibilities these offer for articulating the interdependence of reproductive and economic rights and for advancing the labor rights of surrogates.

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## Introduction

“[Surrogacy], for me, this is work. I basically don’t see anything else in it.”<sup>1</sup>

Commercial gestational surrogacy is an arrangement by which an individual agrees to become pregnant and give birth to a child who is not genetically related to them in exchange for monetary compensation, including but not only compensation for medical expenses.<sup>2</sup> Surrogates may be recruited for hire through a number of channels; for example, the hiring party (typically referred to as the intended parent/s) can recruit surrogates through informal strategies, such as personal advertisements or online forums, or through surrogacy placement agencies that match intended parents with surrogates and receive compensation from the intended parents, sometimes from a portion of the surrogates’ compensation.

Because of the various degrees of legality of hiring surrogates and becoming surrogates, as well as the stigma surrounding the practice of surrogacy, surrogates are not represented in national or international employment data. Further, in economic rights discourses, surrogacy has been undertheorized as a form of labor that complicates the process of claiming these rights. Human rights laws have primarily addressed the relationship between surrogacy and human rights from the perspective of intended parents and children rather than the rights of surrogates, and even where the rights of surrogates are addressed, it is negative rights (e.g., freedom from discrimination) rather than positive rights (e.g., entitlement to a living wage) that are addressed.<sup>3</sup>

Surrogates are working within a rapidly expanding and changing reproductive tourism economy, which is a transnational economy that includes a variety of actors, such as egg donors, sperm donors, and private third-party agencies that coordinate transactions between donors, health care providers, and consumers.<sup>4</sup> In particular, sur-

rogates are central in the ongoing ethical debates around commodifying human reproduction in the reproductive tourism economy; feminist scholars have critically examined the practice of surrogacy as a product and reflection of the historical systemic violation and exploitation of working class women of color’s reproductive autonomy and economic precarity and have raised concerns about the commodification of human reproduction and how it impacts the social construction of motherhood.<sup>5</sup>

The Universal Declaration on Bioethics and Human Rights has attempted to specifically address concerns about the ethical treatment and rights of individuals within this economy. However, while the declaration identifies the right to informed consent, the right to human dignity, the protection of “human vulnerability,” and the right to health “without distinction of ... economic or social condition,” it does not specify the economic rights of workers in the reproductive tourism economy, thus leaving workers in this market in various states of vulnerability to rights violations.<sup>6</sup> Hegemonic powers such as the United States have largely dictated the landscape of reproductive choice through economic influence and coercion to advance specific reproductive agendas, particularly in the Global South, and have influenced the global devaluation of reproductive labor, contributing to what scholar Shelle Colen calls stratified reproduction—the idea that “physical and social reproductive tasks are accomplished differentially according to inequalities that are based on hierarchies of race, class, ethnicity, gender, place in the global economy, and migration status and are structured by social, political, and economic forces.”<sup>7</sup>

Under the lens of Frances Winddance Twine’s work on inequities in the reproductive tourism economy, surrogates are engaged in a form of reproductive labor and face barriers to claiming human rights, often because of the ambiguity of where and how they can make claims for rights based on the work they do.<sup>8</sup> As scholar Amrita Pande notes,

the “commercial surrogacy regime exploits [the] production-reproduction duality” of surrogacy, meaning that surrogates are treated as “productive” workers under contracts and employed by surrogacy agencies and intended parents while also expected to engage with surrogacy as an altruistic, maternal endeavor.<sup>9</sup> Given the lack of regulations and visibility of surrogacy as work, claims for rights may be most clearly made on the contracting party (i.e., the intended parents) or surrogacy placement agencies rather than the state.<sup>10</sup>

This paper explores how human reproduction can be reimagined through the case of surrogacy to advance reproductive and economic rights under international human rights law. Specifically, this paper examines workers’ rights, such as the right to decent work and fair wages, the right to autonomy in reproductive decision-making, and the rights of pregnant workers (e.g., the right to maternal health care) as an important set of rights that explicitly illustrates the relationship between reproductive and economic rights. The following section examines the existing literature on surrogacy as work and the influence of stigma on framings of surrogacy. The next section analyzes the conventions and treaties that link reproductive rights and economic rights to human reproduction as work in the case of surrogacy to make salient the interdependence of reproductive rights and economic rights. The paper concludes with a discussion of recommendations for negotiating rights in the reproductive tourism economy and considerations for future research.

Grassroots movements to promote reproductive rights and justice recognize how socioeconomic status and structural economic conditions shape one’s ability to claim reproductive rights.<sup>11</sup> As Loretta Ross notes, reproductive justice is not only about “including poverty” in reproductive justice debates but also about looking critically at the social context “in which individuals live and make their personal decisions.”<sup>12</sup> However, unlike grassroots reproductive justice movements, few international

rights conventions and standards have effectively articulated this relationship and have failed to capture the structural underpinnings of reproductive injustice, particularly the violations of economic rights along multiple axes of inequality.

## Literature review

### *Existing debates on surrogacy*

Using Colen’s concept of stratified reproduction, Twine maps the intersections between colonialism, globalization, racism, and reproductive labor through her analysis of surrogacy, highlighting how “neoliberal discourse” is invested in “active, responsible, and positive (reproductive) actors.”<sup>13</sup> In the United States, the movement for fertility regulation is connected to the fight to legalize abortion access, the history of reproductive violence against enslaved Black women, and changing demographic shifts in women’s access to economic and educational opportunities, thus making surrogates’ rights a meaningful site for examining the interdependence of reproductive and economic rights.<sup>14</sup>

According to the existing literature, surrogates occupy a variety of economically and socially precarious statuses and thus face interlocking vulnerabilities both in the law and in social life.

There has been much debate about if and how surrogacy should be conceptualized as labor.<sup>15</sup> Marxist feminist scholarship has framed reproductive labor such as surrogacy in productive terms in order to account for new forms of labor that have emerged from the reproductive technologies economy under modern capitalism.<sup>16</sup> Other scholars have examined the commodification of care and intimacy and the ways in which “intimate labors” such as surrogacy, sex work, and care work maintain structural economic inequalities and reflect a pervasive devaluation of care work and feminized labor.<sup>17</sup> Others argue that the commodification of pregnancy impedes the broader rights fulfillment of women and their families and that surrogacy

is “reproductive exploitation.”<sup>18</sup> Further, there is overlap between political communities campaigning for the criminalization of abortion and for the criminalization of surrogacy.<sup>19</sup> Sharmila Rudrappa notes that legal bans on surrogacy risk deepening the exploitation of surrogates and further devaluing reproductive labor.<sup>20</sup>

Ethnographic scholarship looking at the lived realities of surrogates has historically focused on India, Israel, Russia, and, increasingly, the United States.<sup>21</sup> While there is overlap in how scholars interrogate the notion of surrogacy as work and the idea of surrogacy as a challenge to “the ‘ideology of motherhood,’” there are distinct “repro-regional moral frameworks” that play a key role in shaping surrogacy.<sup>22</sup>

Existing scholarship reveals how surrogates reject the label of motherhood. Christina Weis’s work reveals that surrogates in Russia employ an explicit labor framing of their experiences of surrogacy, and Elly Teman’s study of surrogates in Israel, while not explicitly framing surrogacy as work, similarly reveals a rejection of maternal status and notes that surrogates and intended mothers are placed in “unique relations with the nation-state.”<sup>23</sup> When the nation-state is the primary duty bearer of economic rights, the legal ambiguity of surrogates leaves their rights vulnerable to violation. Alternatively, Amrita Pande’s work reveals that Indian surrogates reject the labor framing and connect being a “good mother” with being a “good surrogate,” thus reinforcing a moral framing of motherhood.<sup>24</sup>

Scholars of labor rights have not fully engaged with the challenges of surrogacy as work because it is sometimes considered illegitimate feminized labor; Anindita Majumdar notes how the stigmatization of surrogacy informs the ways in which it is delegitimized as labor.<sup>25</sup> Drawing parallels between productive labor and reproductive labor offers an opportunity to assert the economic rights of surrogates under existing economic rights conventions.<sup>26</sup> Pande and Rudrappa point out how laborers are

rendered disposable under a global capitalist economy, noting that the framing of surrogates as “wombs for rent” contributes to the framing of surrogates as unskilled laborers.<sup>27</sup> Additionally, Pande notes how surrogates are disciplined to become “good mother workers” similar to the construction and reinforcement of the “good worker” in traditional occupations.<sup>28</sup>

### *Sexualized care work and stigma*

Pande’s definition of sexualized care work as “a new type of reproductive labor ... similar to existing forms of care work but [one that] is stigmatized in the public imagination, among other reasons, because of its parallel with sex work” offers greater insight into the stigma around surrogacy and reveals the tension between the rights associated with sexual citizenship and economic rights for those engaged in reproductive labor.<sup>29</sup> This definition is consistent with Sophie Lewis’s observation of a pervasive “whore stigma” shaping the social perception of surrogates’ work in the global economy.<sup>30</sup> Human rights scholars have noted that barriers to sexual and reproductive rights have been largely shaped by stigma and that less stigmatized care work is slightly less contested within international standards around interdependent economic and reproductive rights, such as paid family leave and expanded social security benefits.<sup>31</sup>

The existing literature demonstrates that surrogates are acutely aware of how stigma shapes perceptions of surrogacy: Pande observes how surrogates mitigate stigmas associated with surrogacy, such as framing their role as surrogates through the lens of altruism and emphasizing the differences between sex work and their work as surrogates, and Heather Jacobson’s work similarly finds that US surrogates in some cases also deploy an altruistic framing of their role as surrogates.<sup>32</sup> Zsuzsa Berend’s work shows that the altruistic framing of surrogacy coexists with the language of paid work also simultaneously deployed by surrogates to dis-

cuss their experiences.<sup>33</sup>

How stigma informs perceptions of surrogacy is largely dependent on the local context of the surrogacy market. Indian surrogates in Pande's study reject a framing of their participation in surrogacy as work, instead deploying an altruistic framing to minimize stigma, and Daphne Yeshua-Katz and Natalia Khvorostianov's work similarly shows the strategies that surrogates deploy in response to stigmatization, such as internalizing stigma by self-identifying as "bad-wives" and minimizing the appearance of their surrogate pregnancies by avoiding public spaces and constructing narratives to "cover" their pregnancies.<sup>34</sup> Stigma contributes to the "invisibilization" of surrogacy, which is resonant with other forms of sexualized care work that have been rendered invisible and thus excluded from the ability to claim economic rights under legal frameworks.<sup>35</sup>

### Human reproduction as work

Opponents of legalizing surrogacy often invoke the biological relationship between the fetus and carrier as justification for why surrogates should be considered the mothers of the fetus; this argument is rooted in pronatalist constructions of motherhood as a condition for women's citizenship in social life.<sup>36</sup> Additionally, given the variation in "repro-regional frameworks," there is varied cultural resistance to framing surrogacy as work.<sup>37</sup>

Compared to the literature on reproductive labor as a site for claiming economic rights, less work exists on the framing of human reproduction as work within economic rights.<sup>38</sup> There is some mention of reproduction as work within materialist feminist movements addressing the devaluation of women's reproductive labor; in *Wages Against Housework*, Silvia Federici invokes a framing of reproduction as work, characterizing miscarriages as "work accident[s]."<sup>39</sup> Additionally, in her work on how activists have strategically advocated for hu-

man rights, Shareen Hertel examines how feminist organizers in Mexico fought against pregnancy discrimination in maquiladoras by arguing that human reproduction was ultimately reproducing society and thus was an essential form of labor requiring compensation and labor protections.<sup>40</sup> Framing reproductive rights as economic rights asserts their interdependence in advancing human rights and shows how both need to be fulfilled in order for either of them to be fully realized. Thus, economic rights, like all other human rights, are "indivisible and interdependent," meaning that "one set of rights cannot be enjoyed fully without the other."<sup>41</sup>

One of the challenges of situating surrogacy within economic rights discourse is that the surrogacy market exists across "reproductive, productive, and virtual economies," and, as a form of sexualized care work that is simultaneously framed as productive and reproductive labor, cannot be neatly categorized within mainstream labor rights frameworks.<sup>42</sup> Like other reproductive rights challenges, surrogacy is imbued with moral and political framings rooted in gender injustice, intensifying economic stratification, and stigmas around reproduction and sexuality.<sup>43</sup> Additionally, the legal permission of altruistic surrogacy, alongside restrictions and a lack of legal status for commercial surrogacy, further reinforces the devaluation of reproductive labor and the moral "inferiority" of commercial surrogacy, creating additional barriers to legitimizing surrogates as laborers eligible to claim workers' rights.<sup>44</sup>

Despite these challenges, analyzing legal frameworks and treaties addressing reproductive rights and economic rights can offer meaningful insights into how and where surrogates can claim economic and reproductive rights. One example is the 2011 Convention No. 189 Concerning Decent Work for Domestic Workers, put forth by the International Labour Organization.<sup>45</sup> Having an international treaty that explicitly outlines the

rights of domestic workers globally has given local movements a concrete legal and policy framework through which to frame local struggles for ensuring the economic and social rights of domestic workers.<sup>46</sup> Similarly, the strategic use of conventions such as the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) at the local level has been meaningful in addressing barriers to claiming gender-based rights.<sup>47</sup> These two instruments—Convention No. 189 and CEDAW—which have already been strategically implemented at the local level, may thus provide useful templates for surrogates to organize and to make claims for economic and reproductive rights. This recommendation complements Rudrappa’s call for surrogacy cooperatives as a meaningful reformist measure in addressing the rights of surrogates. The following section examines relevant treaties and conventions linking reproductive rights and economic rights that offer possibilities for strategic implementation to advance surrogates’ rights.

### International rights conventions linking reproductive rights and economic rights

There are several conventions and documents integral to analyzing the legal foundations of protections for the economic rights of surrogates and

to locating where economic rights and reproductive rights intersect in international human rights standards: the International Covenant on Economic, Social and Cultural Rights (ICESCR), CEDAW, the 1994 International Conference on Population and Development (ICPD) Programme of Action, the International Labour Organization’s Maternity Protection Convention No. 183, and a 2018 report from the Special Rapporteur on the sale and exploitation of children on surrogacy (see Table 1).<sup>48</sup> There are limitations to looking solely at existing documents in international law for enshrining human rights. However, while limited, critical examination of existing laws and treaties regarding issues of reproductive rights has been important for fulfilling and protecting reproductive rights. Addressing the specific legal vulnerabilities of surrogates within the international human rights framework reveals opportunities for solidifying the relationship between economic rights and reproductive rights, particularly for those most vulnerable to rights violations.<sup>49</sup>

The ICESCR offers a partial acknowledgment of reproductive rights as necessary for fulfilling economic rights. Article 12(2)(a) emphasizes children’s health as one of four defining conditions of the right to health, but it fails to include specific provisions for the right to maternal health beyond

TABLE 1. Overlap between economic rights and reproductive rights in international human rights standards

ICESCR	CEDAW	ICPD Programme of Action	Special Rapporteur report on surrogacy	ILO Maternity Protection Convention No. 183
<p>Article 7: “equal pay for equal work”</p> <p>Article 10: “protections for working mothers”</p> <p>Article 12(2)(a): “the healthy development of the child”</p>	<p>Article 3: “to ensure the full development and advancement of women”</p> <p>Article 5: “gender stereotypes and maternity”</p> <p>2019 comment on the criminalization of surrogacy in Cambodia</p>	<p>Paragraph 7.3: “negative attitudes towards women and girls”</p>	<p>Paragraph 73: “a properly regulated system of commercial surrogacy”</p> <p>Paragraph 78(b): “the rights of surrogate mothers”</p>	<p>Article 2(1): “atypical dependent work”</p>

“special protection” for mothers “during a reasonable period before and after childbirth,” and it does not include provisions for the right to reproductive choice as it relates to other economic, social, and cultural rights included in the convention.<sup>50</sup> Regarding workers’ rights and reproductive rights, article 10 notes that “working mothers” have a right to special protections such as paid leave and social security benefits “during a reasonable period before and after childbirth.”<sup>51</sup>

The 1994 ICPD Programme of Action, regarded as one of the most ambitious international human rights documents outlining sexual and reproductive rights, does not establish an explicit connection between economic rights and the fulfillment of reproductive rights: article 7.3 notes “high risk sexual behavior,” discrimination, “negative attitudes towards women and girls,” and “the limited power many women and girls have over their sexual and reproductive lives” as explanations for existing barriers to reproductive health, omitting any mention of how these barriers are reinforced by barriers to the fulfillment of economic rights.<sup>52</sup> Despite both naming special protections with regard to the status of women and girls, neither the ICESCR nor the Programme of Action establish explicit connections between economic rights and reproductive rights. Beyond addressing the discrimination that surrogates may encounter, the Programme of Action is limited in its ability to account for the nuances of the reproductive technologies market.

While CEDAW addresses the right to freedom from gender-based discrimination, violence, stereotyping, harassment, and the right to equal opportunities in social life, it addresses neither specific reproductive rights nor the role that fulfilling economic rights plays in advancing reproductive rights. The most explicit acknowledgment of reproductive rights is found in the introduction, which acknowledges the “social significance of maternity” and reproductive labor and states that “the role of

women in procreation should not be a basis for discrimination.”<sup>53</sup> While this addresses the right to freedom from discrimination regarding maternal reproductive labor, it does not address positive reproductive rights, such as the right to accessible reproductive health care services, the right to protections against environmental reproductive health hazards, and the right to economic conditions that support one’s autonomy in family planning.

The ILO Maternity Protection Convention does not address the linkage between reproductive rights and economic rights beyond the right to maternity leave for pregnant workers. The convention has language regarding the protection of mothers employed in formal and informal work (framed as “atypical dependent work”), as well as the enforcement of rights such as maternity leave and the right to employment protection and nondiscrimination as it relates to pregnancy. This convention details the economic benefits that pregnant women are entitled to from the state, protections against discrimination in the labor market, and rights to freedom from their employment infringing on their health or their children’s health. However, the language regarding the reproductive rights of pregnant persons is vague, stating that members should ensure that “pregnant or breastfeeding women” are not forced to perform labor that jeopardizes their health or the health of their “child.”<sup>54</sup> While this addresses the right to freedom from harmful working conditions, it does not acknowledge the myriad other ways in which maternal health is impacted by the fulfillment of positive economic rights, such as the right to an adequate standard of living and the right to fair wages. However, this language establishes that reproductive health and one’s status as a laborer are linked by pregnancy’s impacts on the body of the rights claimant, and thus raises the possibility for future rights laws and standards to consider how recognizing economic rights, like reproductive rights, as embodied rights may help establish their interdependence.<sup>55</sup>

The above analysis demonstrates a lack of internationally consistent standards for surrogates to claim reproductive and economic rights together, as well as a lack of systemic regulation to maintain ethical practices. The challenge of non-regulation is also seen in other sectors of the informal economy, such as sex work and agriculture, as well as in issues such as unregulated fishing.<sup>56</sup>

### Surrogates as rights claimants

There has not yet been a judicial case before an international body adopting an approach to advancing the rights of surrogates through labor law, and, as a result, surrogates are unable as workers to claim economic rights on the state under existing international human rights laws and standards.<sup>57</sup> The aforementioned 2018 report from the Special Rapporteur on the sale and sexual exploitation of children argues that a lack of international regulations for the surrogacy economy risks leaving the children of surrogacy arrangements vulnerable to rights violations, but the report does not address the vulnerability of surrogates' rights.<sup>58</sup> Most of the report's recommendations regarding the regulation of surrogacy and concerns for the human rights implications focus on the perceived threats that surrogacy poses to the rights of children.

A case regarding the criminalization of surrogacy in Cambodia offers insight into how existing conventions could establish state obligations to protect and fulfill the rights of surrogates.<sup>59</sup> Following the 2016 ban on commercial surrogacy in Cambodia, numerous surrogates in the country were arrested. Some women were faced with either a 20-year prison sentence or having to raise the child of the intended parents as their own, placing an additional financial burden on the surrogates who were already living in economic precarity. The ruling essentially favored forced parenthood. Others who were arrested were charged with human trafficking. The Committee on the Elimination of

Discrimination against Women first acknowledged the rights of surrogates in 2019 in response to Cambodia's law, arguing that surrogates should have protections against exploitation, discrimination, and violence.<sup>60</sup> While the committee recognized surrogates' rights to freedom from discrimination and violence, it did not explicitly address surrogates' positive economic rights, such as their right to a decent standard of living, or who should be the duty bearer of these rights for surrogates.

Articles 3 and 5 of CEDAW may also offer a place to advocate for the inclusion of surrogacy in international labor law, because they outline state requirements to address gender-based stereotypes and create measures that "ensure full and equal enjoyment of social, political and economic rights for women."<sup>61</sup> This language explicitly addresses gender-based "stereotypical assumptions" as they relate to labor and thus may be useful in addressing the stigma of surrogacy as "indecent work" in the claims-making process.<sup>62</sup> Additionally, article 11(f) may be an opportunity to assert the relationship between economic rights and reproductive rights, as it outlines "the right to protection of health and to safety in working conditions, including the safeguarding of the function of reproduction."<sup>63</sup> Other than the 2019 comment, the Committee on the Elimination of Discrimination against Women has been largely silent on the rights of surrogates despite the implications for gender-based human rights. Additionally, the language used by the committee to address the status of surrogates speaks more to a framing of surrogates as "mothers" rather than as workers entitled to labor rights.<sup>64</sup> This is also reflected in the ICESCR, which addresses the rights to paid leave and social security benefits for "working mothers," reinforcing the notion that pregnant people's ability to claim economic rights is dependent on claiming maternal status.<sup>65</sup> Yoking the claim-making in this way essentially excludes the many surrogates who do not identify as mothers to the child they are gestating and surrogates

who, although they may consider themselves a mother or “mother-worker,” are not recognized as mothers within their specific regional human rights framework.<sup>66</sup>

Further, the concept of “equal pay for equal work” in article 7(a) of the ICESCR is also limited; this article guarantees states the right to ensure “fair wages and equal remuneration for work of equal value without distinction of any kind, in particular women being guaranteed conditions of work not inferior to those enjoyed by men, with equal pay for equal work.”<sup>67</sup> While this provision addresses the devaluation of women’s work in the productive economy, it fails to capture the nuances of reproductive labor and of the contractual relationships within the reproductive tourism economy.

Similar to the ICESCR and CEDAW, the ILO Maternity Protection Convention outlines the protection of mothers employed in both formal and informal work and the right to maternity leave and the right to employment protection and nondiscrimination as it relates to pregnancy but does not address the unique role of surrogates as laborers.<sup>68</sup> According to article 2(1), the convention “applies to all employed women, including those in atypical forms of dependent work.”<sup>69</sup> However, the protections outlined speak specifically to pregnant *mothers* and thus is limited in its ability to cover surrogates. Additionally, as article 6 states regarding the “means test” for economic benefits when the rights claimant does not qualify under national laws and regulations, the lack of national legal protections leaves surrogates unable to claim rights if their rights as laborers are not recognized at the national level. While the convention has been ratified by 43 states, key commercial surrogacy hubs—such as the United States, India, and Ukraine—have not ratified it. This trend is similarly seen in conventions addressing the rights of migrant workers: ratifiers include the “sending” states from which large numbers of migrant laborers come, while “receiving”

states are reluctant to ratify, leaving migrant workers vulnerable to labor rights violations.<sup>70</sup> Given the variation in laws concerning surrogacy among states, there is a need for international and national legal frameworks regarding the economic rights of surrogates.<sup>71</sup>

### Assisted reproductive technologies and the right to access

The development of in vitro fertilization has dramatically shifted the surrogacy market by “[reducing] the legal and emotional risks” of traditional surrogacy practices by removing the genetic relationship between the surrogate and the fetus, thus making surrogacy arrangements more appealing to intended parents.<sup>72</sup> Reproductive technologies have offered more pathways to parenthood, particularly for same-sex couples and couples who are infertile and desire biological children, and, as a result, questions of access regarding reproductive technologies are also relevant to the intersection of reproductive rights and LGBTQ+ rights. Organizations such as Men Having Babies are advocating to increase gay men’s access to the surrogacy economy in an effort to address barriers to parenthood; however, there is still a centering of the needs of the “consumer” rather than surrogates.<sup>73</sup> National laws restricting or banning commercial surrogacy have also been aligned with conservative agendas to restrict same-sex couples from becoming legal parents, revealing concerns around who has the right to parent in the age of reproductive technologies, a dimension of reproductive rights often overlooked in mainstream reproductive rights discourses.<sup>74</sup> As assisted reproductive technologies expand, it will become more urgent for states to ensure positive reproductive rights and positive economic rights in their national laws and standards, both for intended parents who have been historically marginalized from pathways to parenthood and for workers in the reproductive

tourism economy, and for these protections to be consistent with international standards given the transnationality of reproductive tourism.

## Conclusion

Existing international conventions and standards addressing reproductive rights and economic rights have not sufficiently adapted to the realities of the global reproductive technologies economy, leaving surrogates unable to claim both positive economic and reproductive rights. Additionally, aside from organizations such as Surrogacy360, few organizations have offered policy recommendations or guidelines for ensuring the rights and ethical treatment of surrogates in surrogacy contracts.<sup>75</sup> Support for national legal protections for surrogates as workers may be more likely where there is demonstrated support for legal protections enshrining the rights of queer parents.<sup>76</sup> As this analysis of existing rights conventions shows, the systemic sanctification of motherhood and the existing rights protections for pregnant people being tied to specific expectations of claiming motherhood as a status has created a substantial barrier to recognizing surrogates' rights under international human rights conventions, reinforcing the notion that work associated with motherhood is an altruistic "labor of love" rather than remunerative labor. Raising awareness about the realities of surrogacy through more comprehensive education is one potential avenue to address the stigma surrounding surrogacy and further the conversation around advancing economic and social rights for surrogates.

My recommendations are as follows: first, per Melinda Cooper and Cathy Waldby's work, future research should explore multinational trade organizations such as the World Trade Organization and trade agreements as potential sites for articulating the economic rights of surrogates given the ways that property rights inform the reproductive technologies market.<sup>77</sup> Similar to the work that has

been done on the case of Cambodia, further inquiry into how the legal restrictions on commercial surrogacy impact the fulfillment of surrogates' rights should take a country- or region-specific approach to account for the cultural nuances of surrogacy markets and experiences. Additionally, echoing Andrea Whittaker, Trudie Gerrits, and Christina Weis's recommendation, more research into under-explored surrogacy hubs such as Ghana, Laos, and Kazakhstan is needed to better reflect the current landscape of the industry.<sup>78</sup>

Second, in order to secure protections for reproductive rights, more work needs to be done to articulate the interdependence of reproductive rights within the framework of economic rights in order to better account for reproductive labor and how it has been historically excluded from reproductive rights and economic rights discourses. Recognizing surrogates as claimants of workers' rights offers an opportunity to expand the recognition of reproductive labor as labor within economic rights discourses and challenges the devaluation of work that persists along gendered, classed, and racialized lines. By drawing parallels between reproductive labor and productive labor and understanding surrogacy as work through the lens of stratified reproduction, as scholars such as Twine have done, existing rights frameworks such as ILO Convention No. 189 and strategic state-level implementations of this and other existing conventions may be useful in providing a template that surrogates can use to claim rights as workers and as a tool for organizing collective action against labor exploitation and other human rights violations that emerge within the practice of surrogacy. Ultimately, however, the fulfillment of one's human rights should not be dependent upon participation in paid work.

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# Building a Progressive Reproductive Law in South Africa

DONRICH THALDAR

## Abstract

This article delves into the expansion of procreative freedom in relation to assisted reproductive technologies (ARTs) in South African law, with reference to three seminal cases. In the case of *AB v. Minister of Social Development*, the minority of the South African Constitutional Court held that the constitutional right to procreative freedom is applicable to ARTs. Importantly, both the minority and the majority agreed on the principle of procreative non-maleficence—the principle that harm to the prospective child constitutes a legitimate reason to limit the procreative freedom of the prospective parents. Following this, *Ex Parte KF2* clarified the concept of the “prospective child” as relating to an idea, rather than an embryo. Finally, in *Surrogacy Advisory Group v. Minister of Health*, the controversial issue of preimplantation sex selection for non-medical reasons was examined. The court confirmed that the use of ARTs falls within the ambit of procreative freedom. While holding that preimplantation sex selection for non-medical reasons is inherently sexist, the court found that a woman’s right to procreative freedom—including the sex identification of an in vitro embryo—outweighs other considerations. These landmark cases establish a robust groundwork for a progressive reproductive law in South Africa.

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## Introduction

Assisted reproductive technologies (ARTs) is a collective term for technologies that enable human reproduction in artificial ways—in contrast with natural reproduction. Common examples are in vitro fertilization (IVF) and intra-cytoplasmic sperm injection. However, as technology improves, the list is sure to grow. ARTs have already and will continue to disrupt many of the values that are deeply ingrained in our traditional way of thinking. While the idea of “test tube babies” was the object of scorn for many when IVF started off, it has become normalized in modern society. But what is next? As ARTs incorporate knowledge of the human genome, humanity will gradually gain control over its own genetic composition.<sup>1</sup> Children produced by ARTs will not only be *conceived* but will also be *made* and may ultimately be *designed*. Humanity may change from being a natural phenomenon—the product of evolution—to being a cultural artifact.

Unlike in the United States, the use of ARTs is heavily regulated in many other countries, including South Africa.<sup>2</sup> This new and burgeoning field of the law—often referred to as reproductive law—has been the subject of significant litigation in South Africa over the past decade. In this paper, I analyze the three seminal cases that have made the most significant contributions to the development of reproductive law in South Africa: *AB v. Minister of Social Development, Ex Parte KF2*, and *Surrogacy Advisory Group v. Minister of Health*.<sup>3</sup> I consider these cases through the lens of procreative freedom versus the limitation thereof by the state.

### *AB v. Minister of Social Development*

The factual background of *AB* is a pursuit of motherhood by a woman cited under the pseudonym *AB* that spans over a decade.<sup>4</sup> The initial phase of her journey involved two unsuccessful IVF cycles using her and her husband’s own genetic materials in 2001. Confronted with the diminishing viability

of her own eggs due to age, *AB* resorted to utilizing donor eggs, proceeding with two additional IVF cycles in conjunction with her husband’s sperm. These attempts, however, did not result in a successful pregnancy. The personal challenges compounded in 2002 when, after 20 years of marriage, *AB*’s relationship dissolved, leaving her to face her fertility struggles as a single woman. Undeterred, *AB* underwent nine more IVF cycles, this time using both donor eggs and donor sperm, but none of these efforts culminated in the fulfillment of her dream to become a mother. In a twist of hope, a change of fertility clinics in 2009 led to two pregnancies for *AB*, but both ended in miscarriage. Following these heartbreaking outcomes and amidst her fertility specialist’s grim prognosis of her chances, *AB* came to terms with her infertility. Toward the latter part of 2009, a new possibility emerged for *AB* with the option of surrogacy. She engaged with a surrogacy agency and found a woman prepared to act as a surrogate. However, *AB*’s journey met a new obstacle in the form of a legal complication.

First, some legal background: In South Africa, surrogacy is governed mainly by chapter 19 of the Children’s Act.<sup>5</sup> Under this law, a commissioning parent(s) and the surrogate mother must enter into a surrogacy agreement and have this agreement confirmed by the High Court prior to the planned surrogate pregnancy.<sup>6</sup> Provided that the child is not genetically related to the surrogate mother, a surrogacy agreement that has been confirmed is enforceable and the child must be registered as the child of the commissioning parent(s) at birth.<sup>7</sup> Any surrogacy arrangement not in compliance with this scheme is unenforceable and unlawful.<sup>8</sup>

However, one element of this statutory scheme posed an obstacle to *AB*: Section 294 of the Children’s Act requires that commissioning parents use their *own* gametes for the conception of the child.<sup>9</sup> This excluded *AB*, as it had long since been established that her own eggs were unsuitable for use in IVF.<sup>10</sup> *AB* received this legal advice with a mixture

of shock, sadness, and bafflement—especially given that she had been legally allowed to use both male and female donor gametes for several years while attempting to achieve pregnancy herself through IVF.<sup>11</sup>

Accordingly, AB decided to challenge the constitutionality of section 294 of the Children’s Act in court. In this quest, she was joined by a nonprofit organization, the Surrogacy Advisory Group, as second applicant.<sup>12</sup> This is noteworthy, as some years later the Surrogacy Advisory Group would launch an audacious legal challenge of its own—but I will return to this later.

The gist of AB’s legal argument was that the impugned provision (section 294 of the Children’s Act) was arbitrary and that it discriminated against her based on her status as being infertile.<sup>13</sup> This argument can be summarized as follows: If a woman is purportedly fertile in the sense that she can carry a pregnancy herself, she is legally entitled to select to use male and female donor gametes.<sup>14</sup> However, if she is infertile in the sense that she *cannot* carry a pregnancy herself and must use a surrogate mother, the legal position becomes the inverse: Now she is legally prohibited from using donor gametes.<sup>15</sup> AB submitted that this constituted discrimination based on her infertility. She further argued that the impugned provision infringed her procreative freedom (expressed in the rights to dignity, privacy, and bodily and psychological integrity) and her right to access reproductive health care services.<sup>16</sup>

However, the minister of social development, the member of the national executive responsible for the administration of the Children’s Act, opposed AB’s application.<sup>17</sup> The minister was supported by the University of Pretoria’s Centre for Child Law.<sup>18</sup> Their argument was that the best interests of the prospective child demand that the prospective child have a genetic link with at least one commissioning parent—and if there is only one parent, then the child must have a link with that parent.<sup>19</sup> This argument rests on two presuppo-

sitions. First, a presupposition of a legal principle: that the constitutional protection of the best interests of the child extends to the prospective child.<sup>20</sup> Second, an empirical presupposition: that children are harmed by not knowing their genetic origins, or at least that not knowing one’s genetic origins is not in one’s best interests.<sup>21</sup>

The first presupposition proposed a significant development in South African law: that the court must in constitutional matters concerning prospective children consider their best interests and that the interests of prospective children—persons who are not yet in existence—can limit the rights of existing persons.<sup>22</sup> Interestingly, all the parties involved in the litigation accepted this presupposition, as did the court—both in its minority and its majority judgment.<sup>23</sup> This was a remarkable event and, I suggest, may still be highly consequential in the future. But what exactly is a “prospective child”? Is it an embryo? A fetus? Perhaps a sperm cell? This crucial question was not considered in *AB*, and I return to this question when I discuss the next case.

How was *AB* decided? Since the parties all agreed on the first presupposition, the legal battle focused on the second one, which made an empirical claim that children are harmed by not knowing their genetic origins, or at least that not knowing one’s genetic origins is not in one’s best interests. Here, the applicants, AB and the Surrogacy Advisory Group, filed expert opinions by world-leading psychologists to prove that the second presupposition is false.<sup>24</sup> The minister filed an opposing expert opinion by a bioethicist, but this expert opinion was thoroughly discredited in the applicants’ papers—so much so that the minister eventually abandoned any reliance on her own expert.<sup>25</sup> The Centre for Child Law referred the court to two academic articles on children and genetic relatedness, but the content of these articles was a precarious basis for the empirical claim that children are harmed by not knowing their genetic origins, or at least that not knowing one’s genetic origins is not in one’s

best interests.<sup>26</sup> However, in a stunning display of post-truth jurisprudence, the majority of the Constitutional Court ignored the evidence before it and sided with the minister and the Centre for Child Law.<sup>27</sup> In the end, AB lost her case. But today, a decade later, the new case of *KB*, which was launched in Mpumalanga based on different facts, offers a glimmer of hope to rectify this injustice over time.<sup>28</sup>

While I am critical of the majority judgment in *AB*, the minority judgment penned by Justice Khampepe and concurred to by Justices Cameron, Froneman, and Madlanga is an 84-page-long tour de force infused with both reason and compassion. At the basis of the minority judgment is the recognition that the right to procreative freedom is not limited to natural procreation but also includes the use of ARTs.<sup>29</sup> Importantly, on this basic point, the majority judgment was quiet. Accordingly, the minority judgment's interpretation of the ambit of the right to procreative freedom as including the use of ARTs stands uncontradicted and constitutes persuasive authority.<sup>30</sup> This, I suggest, is a milestone in South African reproductive law. It is worth quoting the following passage from the minority judgment:

*We are fortunate ... to live in an era where the effects of infertility can be ameliorated to a large extent through assistive reproductive technologies. The technological advances seen over the last half century have greatly expanded the reproductive avenues available to the infertile. These reproductive avenues should be celebrated as they allow our society to flourish in ways previously impossible.*<sup>31</sup>

### *Ex Parte KF2*

I now return to the crucial question that was left unanswered in *AB*—namely, what exactly is the “prospective child”? This question was answered in the subsequent case of *Ex Parte KF2*.<sup>32</sup> This case unfolded an array of legal questions that went beyond the scope of a seemingly typical surrogacy confirmation application. At the helm of the case were the commissioning parents—a couple whose

journey to parenthood had been hindered by medical hurdles since their union in 2006.<sup>33</sup> Following the futile pursuit of parenthood through five IVF cycles, the couple was introduced to a potential surrogate, a young woman of 20, who was already a mother of two. The commissioning couple had four unused in vitro embryos remaining after the fifth failed IVF attempt and planned to use these embryos for the surrogacy pregnancy, as they had been created from the couples' own gametes. Despite the seeming simplicity of the case, where the clinical psychologist's reports appeared to favor the suitability of the parties involved, the application faced an unexpected setback in court. The suitability of the intended surrogate mother was questioned by the court. The fact that she became a mother at the age of 17 and never returned to finish school was under scrutiny.<sup>34</sup> The court, despite the psychologist's report, found it difficult to believe that the intended surrogate mother had the emotional maturity to comprehend the magnitude of her decision and dismissed the surrogacy confirmation application.<sup>35</sup>

The problem was that there were no objective criteria for assessing the suitability of an intended surrogate mother.<sup>36</sup> As a consequence, lawyers, psychologists, and judges all applied their own idiosyncratic criteria.<sup>37</sup> Accordingly, the commissioning couples' legal counsel devised the following approach: First, a panel of three psychologists was convened to draft a set of objective criteria for surrogate-mother suitability assessment. Next, a fourth psychologist was asked to interview the same intended surrogate mother in light of the set of objective criteria.<sup>38</sup> This psychologist provided a positive report of the intended surrogate mother and commented that penalizing her for her past decisions was unfair, suggesting instead that the focus should be on her evolved emotional maturity.<sup>39</sup> Thus, the couple relaunched their application in the Johannesburg High Court with supplemented papers.

The Johannesburg High Court accepted the objective criteria developed by the panel of psychologists and incorporated them into its judgment.<sup>40</sup> In this way, the set of objective criteria for surrogate-mother suitability became part of the law and has provided guidance to psychologists, lawyers, and judges ever since.<sup>41</sup> Next, the court also accepted the new psychological report on the intended surrogate mother.<sup>42</sup> However, the court raised a new issue during oral argument. Since the commissioning couple already had four cryopreserved embryos, and the Children’s Act provided that the court should consider the best interests of the “child that is to be born,” was it not incumbent upon the court to consider the best interests of each one of these embryos, and, if so, what would this entail in practical terms?<sup>43</sup> It was a broad and open question, but highly consequential for reproductive law.

Counsel for the commissioning couple argued that the prospective child is not something tangible but rather an idea in one’s mind and that this idea of a prospective child can exist in one’s mind irrespective of whether one already has embryos.<sup>44</sup> In other words, the idea of a prospective child is not linked with a specific in vitro embryo. Accordingly, none of the in vitro embryos can be equated with the prospective child.<sup>45</sup> There is of course a potential link between the in vitro embryos and the prospective child—namely, that the in vitro embryos are the biological material that may, if the pregnancy is successful, give rise to the prospective child.<sup>46</sup> The essence of counsel’s submissions was incorporated into the judgment in *Ex Parte KF2*.<sup>47</sup> This is highly consequential for reproductive law, as it provides a clear theoretical basis for understanding the legal relevance of acts directed toward the in vitro embryo: it confirms the well-established position in South African law that the embryo itself does not have any interests or rights.<sup>48</sup> But this does not mean that there is legal *carte blanche* to do anything with the embryo—if an act directed toward an embryo is likely to have an effect on the

prospective child, the interests of the prospective child are indeed legally relevant.

### *Surrogacy Advisory Group v. Minister of Health*

The third seminal case—*Surrogacy Advisory Group v. Minister of Health*—was surely the most controversial of the three and was a true test of the depth of South Africa’s commitment to procreative freedom.<sup>49</sup> At the heart of this case was the issue of sex selection. To follow the argument in this case, one needs to understand two ARTs, preimplantation genetic testing for aneuploidy (PGT-A) and non-invasive prenatal testing (NIPT).

In normal human development, an embryo inherits 23 chromosomes from each parent to make up a total of 46. However, sometimes errors occur during cell division, and embryos may end up with a missing or an extra chromosome—a condition known as aneuploidy.<sup>50</sup> Aneuploidy is a leading cause of miscarriage and can result in conditions such as Down syndrome.<sup>51</sup> PGT-A is designed to detect aneuploidy in an embryo before the embryo is transferred to a woman’s uterus.<sup>52</sup> It entails taking a biopsy sample of a few cells from an in vitro embryo and then testing the sample for aneuploidy. This test helps identify which embryos have the correct number of chromosomes and therefore have the best chance of leading to a successful pregnancy if implanted.<sup>53</sup> Importantly, PGT-A also discloses whether an embryo has XX or XY chromosomes. As a result, using PGT-A technology, parents can select the sex of the embryo to be transferred to the mother’s uterus.

I now turn to the second relevant technology, NIPT. Whereas PGT-A is performed before an embryo is transferred to a woman’s body, NIPT is performed at about 10 weeks of pregnancy.<sup>54</sup> NIPT entails taking a blood sample from the mother’s arm.<sup>55</sup> This testing detects small pieces of DNA from the placenta, known as cell-free DNA, which circulate in the mother’s bloodstream.<sup>56</sup> Similar to PGT-A, NIPT also tests for aneuploidy and reveals

the sex of an embryo.<sup>57</sup> NIPT is typically used for detecting conditions such as Down syndrome, which can then be followed by an abortion.<sup>58</sup> However, it can also be used for sex selection: a pregnant woman can abort an embryo if it is not of the desired sex.<sup>59</sup> She can then attempt to become pregnant again and repeat the process until she is pregnant with an embryo of the desired sex.<sup>60</sup>

In 2012, the minister of health promulgated the Regulations relating to the Artificial Fertilization of Persons, which prohibit the use of any preimplantation or prenatal test to select the sex of child, except if the selection is for medical reasons—in other words, to avoid a sex-linked genetic disorder.<sup>61</sup> This means that is unlawful to use either PGT-A or NIPT for non-medical sex selection. However, is this prohibition not a limitation on the procreative freedom of intended parents? And, if so, can it be justified? These were the core issues in *Surrogacy Advisory Group v. Minister of Health*.

The Surrogacy Advisory Group, suing in the public interest, challenged the constitutionality of the prohibition of non-medical sex selection. The main thrust of the Surrogacy Advisory Group's litigation strategy was to rely on the Choice on Termination of Pregnancy Act (Choice Act) and to contrast the procreative *freedom* that women enjoy under the Choice Act with the impugned provision in the regulations that *restricts* freedom.<sup>62</sup> Let me explain: Generally speaking, the Choice Act strikes a *balance* between the procreative freedom of the pregnant woman and the interest of the state in protecting prenatal life.<sup>63</sup> During the first trimester, the procreative freedom of the pregnant woman supersedes the state's interest.<sup>64</sup> Then, from the second trimester, and increasingly so in the third trimester, the state's interest supersedes the woman's procreative freedom.<sup>65</sup> For example, in the third trimester, only a select number of factors, such as the life of the pregnant woman, can supersede the state's interest in protecting prenatal life.<sup>66</sup> However, the focus of the lawsuit was on the first trimester. During

this period, the Choice Act provides that a woman can have an abortion without having to provide a reason.<sup>67</sup> In other words, any reason—including sex selection—is a good enough reason to have an abortion.<sup>68</sup> Remember that NIPT can be used as early as the 10th week of pregnancy. As a result, the Surrogacy Advisory Group argued that the Choice Act makes it lawful for a pregnant woman who is intent on selecting the sex of her child to practice first-trimester *prenatal* sex selection.<sup>69</sup> Given that the Choice Act (which is primary legislation) supersedes the regulations (which is subsidiary legislation), the regulations' ban on non-medical *prenatal* sex selection is rendered invalid.<sup>70</sup> But where does this leave *preimplantation* sex selection—that is, sex selection at the in vitro stage?

If South African law allows prenatal sex selection via the Choice Act, but prohibits preimplantation sex selection via the regulations, the law effectively forces a woman who is intent on selecting the sex of her prospective child to use NIPT at 10 weeks of pregnancy, together with elective abortion and repeated pregnancies, rather than allowing her the option of preimplantation sex selection.<sup>71</sup> This of course has a negative effect on such woman's bodily integrity and psychological integrity.<sup>72</sup> Consider her bodily integrity: while preimplantation sex selection entails no medical risks, the abortion does entail physical discomfort and medical risk. Thus, bodily integrity is compromised.<sup>73</sup> Now consider her psychological integrity: while preimplantation sex selection does not require the destruction of the woman's in vitro embryos, abortion by definition destroys an embryo in the woman's body. Many women value embryonic life. Thus, psychological integrity is infringed.<sup>74</sup>

The minister of health answered the Surrogacy Advisory Group's argument by denying that there is any infringement of the right to bodily and psychological integrity of a woman, as the in vitro embryo that can be tested through PGT-A is outside the woman's body.<sup>75</sup> However, this argument is

blind to the *effect* that the ban on sex selection has on a woman's body, and therefore this argument did not pose a significant obstacle. The minister further argued that, in the event that the court found an infringement of the right to bodily and psychological integrity, the state has a legitimate purpose in prohibiting non-medical sex selection, as it is inherently sexist and unethical.<sup>76</sup> This, I suggest, was the minister's strongest position.

In reply, the Surrogacy Advisory Group argued that the South African Constitution embraces the idea of value pluralism and that the state cannot enforce the moral convictions of one section of the population on everyone.<sup>77</sup> Counsel for the Surrogacy Advisory Group elaborated on this argument as follows:

*In our country, we have, inter alia, traditional nuclear families (husband, wife, and children), polygamous marriage families, inter-racial families, same-sex families, adoption families, and single-parent-by-choice families ... There is clearly significant diversity. But all these families deserve equal concern by the state. And the family life of each family is protected under the auspices of the right to privacy ... There can be a multitude of reasons for wanting a child of a certain sex, which would depend on each family's circumstances: It can be a parent wanting a companion of a certain sex, feeling more able to rear a child of a certain sex, or wanting to build a family with the desired composition of boys and girls ... These are all personal reasons within the context of the family life of different families ... Importantly, one may not agree with the way in which other families live their lives or raise their children. For example, one may believe that polygamy is immoral, or same-sex marriage is immoral, or inter-racial marriage is immoral, but this is one's private moral opinion. It would be antithetical to our constitutional dispensation to try to enforce such private morality through the law. However, that is exactly what the impugned provision does.<sup>78</sup>*

The court's judgment on the issue of sex selection is over 5,000 words. Contrary to the Surrogacy

Advisory Group's position, the court held that sex selection is inherently sexist because it relies on stereotypes of what it means to be a girl or boy child.<sup>79</sup> However, the court held that this issue is overshadowed by a woman's right to procreative freedom.<sup>80</sup> The court agreed with the Surrogacy Advisory Group's argument that contrasted the Choice Act and the impugned provision in the regulations.<sup>81</sup> The court observed that a woman need not give reasons for an abortion in the first trimester and that this means that should a woman choose to abort because of the sex of the child, she is free to do so.<sup>82</sup> The court held that this creates an untenable situation where *prenatal* non-medical sex selection is lawful in terms of the Choice Act, but *preimplantation* non-medical sex selection is prohibited.<sup>83</sup> As a result, the court held that the impugned provision in the regulations is unconstitutional.

What is most remarkable about the judgment is that it explicitly held that sex selection falls within the ambit of procreative freedom: "Sex selection can be understood as part of reproductive autonomy ... The available technology just increased the number of options, thereby increasing reproductive liberty."<sup>84</sup> I suggest that this is the correct legal view of how the ambit of rights should evolve in synchronization with the advent of new technology—even if the new technology is controversial. As Justice Sachs remarked in the momentous case of *Minister of Home Affairs v. Fourie* (the 2005 Constitutional Court judgment that ordered Parliament to enact legislation to legalize same-sex marriage in South Africa), "Indeed, rights by their nature will atrophy if they are frozen."<sup>85</sup>

This interpretation of the ambit of procreative freedom—both by the *AB* minority and by the court in *Surrogacy Advisory Group*—lays a solid foundation for building a progressive reproductive law in South Africa.

It is interesting to note that the judgment in *Surrogacy Advisory Group* was handed down less than a month after the US Supreme Court's decision

in *Dobbs v. Jackson Women’s Health Organization*.<sup>86</sup> However, while *Dobbs* walked back procreative freedom in the US, *Surrogacy Advisory Group* was a bold move forward in South Africa. In fact, it relied on the South Africa’s national abortion legislation, the Choice Act, to reach its conclusion related to the use of ARTs. This highlights the foundational nature of abortion legislation in reproductive law.<sup>87</sup>

## Conclusion

I suggest that two core principles have crystallized in the three seminal cases analyzed in this paper. First, procreative freedom includes within its ambit the use of new ARTs—irrespective of whether the use of such new technologies is socially controversial. Although the use of new ARTs does not directly affect any existing person, it does potentially affect the prospective child. From this flows the second principle—namely, that the scope of possible procreative decisions that prospective parents may take (at least in the context of using ARTs) should be legally limited to exclude decisions that will cause harm to the prospective child. My colleague Bonginkosi Shoji and I call this the principle of “procreative non-maleficence.”<sup>88</sup> Although for legal analytical purposes it is based on the *AB* judgment, it aligns with classic liberal theory and essentially applies John Stuart Mill’s dictum that freedom can be limited only if it harms someone else in the context of the use of ARTs.<sup>89</sup>

Guided by the twin principles—the progressive, pluralist interpretation of procreative freedom, and the principle of procreative non-maleficence—South Africa stands poised and ready to embrace the challenges emerging in the landscape of reproductive law, as science marches forward.

## Note

This paper is based on a lecture that I delivered at the University of KwaZulu-Natal on August 23,

2023. The lecture can be accessed at <https://www.youtube.com/watch?v=apfykqtMvok&t=46s>.

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# Using Ethics Committees to Justify Force-Feeding Political Prisoners in Israel

ZOHAR LEDERMAN AND RYAN ESSEX

## Abstract

Thousands of Palestinian prisoners are held in Israeli prisons without trial. For some of them, engaging in hunger strikes is the last resort in opposing unlawful detention and inhumane prison conditions. While mainstream bioethics deliberation, reasonable arguments, and international legal and medical professional declarations prohibit force-feeding, local ethical deliberations, professional medical guidelines, and legislation allow the use of medical judgment and clinical ethics committees to force-feed these prisoners. Until now, Israeli physicians have refused to do so, but this may change in the future. The international medical and bioethics communities need to stand behind these medical professionals, as well as prisoners. Clinical ethics committees in Israel must choose whether they serve the interests of these prisoner-patients and perhaps their political or human rights agenda, or whether they are subservient to an unjust, oppressive regime.

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“Our resistance embodies our humanity ... [which] lies in the idea of sacrifice for freedom. It is like the candle that burns and consumes itself for others ... It lights the way for the other including you, you write this research so that you can see the road ... For us this is our humanity, to sacrifice for the other. Those who have gone away [the martyrs] did not take anything with them but they just sacrifice the self for the other.”

—Hasan Safadi, a Palestinian citizen formerly arrested without trial  
by Israel<sup>1</sup>

## Introduction

This paper is being written in the midst of ongoing civil unrest in Israel, where millions of people have been protesting for several months against the government’s attempt to curb the judicial power of the Israeli Supreme Court. (While our manuscript was being evaluated, war broke out in Israel. In consultation with the editors, we opted not to address the war in this paper and leave it largely in its original form). The Reasonableness Clause, which prevents the court from evaluating governmental decisions based on public reason, has in fact been introduced as law and is the first step in the process. This law practically nullifies Israel as a democratic country.

What is perhaps most striking in this civil unrest is the tension between the Israeli public’s opposition to losing political rights in a country that is no longer a democracy on the one hand, and the seeming apathy of some toward the continuous violation of political and moral rights of Palestinians living in the Occupied Palestinian Territory on the other (people in Israel have been protesting against the occupation through the years, but their numbers and impact have been dwindling).<sup>2</sup> Several major human rights organizations and scholars have indeed defined the Israeli regime in the Occupied Palestinian Territory as apartheid, and a recent report by 17 human rights organizations in Israel describes how such violations have contin-

uously worsened in the past 56 years.<sup>3</sup> The report specifically highlights three trends: increasing violent policies (e.g., torture during investigations); increasing violence, as shown in the number of deaths among Palestinian citizens, including women and children; and increasing anti-Palestinian and anti-democratic legislation. Importantly, the report also warns against the judicial overhaul, while acknowledging that the Israeli Supreme Court has actually played an important role in backing and legitimizing Israeli policies against Palestinians.<sup>4</sup>

The bioethical implications of the Israeli occupation have been reviewed elsewhere.<sup>5</sup> The focus here is the impending violation of the moral and political rights of Palestinians to bodily integrity and autonomy, specifically by the threat of force-feeding. Discussing force-feeding in the Palestinian context is enlightening for several reasons. First, it provides one example of the complicity of the Supreme Court in the Israeli occupation and gross violations of basic human rights. Second, it illustrates how unreasonable argumentation and a misguided interpretation of empirical data can lead to and justify unjust acts.<sup>6</sup> Third, it sheds light on the current state of affairs of Israeli bioethics and how this state of affairs at once feeds into and is perhaps influenced by the political environment. Fourth, and relatedly, it demonstrates the potential of clinical ethics committees to do wrong and cause significant harm. It specifically highlights the political role that ethics committees play or might play in this and similar contexts.

This paper first reviews the political context of hunger strikes by Palestinian prisoners and force-feeding in Israel. It next critically reviews how clinical ethics committees have been used or may potentially be used to justify the force-feeding of Palestinian political prisoners. Lastly, the paper argues that the force-feeding of Palestinian political prisoners (and in fact all prisoners for that

matter) is ethically unjustified. Using the concept of “resistance,” the paper also argues that the decision of ethics committees will inevitably place them on one side of history: the wrong one (that of the oppressors) or the right one (that of the resisters). These committees’ decisions may also influence the outcome of hunger strikes as acts of resistance.

### Legal, moral, and political rights

The paper greatly relies on the use of “rights” of different kinds, so in order to prevent confusion, a note of clarification is warranted. Rights in general denote entitlements of individuals that confer corresponding duties on others to do or provide something or refrain from doing something. “Basic” rights simply denote rights that are fundamental to other rights: they are the building blocks of other, non-basic rights and, in turn, are not dependent on any other rights. From a normative perspective, basic rights claims trump non-basic rights claims.

Legal rights denote a legal authority’s sanctioned, or positivistic, entitlements that provide the basis for claims for and against certain conditions, resources, actions, and so forth. Legal rights arguably make sense only in the context of a legal authority such as a liberal or decent (to modify from John Rawls) state that grounds and legitimizes its normative power.<sup>7</sup> Moral rights, in contrast, refer to natural entitlements that stem and draw their normative power directly from the fact of being a human being, or a person, on this planet. Moral rights exist a priori to any legal or political institution and are thus independent of such institutions. Following others, moral rights will be understood here as a dialectical shortcut to avoid the need for deeper argumentation.<sup>8</sup> Thus, for most of the paper, prisoners are simply assumed to have a moral right to starve to death and not be force-fed. This moral right will be defended in the last section.

Lastly, political rights denote entitlements owed to individuals as “legal persons.”<sup>9</sup> These rights

are guaranteed by often idealistic or aspirational international human rights conventions and customary law. They exist independently of any state powers; hence, any regime that does not respect them can be deemed unjust. The function of political rights is to ensure the ability of individuals to participate in the civil and political life in their countries of origin or at least to some extent in their country of residence. Article 26 of the International Covenant on Civil and Political Rights provides a good example of political rights:

*All persons are equal before the law and are entitled without any discrimination to the equal protection of the law. In this respect, the law shall prohibit any discrimination and guarantee to all persons equal and effective protection against discrimination on any ground such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.*<sup>10</sup>

More abstractly, political rights are about ensuring equal access to the political space in which individuals can speak and act, in the words of Hanna Arendt.<sup>11</sup> Only in such safe spaces, where individuals are equally and adequately respected and their voices heard, can individuals fulfill their constructive role in society. Depriving one of one’s political rights deprives one from acting and speaking, from participating in the political. This deprives one of the possibility of living life to the fullest.

In what follows, political and moral rights may at times be used interchangeably since there is a significant overlap between the two.

### Force-feeding in Israel

According to the Council of Europe:

*A person deprived of his or her personal liberty is to be regarded as a “political prisoner”:*

- a. if the detention has been imposed in violation of one of the fundamental guarantees set out in the European Convention on Human

Rights and its Protocols (ECHR), in particular freedom of thought, conscience and religion, freedom of expression and information, freedom of assembly and association;

- b. if the detention has been imposed for purely political reasons without connection to any offence;
- c. if, for political motives, the length of the detention or its conditions are clearly out of proportion to the offence the person has been found guilty of or is suspected of;
- d. if, for political motives, he or she is detained in a discriminatory manner as compared to other persons; or,
- e. if the detention is the result of proceedings which were clearly unfair and this appears to be connected with political motives of the authorities.<sup>12</sup>

The council adds that “those deprived of their personal liberty for terrorist crimes shall not be considered political prisoners if they have been prosecuted and sentenced for such crimes according to national legislation and the European Convention on Human Rights.”<sup>13</sup>

Palestinian political prisoners are considered by Israel to be terrorists or promoters of terrorism. They are considered by their own compatriots, other activist groups in other parts of the world, and perhaps the entire Arab world as freedom fighters. They might see themselves as part of a Palestinian resistance movement or a global resistance movement of the oppressed. Yet at the same time they cannot but be parents or children of those who await them in the Occupied Palestinian Territory. They thus want to be reunited with their family at the same time that they might want to resist what they experience as an injustice toward them and their people.<sup>14</sup>

While a limited use of imprisonment without trial—or administrative arrest—to protect the public good may at times be warranted under international law, the Office of the United Nations High Commissioner for Human Rights has determined that it is allowed only under the conditions

of several safeguards:

*The power of administrative and ministerial authorities to order detentions is highly controversial, and some experts believe it should be abolished. It is important to be aware, however, that this form of detention is not outlawed by international law, even though it is surrounded by some important safeguards.*<sup>15</sup>

These safeguards include the following: (1) non-arbitrariness; (2) arrest must be based on grounds and procedures established by law; (3) information of the reasons must be given promptly; and (4) court control of the detention, as well as compensation in the case of a breach, must be available.

Based on these criteria and other international legal instruments, the United Nations Special Rapporteur for the situation of human rights in the Occupied Palestinian Territory has berated Israel since 1967 for its excessive use of this policy, particularly in the case of Maher Al-Akhras (see below).<sup>16</sup>

With their basic human right of liberty crushed, and without any real legal recourse, Palestinian prisoners have for the past 60 years engaged in hunger strikes.<sup>17</sup> Inspired by other freedom fighters such as members of the Provisional Irish Republican Army, Palestinian prisoners have opted to sacrifice their health and lives for a greater good: equal respect, political freedom, and basic and non-basic political human rights, including the right to a fair trial and humane imprisonment conditions.<sup>18</sup> Their resistance to oppression is literally embodied.<sup>19</sup> Locked in a legal and political system of oppression and despair, they see the act of hunger strike primarily as an act of hope and love toward their families and homeland.<sup>20</sup> This is well expressed in the testimony of Hanna Shalabi, a Palestinian woman who was imprisoned for 27 months in Israeli prisons without trial:

*I wondered where was humanity and dignity, when all they brought was darkness and pain ...*

*I thought to myself, people all over the world were sleeping in peace and tranquillity, here we are in our homes, being hit by guns and sticks in the middle of the night ... I was sentenced to administrative detention without a charge against me. I had to make a decision whether to die or live in dignity. I decided to go on hunger strike until I obtained my freedom from the clutches of the occupier. As days went by, the hunger strike was taking its toll, my body was becoming weaker, I was having blackouts, my bones were protruding from my wasting body, my life was a misery. On day forty-seven I declared that I would not abandon my strike, I would not be sentenced to administrative detention seven times without charge. Oh, Allah, at last they have relented and I have achieved my liberty. Yes, sacrifice is the brother of freedom. Now I will be expelled to Gaza, away from my family and friends, but moving to a part of my homeland and freedom means everything to me.<sup>21</sup>*

Thirty Palestinian prisoners initiated a hunger strike in September 2022, protesting their unlawful administrative arrest and prison conditions. Luckily this strike ended the following month upon Israeli concessions.<sup>22</sup> Israeli hospital physicians have so far withstood the pressure from various sources to force-feed these prisoners. But a perfect storm is brewing, as professional medical guidelines, existing legislation, a non-democratic right-wing government, and local ethical discourse place health care professionals between a rock and a hard place.<sup>23</sup>

The Israeli Medical Association (IMA) prohibits the force-feeding of hunger strikers but allows some flexibility once a striker loses consciousness. Thus, the IMA code of ethics reads, “A physician shall not participate in forced feeding of a hunger striker.”<sup>24</sup> On the very same page, however, the code requires the physician to inform the prisoner whether she would indeed be willing to respect the prisoner’s wishes: “A physician must inform the hunger striker whether he will be willing to accept the latter’s request to refuse any food and/or liquids, including artificial feeding, if he should

lose consciousness.”<sup>25</sup> One wonders how the two statements can be true: that physicians should not force-feed and that physicians must tell prisoners whether they are willing to respect their wishes not to be force-fed, thus allowing for the possibility that some physicians would indeed insist on force-feeding.

One page later, the IMA’s true position is revealed:

*If the hunger striker loses consciousness and is no longer able to express his wishes, the physician shall be free to decide to the best of his awareness and conscience how to continue to treat the hunger striker, while respecting to the utmost the views and wishes of the hunger striker as expressed to him during the hunger strike.<sup>26</sup>*

This is not how a surrogate decision-making process works.<sup>27</sup> The first level in such a process respects the patient’s continued autonomy as expressed while competent, either verbally or by way of some form of advance directive, a living will, or instructions for treating health care professionals. The physician should not have any say in the matter. The IMA position here is actually extreme in its divergence from mainstream bioethical scholarship.

A 2015 law in Israel allows the prison system to force-feed prisoners in case of risk to their lives. The Israeli Supreme Court has upheld the law.<sup>28</sup> Several Israeli and Jewish scholars have supported such legislation and force-feeding in general with arguments that have been debunked.<sup>29</sup> Several United Nations Special Rapporteurs on torture and the right to health have strongly opposed the law, equating force-feeding to torture.<sup>30</sup> Previously, a report by Special Rapporteur Joan Mendez specifically discussed torture in health care. Relying on the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment and its authoritative interpretations, Mendez particularly questions the validity of the doctrine of “medical necessity,” often espoused to justify the

force-feeding of prisoners.<sup>31</sup>

Here we focus on the use or potential use of clinical ethics committees to force-feed political prisoners, and an argument that was actually used by an ethics committee for that purpose—namely, that a prisoner is likely to change their mind once they are force-fed. While we are not alleging torture in this instance, as discussion with the chair of the relevant ethics committee made clear that there was no intent to inflict harm and that force-feeding was considered a medical necessity, force-feeding in such a case could still be considered to meet the definition of cruel, inhuman, or degrading treatment.

### Clinical ethics committees to justify the unjustifiable

Legislation, policy, and professional guidelines in Israel involve clinical ethics committees in decisions about force-feeding. Other than institutional and superior (national) research review committees, several kinds of clinical ethics committees operate in Israel, including committees that approve abortions, committees that define biological death, and the more traditional, hospital-based or health maintenance organization-based committees.

Hospital clinical ethics committees may be classified into two kinds. Statutory committees draw their authority from the Patient's Rights Act passed in 1996. The act grants these committees three main functions: approving treatment despite the patient's disagreement; allowing the withholding of private medical information to the patient to prevent unnecessary harm; and compromising confidentiality in order to reduce public health risks. By law, these committees should consist of a person with legal qualifications equivalent at least to a district court judge and who will serve as chair, two specialist physicians from different specialties, a social worker, a nurse (a late addition to the act), and a community representative. Statutory com-

mittees' decisions ought to be based on a majority rule and are legally binding.<sup>32</sup>

A committee may be activated by clinicians, hospital administrators, or, rarely, relatives to deliberate on dilemmas arising from clinical practice. While the extent to which these committees are used varies across different institutions in Israel, a survey done more than two decades ago has revealed that most hospitals did not use or rather minimally used these committees. A recent, yet unpublished survey by the first author points to very little improvement since then. The law also dictates that members of the committees undergo periodic training in bioethics, but the same survey by the first author reveals that this is not followed.

Perhaps because these committees are somewhat cumbersome and resource intensive, an advisory committee—the second type of hospital-based committee—is the model most often used in hospitals. These committees consist of one to two members with or without medical background who may or may not have formal ethics training. Advisory committees draw their authority strictly from the hospital management. They may be consulted via the same mechanism as statutory committees.

A 2018 memo by the Israeli Ministry of Health grants a statutory hospital ethics committee the option of deliberating the case of a prisoner who engages in a hunger strike.<sup>33</sup> Similarly, a memo issued in January 2022 by the Israeli prison system allows the use of an ethics committee to force-feed a prisoner against his explicit refusal. What general considerations are to be weighed by the ethics committee?

The Patient's Rights Act states the following regarding bypassing patients' objection to treatment:

*Should the patient be deemed to be in grave danger but reject medical treatment, which in the circumstances must be given soon, the clinician may perform the treatment against the patient's will, if an Ethics Committee has confirmed that all the following conditions obtain:*

1. *The patient has received information as required to make an informed choice;*
2. *The treatment is anticipated to significantly improve the patient's medical condition;*
3. *There are reasonable grounds to suppose that, after receiving treatment, the patient will give his retroactive consent.*

In September 2020, the ethics committee at Kaplan Medical Center in Israel was consulted regarding the force-feeding of Maher Al-Akhras, who at that time had been hunger striking for 46 days. Maher was protesting his unlawful arrest due to alleged links to Palestinian terrorist organizations. According to the committee's report, Maher was suffering from vomiting and nystagmus, but nothing in its reporting suggests that he lost his cognitive ability to make medical decisions. Maher did ask his physicians to treat him if he lost consciousness and told the committee that if he felt to be critically ill, he would request treatment.

Despite ostensibly acknowledging the patient's full autonomy at the time (meaning *while* Maher was fully conscious), the ethics committee allowed his force-feeding. In its approval, the committee confirmed all three criteria mentioned above:

1. Maher received the information required to make an informed choice.
2. Maher risked irreversible harm, and force-feeding him by intravenous fluid and vitamin administration was likely to improve his condition and prevent such harm.
3. Since Maher expressed his wishes to live and return to his family, there was reason to think that he would give his retroactive consent to be force-fed.

Fortunately, physicians at the hospital refused to force-feed Maher and he ended his hunger strike after 103 days, once the Israeli government promised to refrain from arresting him again.

The committee's conclusion and its cynical use of the Patient's Rights Act would be abhorring to most ethicists and clinicians, but in the current Israeli context it may be used to justify the force-feeding of other Palestinian prisoners in the future. But it should not, because the committee's conclusion was misguided.

### Making a case against the force-feeding of political prisoners

To recap, Maher was deemed to be fully competent to make medical decisions by the same ethics committee that recommended his force-feeding. The ethics committee approved his force-feeding under the assumption that he would give retroactive consent. Note, however, that "retroactive consent" in clinical practice does not exist; it is rather an oxymoron. Patients may either be competent to make medical decisions—and therefore their wishes should be respected unless they clash with other considerations, such as public health—or they may not be competent, and then decisions would be based on a three-tiered model of surrogate decision-making processes.<sup>34</sup> As mentioned above, the first step in this model consists of abiding by the patient's continued autonomy either previously expressed verbally or as reflected in any form of advance directive, where the patient specifies what should be done once they lose autonomy. Even in research settings, the notion of retroactive consent is highly controversial and mostly untenable.<sup>35</sup> The alleged reliance on "retroactive consent" is simply paternalism in disguise, and in clinical care this kind of paternalism is usually unjustified.<sup>36</sup> This means that the Israeli Patient's Rights Act should be revised. This also means that the committee was mistaken in relying on it in its judgment.

In defense of the Israeli Patient's Rights Act, it has been argued that the act differs from Western law in allowing a critical evaluation of the patient's current expressed wishes against their past char-

acter, even though English courts occasionally did exactly that.<sup>37</sup> The argument given to justify this part of the law is that for various reasons the patient's current explicit wishes do not really reflect their authentic autonomy. This argument has received some backing in the mainstream bioethics and medical literature.<sup>38</sup> Our response to such an argument is threefold: First, patients are allowed not to be "authentic" in the sense of making medical decisions in a fashion that is out of character. Second, rather than referring to these patients as "not authentically autonomous," they might more simply be referred to as non-autonomous and, as such, incapable of making medical decisions. Third, even if this argument is plausible generally, it should apply only in rare cases, and the case discussed here is not one of them.

In any case, while the committee's conclusion may be aligned with the Israeli Patient's Rights Act, it is not aligned with virtually any international legal or professional guidelines regarding force-feeding, including the World Medical Association Malta Declaration.<sup>39</sup> It is also not aligned with mainstream medical ethics, where the patient's autonomy, or more specifically the principle of respect for personal autonomy, is key.<sup>40</sup> The normative value of this principle may be sufficiently established via any one of different pathways. It can first be established by way of a maxim, well accepted in medical ethics, even by those who advocate relational autonomy.<sup>41</sup> It secondly may be established by relying on a comprehensive moral theory.<sup>42</sup> A third pathway draws from common morality, arguably captured by a set of well-established human rights.<sup>43</sup>

The International Covenant on Civil and Political Rights determines that humans have an inherent dignity, which in turn engenders several inviolable moral and political rights. Such inviolable or non-derogable rights include the right to freedom of opinion and expression, right to

privacy, right to be free from torture and inhuman treatment, and right to life, liberty, and security of person. The moral and political right over one's body—often called bodily or physical integrity—is also considered to be an inviolable right.<sup>44</sup> Article 10 of the covenant particularly pertains to those stripped off their liberty: "All persons deprived of their liberty shall be treated with humanity and with respect for the inherent dignity of the human person."<sup>45</sup> Being non-derogable means that the right must be respected under all conditions.

In medical practice and ethics, these basic rights translate to a patient's right to self-determination, self-authorization, and self-governance, otherwise known as autonomy.<sup>46</sup> Respect for autonomy means respecting the wishes of patients and their ability to make medical decisions regarding their own care regardless of the consequences to themselves. It also means respecting their bodily integrity. In clinical contexts, this right stands unless it is infringed by public health considerations. Another way of expressing this argument is that the principle of respect for personal autonomy entails both positive entitlements for something (i.e., positive rights) and entitlements against something (i.e., negative rights). As was established many years ago, "the limits on positive rights may be greater than the limits against negative rights."<sup>47</sup>

Autonomy-based and other arguments to justify basically the right to starve to death have been articulated and defended elsewhere.<sup>48</sup> Since hunger striking invariably has health consequences and because these consequences are usually dealt with by health professionals, the same reasoning may be used to spell out the ethical case that applies to all prisoners, regardless of whether they stood trial.

Prisoners lose their personal autonomy but not their moral autonomy.<sup>49</sup> They also do not lose their ethical claim to bodily integrity.<sup>50</sup> If anything, since they are a vulnerable population, more attention should be devoted to respecting their

moral autonomy and bodily integrity.<sup>51</sup> Competent political prisoners who engage in a hunger strike and become patients are entitled to make medical decisions, including dying as a result of their starvation. They do not wish to die; their goal is not death. Rather, they risk death or ill-health for a perceived greater cause—namely, equal human dignity and respect. For them, equal human dignity and respect might entail better prison conditions or general freedom of movement and from oppression. The same arguments apply to prisoners who have lost their competence, such as after losing consciousness. A surrogate decision-making process is generally used and advocated in medical practice in such situations, whereby the first step is probably the most relevant here: follow the previous expressed wishes and intentions of the prisoner, which are most likely to represent his true wishes even after losing competence.<sup>52</sup>

Using perhaps less dramatic language, prisoners who hunger strike and object to feeding—forced or otherwise—are simply refusing care. Refusing care is, and should be considered, a patient prerogative. The same way patients are allowed to forego treatment in most cases (barring cases in which other considerations apply, such as directly observed therapy for tuberculosis), they should, *inter alia*, be allowed to forego food and force-feeding. Again, this applies both to prisoners under administrative arrests and those under normal (just) circumstances.

Leaving aside the language of bioethics, administrative arrests are justified only if certain safeguards are in place. In the Israeli context, the safeguards are inadequate, thus making the policy unjustified and unlawful according to international law. Regardless, legal persons who lose their freedom—even legitimately—still warrant respect and still maintain their non-derogable political rights. Force-feeding, then, is arguably more of a biopolitical issue than a bioethical one.<sup>53</sup>

## The biopolitics of hunger strikes

Non-derogable political rights include freedom of expression and protest. Hunger strikes fit comfortably alongside almost all mainstream conceptualizations of protest or resistance, with clear opposition in mind and often with clear political motivation.<sup>54</sup> They are also a form of protest that shines a light on the intersection of health and protest. Protest and health intersect in a variety of ways, from how health knowledge is contested, to how health is used to frame or motivate acts of resistance.<sup>55</sup> Not only are hunger strikes a form of protest that has health consequences, but they also leverage health and well-being to communicate suffering, make demands, or even disrupt. Ashjan Ajour, in a book based on interviews with several political prisoners, captures this well:

*The prisoners choose to transform their bodies into a site of revolution. The body here becomes more than the material body, for the singularity of hunger strike becomes an emblem of Palestinian self-determination and the body of the hunger striker a symbol of a communally shared body politic. From their singular encounter with colonial power, they constitute an intersubjective political consciousness of Palestinian self-determination at the collective level.<sup>56</sup>*

Thinking about hunger strikes as a political issue as opposed or in addition to a medical issue may be helpful for different reasons, but particularly relevant for this discussion are the implications for clinical ethics committees in Israel. First, conceptualizing hunger strikes as a political issue foregrounds the political nature of the decisions made by clinical ethics committees. While clinical ethics committees are independent bodies, they cannot escape influence from the broader political climate. Additionally, any decision made by a committee has political implications—that is, an ethics committee that is deliberating on such a politically motivated act of hunger striking in what is clearly

a highly politicized milieu *cannot but* play a political role.<sup>57</sup> One wonders, then, why clinical ethics committees should be involved in this kind of case at all—hunger strikers should be considered competent until they are clearly not, and health care professionals should simply provide them nutrition such as vitamins and water with salt if that is what patients want.

Second and conversely, resistance opens new opportunities for action and opposition. Using the language of resistance and acknowledging the relevance of political in addition to bioethical arguments in the context of hunger strikes, clinical ethics committees should understand and make explicit that their decision places them either on the side of the oppressors or wrongdoers or on the side of resisters who in this case have the moral upper hand. The former include Israeli legislators, the Israeli Supreme Court, and those who devised and uphold institutional and professional guidelines permitting the force-feeding of political prisoners. The latter obviously include those political prisoners who engage in hunger strike, but also health care professionals who oppose pressure from their professional superiors, from various scholars, and from the Israeli government and refuse to force-feed these prisoners in accordance with the Malta Declaration.<sup>58</sup> In a practical sense, this could involve openly opposing force-feeding. As mentioned, health care professionals in Israel have so far resisted the political pressure to force-feed, so much so that at one point the government considered importing physicians from India to conduct the force-feeding.<sup>59</sup> The motivation behind their resistance is probably their perception of fundamental professional ethics as captured by formal professional ethical codes issued by the IMA or the World Medical Association, or even the Hippocratic Oath. But in Israel's increasingly conservative political atmosphere, pressure on health care professionals to engage in force-feeding is likely to increase, and health care professionals whose political position

already aligns with the government may be more inclined to do so. Clinical ethics committees may then be the only thing separating the prisoner from force-feeding.

Resistance can also involve the facilitation or enablement of more covert acts of resistance. Ethics committees could work with health care workers to enable hunger strikers in making their stand against injustice. An ethics committee, for instance, may instruct health care workers to secretly provide liquids and vitamins for sustenance while still allowing prisoners to make a public stand against injustice.

Third, and in the broader political context, consideration of the political nature of hunger strikes brings into question the decision-making processes of clinical ethics committees, which are made with little oversight and with no means to appeal. In this regard, the fact that Maher was eventually not force-fed highlights the complexity and current tensions within the Israeli health care system. Maher was caught between the law and a statutory ethics committee on the one side, warranting and recommending for his force-feeding, and health care providers on the other end, refusing to do so and opting to respect his moral autonomy. Luckily for Maher, the IMA code allowing for force-feeding did not apply here, as Maher was still conscious and competent to make medical decisions. But health care providers may indeed be more inclined to force-feed once prisoners lose their consciousness, in accordance with the IMA code and as allowed by Israeli law. It is again this type of case where an ethics committee may be the only thing separating the political prisoner from being force-fed. For this to happen, however, further training for these committees may be warranted, focusing on commonly accepted arguments in mainstream bioethics. This is also the reason why decisions by these committees should be made public and open to scrutiny by members of the public as well as the national and international bioethics community.

As in the present case, committee members could then realize that they have gotten it wrong and hopefully be better informed in similar cases in the future.

To alleviate some of the complexity described, we conclude by offering explicit recommendations to health care professionals and clinical ethics committees in Israel on the management of prisoners who engage in hunger strikes:

1. Prioritize moral autonomy, including obtaining advance directive where possible.
2. Be publicly transparent in your decisions.
3. Enable a rigorous support system for prisoners that is separated as much as possible from the prison apparatus and local security services (for example, by having a consultation by an independent health care provider).
4. Recognize the broader political context in which the hunger strike is occurring, including the patient's right to protest.
5. Be aware of your own biases and potential sources of influence. If you are somehow placed under undue political pressure to engage in force-feeding, refuse, and seek guidance by relevant organizations in Israel, such as Physicians for Human Rights or the Red Cross.
6. Leverage the media and activist groups to amplify the patient's wishes in case they are being unjustly silenced.
7. Before making a decision, consult the international literature on the ethics of hunger strikes and force-feeding and consider consulting peers with expertise in medical ethics.
8. Consider whether the decision to force-feed should even be made by a clinical ethics committee. Ethics committees may simply decide to support the clinician in her refusal to force-feed the patient.

The Israeli government, in turn, ought to allow health care professionals to opt out of their professional role in the case of force-feeding. It should reconsider the lawlessness of force-feeding and whether it wishes to stain the purity of the medical profession by expecting it to take an active role in a practice that may be more politically than medically motivated.

## Conclusion

A perfect storm is brewing in Israel, with the rise of political and religious extremism and perhaps a descent of mainstream bioethics. Political pressure on clinicians to force-feed political prisoners will undoubtedly increase in this environment. More than ever, they will need the backing of the global medical and bioethical community.

The quotation that opens this paper highlights how for Palestinian prisoners in Israel, a hunger strike remains the last resort to express their resistance to oppression and to hold on to what they perceive as their fleeting humanity. Legislation in Israel is unlikely to become more friendly toward Palestinians. Clinical ethics committees will increasingly have to decide whether to be part of an unjust oppression, or rather contributors to humanity.

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# Why Has a Progressive Court Failed to Protect the Prison Population against COVID-19? Mass Incarceration and Brazil's Supreme Court

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## Abstract

Despite acknowledging the risks of the COVID-19 pandemic for the prison population, Brazil's Supreme Court declined to issue structural injunctions during the health crisis ordering lower courts to consider these risks when making incarceration-related decisions. These injunctions could have been crucial to mitigate mass incarceration and protect the prison population during the pandemic. Through an examination of the Supreme Court's rulings in structural cases and in a sample of over 4,000 habeas corpus decisions, this paper argues that granting these injunctions would have overwhelmed the court

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with an unmanageable influx of individual claims. Consequently, the Supreme Court acted strategically in anticipation of its limited institutional capacity to enforce compliance with structural injunctions among lower courts. This case study illustrates how practical considerations can hinder structural decisions in criminal law and highlights the limits of structural litigation and constitutional jurisdiction to address mass incarceration.

## Introduction

A poorly controlled COVID-19 pandemic combined with overpopulated prisons represented an unprecedented threat to the health of the prison population in many countries during the recent global health crisis. Brazil was one of them. Until February 2023, COVID-19 was the confirmed cause of death for nearly 700,000 people, behind only the United States in the total number of reported deaths.<sup>1</sup> Brazil also has the third-largest prison population in the world and faces a severe problem of prison overcrowding.<sup>2</sup> In 2020, the prison system accommodated 668,135 people despite having the capacity for only 455,283, and 72% of the country's prison units held more prisoners than their designed capacity.<sup>3</sup>

The connection between overcrowding and poor health in the prison population has already been established.<sup>4</sup> Infectious diseases in particular tend to have a much higher prevalence among people in prison than the general population. Besides being an obstacle to social distancing measures, overcrowding is associated with inadequate sanitary conditions (e.g., lack of running water and ventilation), nutrition, and health care in prison. Despite the lack of reliable national statistics on COVID-19 infection and deaths in the Brazilian prison population and the possibility that many positive cases went underreported due to limited testing, there is

evidence that the infection rate in prison was significantly higher than in the general population.<sup>5</sup>

The possible impact of COVID-19 in overpopulated prisons has been acknowledged since the beginning of the pandemic by scholars, activists, governments, and organizations around the world, and calls for the release or non-incarceration of low-risk offenders and those in vulnerable groups have been widely voiced.<sup>6</sup> During the pandemic, international organizations such as the Regional Office for Europe of the World Health Organization, the Inter-American Court of Human Rights, and the Inter-American Commission on Human Rights explicitly called for the prioritization of non-custodial measures, such as parole, home confinement, and early release.<sup>7</sup> Failing to take measures to protect the prison population during the COVID-19 crisis was possibly a breach of several international human rights norms and standards.<sup>8</sup>

In Brazil, the main initiative for releasing prisoners during the pandemic came from the National Council of Justice (CNJ for its Portuguese initials), an agency that integrates and oversees the judiciary. On March 17, 2020 (six days after the World Health Organization declared the novel coronavirus outbreak a global pandemic), the CNJ issued Recommendation 62 urging courts to release or avoid detaining people with a higher risk of serious disease in case of COVID-19 infection and who pose a lower risk for public security.

Despite the severe impact of COVID-19 in Brazil, the recognition of the increased risk among populations incarcerated in notoriously unsanitary conditions, and Brazil's domestic and international human rights obligations, Brazilian courts took few steps to apply the guidance issued by the CNJ. The Supreme Court had the opportunity, which it did not seize, to issue an order obliging trial and appeals courts to consider the heightened risk of COVID-19 when deciding about incarceration, along the lines of the CNJ's Recommendation 62.

This paper examines why Brazil's Supreme Court—which has generally held a progressive stance in high-profile cases related to prisoners' rights and which confronted the government's refusal to act against COVID-19—did not act decisively to safeguard the prison population during the pandemic. Drawing on a strategic account of judicial behavior, this paper argues that the Supreme Court's self-restraint can be better explained through its limited capacity to enforce a decision obliging lower courts to consider the risks posed by COVID-19 in decisions regarding incarceration.

### COVID-19 in detention settings: The response by the National Council of Justice and the courts

In February 2020, the Brazilian Ministry of Health declared COVID-19 a public health emergency. In March, 2020, the CNJ issued Recommendation 62 asking judges to reconsider, in each case that came before them, the need for pretrial detention, especially for (1) pregnant or lactating women, mothers or carers of young children or people with disability, elderly people, indigenous people, and people with disability or health conditions that increase the risk of death or severe disease if infected; (2) people detained in institutions running above total capacity or without dedicated health care professionals; and (3) people provisionally detained for more than 90 days or accused of crimes that do not

involve violence or the threat of violence against people. The recommendation also called for the early release of those in groups (1) and (2) serving prison sentences (i.e., those who had already been found guilty). On September 15, 2020, the CNJ amended the recommendation, excluding from its scope those convicted of belonging to a criminal organization or convicted of committing financial crimes, corruption, heinous crimes (as defined in Statute 8,072/90), or domestic violence against women.

Although the CNJ has no adjudicative power and cannot review judicial decisions, it is responsible for providing guidance to improve courts' efficiency. Its recommendations are not binding on judges but aim to provide a framework for adjudication and purportedly impose an argumentative burden on any judge who decides not to follow them.

Yet the data from the three most populated states in Brazil suggest that the CNJ's Recommendation 62 and the COVID-19 pandemic had a minimal impact on appellate courts' decisions related to incarceration. An analysis of 6,771 habeas corpus petitions decided by the State of São Paulo Court of Appeal found that 90% of such petitions were denied and that neither the pandemic nor the CNJ's guidance was usually relevant to the outcome of a case.<sup>9</sup> A study in the State of Rio de Janeiro Court of Appeal analyzed a sample of 137 petitions for home confinement and found that judges granted only one due to the COVID-19 threat.<sup>10</sup> Similar conclusions were found in the State of Minas Gerais Court of Appeal.<sup>11</sup>

The same pattern was found in high courts during the initial months of the pandemic. The Superior Court of Justice, which oversees all appellate courts, saw an increase in habeas corpus petitions in 2020. However, there was no increase in the proportion of writs of habeas corpus granted compared to the previous year.<sup>12</sup> The same conclusion applies to the Supreme Court, the highest court in

Brazil, where justices rarely mentioned the risks associated with the pandemic to grant a writ of habeas corpus.<sup>13</sup>

Further investigation is warranted into the Supreme Court's inaction, as it extends beyond its decision on habeas corpus petitions, but a point of clarification is pivotal before we proceed. Brazil has a hybrid model of judicial control of constitutionality.<sup>14</sup> The *diffuse review of constitutionality* can be exercised by any court when, in a concrete case, the constitutionality of a norm, policy, or decision is questioned. The Supreme Court is the final appellate court for the diffuse control of constitutionality, which gives the court jurisdiction to review decisions by criminal courts, including via habeas corpus petitions. In contrast, the *concentrated control of constitutionality* is exercised through actions filed directly before the Supreme Court. These *direct actions* historically have been used to control the constitutionality of norms in the abstract, although they also encompass challenges against executive and legislative omissions. In recent years, a specific type of direct action called "action against a violation of a fundamental right" (*arguição de descumprimento de preceito fundamental*, or ADPF) has been used for filing *structural cases*, which aim to protect the rights of large groups via judicial rulings ordering multiple public bodies to promote broad reforms in policy and institutional practices.<sup>15</sup>

In two direct actions—ADPF 347 and ADPF 684—the Supreme Court had the opportunity, which it did not seize, to rule that measures similar to those in Recommendation 62 were binding on the courts during the pandemic. This ruling would have given the Supreme Court the power to promptly review trial and appeals courts' decisions about incarceration that failed to consider the risks of COVID-19. Brazilian law provides that a judicial decision from any court that conflicts with a Supreme Court ruling in a direct action can be challenged through a constitutional complaint

(*reclamação constitucional*) filed directly before the Supreme Court—that is, without going through a lengthy appeal process. In the absence of a binding Supreme Court order, lower courts were allowed to brush aside the CNJ's recommendation and to disregard the risks of COVID-19 in decisions about the detention of individuals.

But why did the Supreme Court fail to change its practices and force lower courts to change theirs concerning imprisonment when the fundamental rights of the prison population faced such a grave and imminent threat?

### Explaining the Supreme Court's lack of decisive action

It could be argued that the Supreme Court's refusal to take more decisive action to reduce incarceration during the pandemic reflects the negative social attitude toward the prison population in Brazil, seen by many as responsible for their own condition and a threat to others and hence undeserving of rights protection.<sup>16</sup>

However, this explanation contradicts the fact that the Supreme Court held progressive stances in prominent judgments on the issue of the prison population's rights. In 2015, it declared an "unconstitutional state of affairs" in the prison system and ordered the investment of public funds to improve the conditions in prisons.<sup>17</sup> In 2018, the court ruled that judges shall consider the release of all women provisionally detained who are pregnant or the carers of young children or people with disability.<sup>18</sup> The court also set a binding precedent establishing that courts have the power to order states to improve the material conditions in prisons when there is a risk to the human rights of prisoners (*Tema 220*). In October 2023, it set another binding precedent stating that custodial sentences shall not be imposed on low-level drug dealers in cases with no aggravating circumstances (*Súmula Vinculante 139*). In October 2023, the court reiterated that there is an "unconsti-

tutional state of affairs” in the prison system and, among other things, ordered the federal and state governments to develop and execute a comprehensive plan to address this situation.<sup>19</sup> In these cases, the court aimed at protecting prisoners’ rights and reducing prison overcrowding.

It is also important to remember that the CNJ was chaired by Dias Toffoli, the chief justice of the Supreme Court, at the time when Recommendation 62 was issued. Toffoli championed the measure as an imperative response to extraordinary circumstances. He stated that the judiciary could not remain inert in the face of the pandemic and emphasized the need for swift and uniform action to avert “irremediable damage.”<sup>20</sup> More recently, in July 2023, Justice Rosa Weber, a Supreme Court justice acting as the chairwoman of the CNJ, launched a nationwide judicial task force directing lower courts to reconsider the detention of thousands of prisoners nationwide. As outlined by the CNJ, the overarching objective of this administrative measure was to ensure “strict adherence to legislation and binding precedents set forth by the Supreme Court and alleviate congestion within the state prison system.”<sup>21</sup>

One could question the practical impact of these decisions and initiatives. Still, they show a clear legal policy position: mass incarceration and the current conditions in prison breach human rights, and the courts’ practice and culture of incarceration that contribute to this result need to change. They certainly go in the opposite direction of reflecting or reinforcing the prevalent negative attitude regarding the prison population in society and in the lower courts.

Another hypothesis is that the Supreme Court acted cautiously to avoid confronting the federal government. The president at the time was Jair Bolsonaro, a tough-on-crime populist who openly advocated for more incarceration and state violence.<sup>22</sup> His followers widely supported his negative attitude toward the rights of criminals and

prisoners.<sup>23</sup> Moreover, Bolsonaro and his supporters were openly hostile toward the Supreme Court, threatening disobedience, military intervention, and physical violence. In this context, a ruling leading to the mass release of prisoners could have escalated the tension between the president and the court and increased the risk of institutional instability.

However, this is not a compelling rationale for the court’s behavior concerning the prison population during the pandemic. The Supreme Court openly took positions against President Bolsonaro and his supporters on multiple previous occasions.<sup>24</sup> For instance, it ruled in favor of compulsory COVID-19 vaccination, which Bolsonaro vehemently opposed.<sup>25</sup> The court also took away decision-making power from the president to allow state and city governments to impose restrictive social distancing measures.<sup>26</sup> Furthermore, the court defended the electronic voting system against repeated attacks from Bolsonaro on its reliability and opened criminal proceedings against pro-Bolsonaro militants. All these decisions elicited strong backlash from Bolsonaro and his supporters, but no substantiated evidence suggests that the court yielded to the threats.

Because these two hypotheses (the negative attitude toward the prison population and the fear of confrontation with Bolsonaro and his followers) cannot satisfactorily explain the Supreme Court’s behavior on the issue of incarceration during the pandemic, this paper proposes an alternative explanation that can be backed up by stronger evidence: the Supreme Court did not make a binding decision ordering lower courts to consider the heightened risk of COVID-19 in prison settings because it was aware of the practical constraints related to its capacity to enforce such a decision. This argument will be developed by examining how the Supreme Court handled (1) the most overarching structural case on the issue of the prison population, which was filed before the COVID-19 pandemic, (2) the structural claims that aimed at reducing the

prison population during the pandemic, and (3) a representative sample drawn from a set of 4,247 individual criminal law decisions rendered by the Supreme Court during the pandemic.

### *ADPF 347 and the Supreme Court's preliminary decision in 2015*

As explained above, an ADPF is a direct action filed before the Supreme Court that has been used to bring structural cases in the face of public authorities' failure to protect fundamental rights. The ADPF offers promising opportunities for structural litigation in Brazil, since an argument before the Supreme Court gives more visibility to issues while avoiding the time- and resource-consuming appeal process.

ADPF 347 was filed in May 2015 by a left-wing political party on the grounds that the violence and deprivation suffered by the prison population amounted to a blatant violation of human rights. They argued that this situation resulted from mass incarceration, for which all the branches of power were responsible—the legislative for the highly punitive legislation, the judiciary for excessive use of pretrial detentions and its resistance to disposing of legal alternatives to imprisonment, and the executive for insufficient funding for the prison system.

The Supreme Court issued a preliminary decision in September 2015. All the justices agreed that the “inhumane” status of the prison population caused by mass incarceration constituted an “unconstitutional state of affairs” for which the Brazilian state was responsible. The court was unanimous in guaranteeing the right to a hearing within 24 hours of pretrial detention (a measure beginning to be implemented at the time) and ordering the disbursement of federal funds for the prison system.

Despite the Supreme Court's willingness to interfere with the internal organization of the courts and reallocate public resources, it did not grant any preliminary injunction that could directly interfere

with the lower courts' discretion. More specifically, the court refused to order lower courts to consider the inhumane conditions in prison and the alternatives to prison when sentencing or deciding about pretrial detention or regime progression.

The Supreme Court gave three reasons for not interfering with lower courts' decisions. First, it pointed to the need for further debates about the required measures.<sup>27</sup> Second, the existing legislation already required judges to consider the alternatives to incarceration available before imprisoning a person, making a Supreme Court's declaration redundant. Third, an order from the Supreme Court would allow the filing of constitutional complaints against any decision providing insufficient reasons for imprisoning an individual, rendering the Supreme Court's workload unmanageable.

The first and second arguments contrast with several *obiters* in the decision recognizing that the “culture of incarceration” in the courts contributes to mass incarceration in Brazil. They also contradict strong evidence that trial courts' overuse of pretrial detentions and prison sentences is a pivotal contributor to the problem of mass incarceration. More than one-third of prisoners in Brazil are provisionally detained (i.e., held in custody while awaiting trial).<sup>28</sup> A 2019 study by Máira Rocha Machado et al. analyzed drug trafficking convictions and concluded that the refusal of courts to dispose of the alternatives to prison when sentencing is a “direct contribution” to mass incarceration.<sup>29</sup>

The third argument, regarding workload, seemed to be a key obstacle to granting the requests. Justice Luís Barroso expressed his hesitation to issue an order that would make space for a constitutional complaint against any insufficiently motivated detainment decision.<sup>30</sup> Justice Teori Zavascki referred to the risk of a “flood of constitutional complaints.”<sup>31</sup> Justice Gilmar Mendes also considered the possibility of a significant increase in the number of constitutional complaints.<sup>32</sup> Justice Luiz Fux, who voted in favor of issuing wide

orders in the case, unsuccessfully tried to persuade his colleagues in his partially dissenting opinion that the risk of “an epidemic of constitutional complaint” was overblown. He went as far as to propose that the court consider making a declaration to bar the filing of constitutional complaints in this particular case.<sup>33</sup>

Yet the majority’s concern was credible. According to Brazil’s Civil Procedure Code, constitutional complaints can be filed directly before the Supreme Court against any judicial decision that contradicts a Supreme Court decision in a direct action, such as an ADPF. Therefore, had the majority ruled that courts were obligated to justify not choosing alternatives to imprisonment or not considering prison conditions when deciding on incarceration, the aggrieved party would have had the option to file a constitutional complaint.

Considering that Brazil’s prison population exceeds 600,000 people, that any decision regarding incarceration is fact specific and fact intensive, and that the Supreme Court has no power to deny certiorari in cases of constitutional complaint, then granting the requests that interfere with lower courts’ decisions could have led to an unmanageable increase in workload. The same concern also seemed relevant during the pandemic.

### *Structural cases at the Supreme Court during COVID-19*

The Supreme Court did not make a decision on the merits of the case ADPF 347 until October 2023. However, following the emergence of the COVID-19 pandemic, a nongovernmental organization filed a petition within ADPF 347 requesting the Supreme Court to order lower courts to consider releasing prisoners at high risk of developing severe disease in case of infection and whose detention was related to crimes that did not involve violence or serious threat. In March 2020, a preliminary decision was made by Justice Marco Aurélio Mello “urging”—but

not ordering—courts to consider these measures.

The full court, however, soon overturned this interim measure on procedural grounds and expressed concerns about the breadth and intrusiveness of the preliminary injunction. The Supreme Court recognized the threat to the prison population and mentioned approvingly the CNJ’s Recommendation 62. However, the Supreme Court refused to issue an order that could be interpreted as an imposition on lower courts to consider the risks of COVID-19 in their decisions and review thousands of cases. According to the majority opinion, the CNJ’s *recommendation* was a better approach than a Supreme Court *order*.

A few weeks after the full court’s ruling, Justice Fux wrote an op-ed praising the “humanitarian motives” behind Recommendation 62. Nevertheless, he defended the Supreme Court’s decision that refused to set a general rule directing lower courts’ decisions. He argued that in each individual case courts should weigh the risks of COVID-19 to the prisoner’s health against the risks of their release to public safety.<sup>34</sup> Ironically, lower courts often cited the full court’s decision to brush aside the CNJ’s recommendation and deny habeas corpus petitions based on the risks associated with COVID-19. Lower courts often argued that, as per the Supreme Court, they were *advised* but not *obliged* to consider the pandemic in their decisions.<sup>35</sup>

The Supreme Court missed another opportunity to issue a binding order on the same issue when ADPF 684 was filed in May 2020. The claimant argued that mere recommendations were insufficient to convince courts to consider the risks of the pandemic when deciding on imprisonment, requesting the court to order trial courts to release from preventive detention or transfer to house arrest those who had not committed crimes involving violence or severe threat and were at high risk of dying from COVID-19. The Supreme Court never ruled on ADPF 684, which is still on its docket.

The Supreme Court’s omission in ADPF 347

and ADPF 684 contrasts with a preliminary order made in the Collective Habeas Corpus 188,820 on December 2020. The claimants here argued that Recommendation 62 was largely being ignored and requested the immediate release of prisoners who met conditions similar to those in this recommendation. Justice Edson Fachin ordered courts (1) to anticipate the progression to a less strict regime for those serving a sentence or (2) to grant conditional release or house arrest for those provisionally detained in institutions running above their designed capacity, belonging to a group with higher risks of severe disease in case of COVID-19 infection, and whose related crimes did not involve violence or serious threat.

Justice Fachin, however, conceded “escape routes” for lower courts: a prisoner did not have to be released if there were no confirmed cases of COVID-19 in the institution where they were located or if preventive measures had been adopted and adequate health care was available. Release from prison could also be denied if there was no substantial health risk for the prisoner but the risk for public security if they were set free was high. In other words, a case-by-case approach was not excluded.

A chamber of the Supreme Court confirmed this preliminary decision, which can be considered a structural case since it is applicable to whole categories of prisoners rather than specific individuals and is directed to all trial and appeals courts. Nevertheless, when deciding on a collective habeas corpus, the Supreme Court exercises a diffuse review of constitutionality, which differs from the concentrated control exercised in a direct action, such as an ADPF. The occasional noncompliance with the ruling would have to be challenged through the normal appeal process rather than through a constitutional complaint filed directly before the Supreme Court.

Echoing Justice Fux’s op-ed, Justice Fachin stated that the release of a prisoner would depend

on the analysis of the facts in each case and that lower courts were in the best position to make such an assessment. Subsequently, Justice Fachin dismissed requests to release individual prisoners who had directly petitioned the Supreme Court asserting fulfillment of all conditions. Justice Fachin contended that appeals against decisions contravening the precedent set by Collective Habeas Corpus 188,820 should follow the regular appeal process.<sup>36</sup>

The Supreme Court’s grant of a collective habeas corpus, which involved issuing orders it had previously denied during the pandemic in ADPF 347 and had not addressed in ADPF 684, reverberates the notion that, despite its stated legal policy inclination, the court harbors apprehensions about becoming inundated with constitutional complaints—and being forced to review thousands of fact-specific individual decisions regarding incarceration during the COVID-19 pandemic.

### *COVID-19 and habeas corpus petitions by the Supreme Court*

Despite avoiding decisions that could increase the number of constitutional complaints, the Supreme Court received thousands of individual habeas corpus petitions seeking release from prison based on the augmented risks due to COVID-19. This volume of petitions decided by the Supreme Court could challenge our hypothesis that it would be concerned about its capacity to judge a high number of constitutional complaints. Therefore, it is important to understand the volume of habeas corpus petitions filed at the Supreme Court and how they were handled.

Using the Supreme Court’s website search tool, we developed automated routines using Python to collect and organize all Supreme Court decisions issued between January 1, 2020, and June 22, 2021, containing the words “covid,” “pandemia” (pandemic), or “corona.”<sup>37</sup> This time frame covers

the harshest period of the COVID-19 pandemic, which became less deadly as vaccination coverage increased over the first half of 2021.

All results were aggregated, and duplicates were excluded, resulting in 5,412 decisions. With the support of machine learning algorithms, we organized these decisions into clusters based on text similarity. As a result, we found 4,247 decisions (78%) in criminal law cases. This is the material analyzed in this paper.

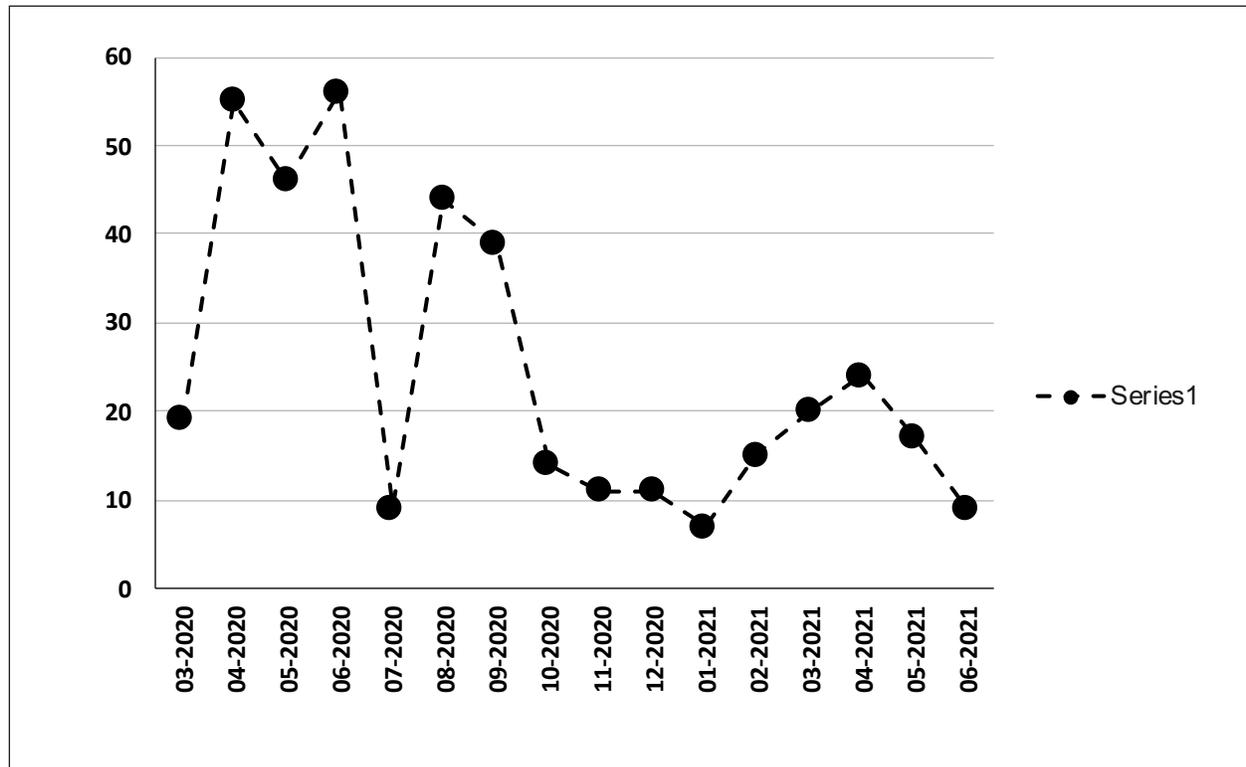
We then drew a representative sample of 396 decisions (95% confidence interval,  $\pm 4.8\%$  margin of error) and developed a Google Forms questionnaire to extract data from the cases. To reduce human error, each decision was classified by random sets of three researchers, with the unanimous or majority response (i.e., when at least two out of three researchers indicated the same answer)

prevailing.

In our sample, claimants requested the revocation of pretrial detention (n=249), transfer from prison to house arrest (n=180), application of alternative precautionary measures to custody (n=136), and progression to a less restrictive detention regime (n=41). Most of the 396 criminal law decisions were issued in response to a habeas corpus petition (83%, n=330), with a predominance of individual habeas corpus (n=327) compared to collective habeas corpus (n=3). Constitutional complaints represented 12% of the case sample (n=46) and other types of appeals represented 5% (n=19).

Most constitutional complaints sought the enforcement of binding precedents unrelated to the pandemic; COVID-19 was only marginally relevant to the claims. Without a binding precedent specifically addressing the grounds for reviewing

FIGURE 1. Monthly distribution of the sampled decisions



imprisonment due to the pandemic, a habeas corpus petition was the main instrument available to reach the Supreme Court. This section will analyze decisions rendered in response to such petitions.

In a habeas corpus petition, the decision rendered by an individual Supreme Court justice tends to be definitive.<sup>38</sup> Although it is possible for the aggrieved party to appeal to a chamber of the court—which has two chambers, each with five justices—chambers rarely overturn single-justice habeas corpus decisions. Indeed, in our sample we found only one reversion out of 26 appeals filed against an individual decision.

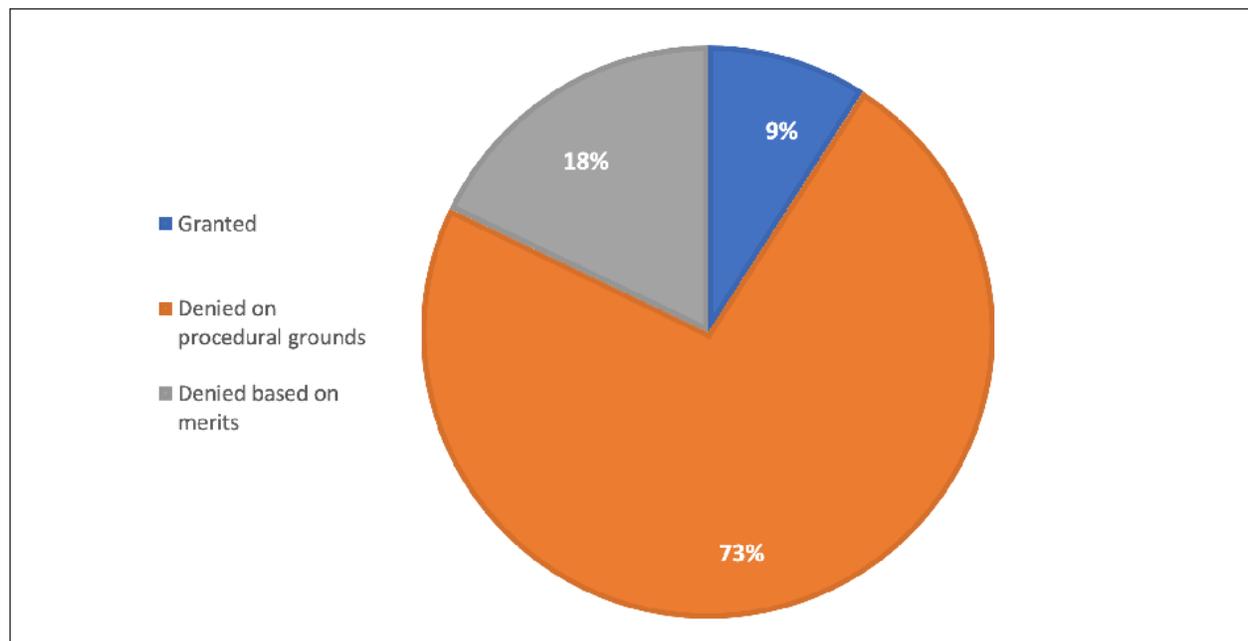
In our sample, the Supreme Court denied 300 of the 330 habeas corpus petitions (91%). Seventy-three percent (n=241) of the habeas corpus petitions were dismissed on procedural grounds that prevented an analysis of the merits. Only 18% (n=59) of habeas corpus petitions were denied based exclusively on merits (in these cases, the court did not use any procedural argument to state that the

habeas corpus should be dismissed) (Figure 2).

In 94% (n=227) of the cases in which the habeas corpus was dismissed on procedural grounds, the Supreme Court stated that it could not process a habeas corpus petition in a case where the jurisdiction of lower courts had not yet been exhausted. This reasoning, rooted in the court’s own precedents, implies that the Supreme Court’s jurisdiction is limited to cases that have culminated in a definitive judgment at the lower court level, except when there exists a “blatant illegality” in the detention. Therefore, as a general principle, a habeas corpus petition cannot serve as a means to bypass stages in the appeal process.

The term “blatant illegality” lacks a precise definition, often being described by the Supreme Court using synonyms like “teratological” and “manifestly illegal.” This circumstance gives rise to apprehensions concerning the vagueness and inconsistency surrounding the circumstances under which the Supreme Court decides to direct the re-

FIGURE 2. Outcome of habeas corpus decisions related to the COVID-19 pandemic decided by the Supreme Court between January 1, 2020, and June 22, 2021



lease of a detainee when the possibility of an appeal to a different court exists.

Another common procedural argument used by the Supreme Court was that analyzing the habeas corpus petition would involve reexamining the factual evidence of the cases, for which the writ is unsuitable. Of the 300 writs denied by the court, 63 (21%) were based on this argument. In these cases, in order to grant the writ, the Supreme Court indicated that the claimants bore the burden of proving that their prison facilities did not provide adequate care, which most claimants could not do. However, there were a few cases in which this argument was not mentioned, and the Supreme Court found sufficient proof of the need for medical treatment unavailable within the claimant's prison facility.<sup>39</sup> Again, the court applied a procedural rule for dismissing most habeas corpus petitions while retaining the power to grant it in selected cases.

In sum, the Supreme Court managed to control the floodgates by dismissing most cases through procedural rules without analyzing the merits of the cases, while at the same time retaining discretion to grant requests in vaguely defined exceptional circumstances. The procedural obstacles to having a habeas corpus writ granted by the Supreme Court existed long before the COVID-19 pandemic. However, the Supreme Court maintained these obstacles despite the threat of COVID-19 to the prison population.

In a counterfactual scenario in which structural injunctions in direct actions were granted to compel lower courts to consider pandemic-related risks, individual cases would have been expedited directly to the Supreme Court via constitutional complaints. This would have bypassed the appeal process, which often spans months or years in lower courts, and would have been less susceptible to procedural dismissals. While the Supreme Court could have devised procedural grounds for rejecting constitutional complaints, dismissing habeas

corpus petitions would likely be less detrimental to the court's standing and credibility than failing to uphold its own structural decision.

## Discussion

The literature frequently delves into the topic of courts' institutional capacity when exploring the potential avenues for driving social change and protecting the rights of vulnerable groups through structural litigation.<sup>40</sup> The argument centering on courts' limited institutional capacity typically refers to the alleged lack of power of the judiciary to compel the government to act, as well as the limited resources and expertise of judges to perform tasks that are traditionally seen as falling under the responsibility of the executive and legislative branches. This paper, however, shows that institutional capacity can also be an issue when courts are performing roles that are unquestionably within their domain, such as reviewing decisions about the imprisonment of individuals.

Not everyone may agree that a court's apprehensions regarding its constrained institutional capacity, which encompass concerns about workload, constitute valid legal grounds in a judgment, particularly when the human rights of a vulnerable population are involved. Additionally, it is uncommon for a court to openly acknowledge such reasons for rejecting a request. However, that courts consider their capacity to enforce a decision should not be surprising if judges are seen as strategic agents who decide based on their legal policy preferences as well as on their personal (e.g., workload and reputation) and institutional (e.g., prestige and power of the courts) interests, the behavior of other actors, and the institutional context in which they act.<sup>41</sup>

Strategic courts will be attentive to the behavior of other actors, including the risk that those to whom their decisions are directed may not follow their orders. This risk is higher when courts try

to impose measures that conflict with established practices, such as the lower courts' overreliance on imprisonment to respond to crime. Noncompliance seriously threatens a court's legitimacy, as it can damage its institutional prestige and credibility.<sup>42</sup> The anticipation of this risk may constrain courts from acting on their legal policy preferences.

Courts have their means to induce compliance. In the case of the Supreme Court's orders addressed to lower courts, the Supreme Court has the power to overturn decisions. Moreover, the Supreme Court does not have to actively monitor compliance, as claimants can bring noncompliance cases. This is significantly less costly than controlling administrative agencies and governments. When courts control other branches, the principal-agent problem and information asymmetry are more accentuated, as are the risk of retaliation against the court and the concerns about its legitimacy in interfering with policy.

However, as this paper shows, there may also be challenges for a high court to enforce compliance against lower courts. Given the procedural rules and the prevailing judicial practice, the volume of expected constitutional complaints against decisions contravening a binding Supreme Court order on incarceration during the pandemic would be very high. Apart from the volume, Supreme Court justices see these decisions as involving difficult trade-offs between prisoners' rights and public safety. Striking the right balance would involve considering, for each claim, complex factual issues such as the conditions of the inmate, the situation in the prison where they are detained, and the risks of her release to the public.

Granting structural requests in direct actions such as ADPFs would have created a dilemma for the Supreme Court. On the one hand, if it abdicated from exercising its jurisdiction to enforce its structural decision, it would have risked being perceived as lacking authority over lower courts. On the other, the Supreme Court was—and is—probably unable

to properly judge thousands of constitutional complaints seeking to review lower courts' decisions.

This task would have consumed much of the court's resources, energy, and time. Other things being equal, judges (like people in any other profession) likely prefer smaller rather than larger workloads and modulate the time spent on any issue to control their agenda and be able to focus on other priorities, including cases that may have a more significant impact on law and policy.<sup>43</sup> From a strategic perspective, it was rational for the Supreme Court to avoid reviewing an unmanageable volume of low-visibility decisions that were so fact specific, especially when the court was already making several decisions with broad implications for the responses of the Brazilian state to COVID-19.<sup>44</sup>

Therefore, endorsing Recommendation 62 and making orders to lower courts via a collective habeas corpus but not granting similar (but binding) orders when exercising concentrated control of constitutionality was not necessarily a contradiction (although it was disappointing from a human rights perspective). It may be seen as the strategic compromise found by a court that tried to advance its preferred legal policy, but up to the point that it did not risk damaging its authority if ignored by lower courts or opening the floodgates that it controlled through procedural rules to dismiss habeas corpus petitions.

## Conclusion

Brazil's Supreme Court decisions during the COVID-19 pandemic on the issue of incarceration exemplify how practical concerns about institutional capacity may stand in the way of structural decisions that could protect the human rights of the prison population. In our view, this is the strongest explanation for why the Supreme Court failed to take decisive action to protect the prison population during the pandemic. Future research aimed at assessing how courts navigate the trade-off between

advancing their policy preference and the potential burden of escalated workload could further test the strength and generalizability of these findings.

It is noteworthy that in October 2023 the Supreme Court finally issued a long-awaited ruling on the merits of ADPF 347. This decision reaffirmed the “unconstitutional state of affairs” in the prison system and ordered the government to develop and implement a plan to address this situation. Additionally, it decreed that lower courts “provide a rationale for not opting for alternative penalties or precautionary measures to imprisonment when such alternatives are feasible, taking into consideration the dire state of the prison system.” In contrast to the 2015 preliminary decision in this case, the court, during its deliberations, did not mention the risk of being flooded with constitutional complaints.

It is still too soon to analyze the implications of this decision, especially if there will be an unmanageable volume of constitutional complaints and, if so, how the court will handle them. Future research is essential to ascertain whether there has been a shift in the Supreme Court’s position on the issue of constitutional complaints or if our hypothesis has limitations that were not discernable given the available information at the time of writing this paper.

In sum, in addition to analyzing a substantively important and paradigmatic case, this paper sheds light on the limits of structural litigation and constitutional jurisdiction in tackling mass incarceration in Brazil and beyond. Sympathetic judges within independent and powerful courts are a prerequisite for effecting a rights revolution.<sup>45</sup> But even a Supreme Court with a relatively progressive stance and extensive jurisdiction can be restricted by the practical constraints of overseeing myriad fact-specific decisions, encompassing intricate trade-offs rendered by trial and appellate judges. This underscores a lesson that practitioners engaged in strategic litigation at national and in-

ternational levels should bear in mind in order to adjust their expectations and strategies.

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## PERSPECTIVE

# Justice in Transitioning Health Systems

LUCAS MIOTTO AND HIMANI BHAKUNI

### Introduction

There is a proliferation of “justice” talk in health—and perhaps rightly so. We often hear about climate, distributive, epistemic, gender, racial, reproductive, and other forms of justice. This essay adds another form of justice to the list: transitional health justice. “Transitional health justice” derives its core from “transitional justice.” The latter is used by human rights scholars, political scientists, and philosophers to describe the demands of justice that appear in the context of rebuilding collapsing political systems in conflict-affected states and the processes and institutional framework required to satisfy such demands. Derivatively, transitional health justice (THJ) applies to health systems and can loosely be defined as “a set of processes and guiding principles which should be followed by states and communities affected by health emergencies in their attempts to rebuild their (failing) health systems in a just manner.”<sup>1</sup>

Our latest brush with a global health emergency made many repeat the truism that health emergencies put an immense stress on, and sometimes lead to the failure or collapse of, health systems. Much has been written about the need to reform our health systems to render them more resilient, more prepared to deal with future large-scale health emergencies, and, overall, more just.<sup>2</sup> In early 2021, for example, the World Health Organization (WHO) announced its proposal to develop a convention for pandemic preparedness and response, and earlier this year a consortium released a document entitled *Principles and Guidelines on Human Rights and Public Health Emergencies* to clarify and consolidate legal standards for preventing, preparing, and responding to health emergencies.<sup>3</sup> Such a focus on reforming our health systems to make them more resilient, prepared for future emergencies, and more just is both helpful and needed. But often discussions about reforms center too much on the *ends* of reform: the kind of health systems that should be built and the material and ethical demands that they should be able to satisfy once reformed. And in doing so, a different kind of demand of justice is neglected—namely, demands of justice *in* or *during* health reforms. Demands of justice are context sensitive, and calls for establishing just systems are not the same

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as following the requirements of justice *during* the process of establishing those systems. Just systems are the end goal, but the pursuit of just reforms or transformation of health systems might require compromising on the demands of some other types of justice (like distributive and retributive).<sup>4</sup>

THJ becomes relevant because rebuilding health systems, particularly after emergencies, within a larger and ever-looming background of scarcity of resources and inequality, will require the relevant actors to make important choices and compromises. These choices will inevitably be about how to deal with past failures and the wrongs perpetrated within their respective health systems. They will also require a balance between distribution and reparation, blame and forgiveness, and truth and efficiency. Essentially, they will require attention to what we call “the circumstances of THJ.” Here we intend to highlight the existence of a problem of transitional justice in the context of health. We argue that health reforms must be sensitive to the demands of THJ and that the realization of the right to health is both central to, and dependent on, the just pursuit of transformation of health and health-allied institutions.

### Transitional health justice and its circumstances

The idea of THJ shares some theoretical gear with its counterpart, the transitional justice framework. Transitional justice (TJ) describes the different processes and apparatuses associated with a state’s attempt to address large-scale human rights violations and abuse from past conflict and repression to serve justice and seek certainty about legitimate political authority.<sup>5</sup> Our account of THJ borrows some insights from Colleen Murphy, who in laying down the philosophical framework for TJ argues that demands of justice are context sensitive, in the sense that they emerge as responses to the salient

problems a given society faces in a specific set of circumstances.

Given context sensitivity, the demands of TJ are conceptualized as demands of a distinct kind; they are responses to a core problem faced by transitioning societies—namely, “how to justly pursue societal transformation.”<sup>6</sup> Traditionally, the scope of TJ is limited to an individual conflict-affected state, but given the nature of health emergencies, which are not strictly dependent on national borders, the scope of THJ is global. This means that demands of THJ will also be global in scope and character and therefore require transformation of both national and global health systems. Since the primary demand of TJ relates to the just pursuit of transformation, even if that means a momentary compromise with other ideals of justice, such as distribution, correction, and retribution, our challenge then is to identify the relevant circumstances of TJ and draw an analogy with the context of health.

Following Murphy, we list four circumstances of TJ: (1) pervasive structural inequality, (2) normalized collective and individual wrongdoing, (3) serious existential uncertainty, and (4) fundamental uncertainty about authority.<sup>7</sup> It does not take much to establish that analogous circumstances exist in the context of health. To take the first circumstance, it is now common knowledge that health emergencies like COVID-19, the HIV/AIDS pandemic, and even some endemics exacerbate existing structural inequalities. Structural inequalities are “reproduced social processes that reinforce one another to enable or constrain individual actions in many ways.”<sup>8</sup> These inequalities can become widespread when they enter institutions that govern health. When this happens, and one would not be amiss to believe that this might be the case in arguably all health systems, not only are people’s basic health needs put at risk, but people are also robbed of their capacity to fully trust their health systems.<sup>9</sup>

The second circumstance is that of normalized collective and individual wrongdoing. Collective wrongdoing during and post-emergency can range from censoring information relevant to the management of disease, to greenlighting political rallies during a viral contagion, to hoarding vaccines and then recklessly discarding the unused vaccines during a global vaccine shortage. Individual wrongdoing includes individuals aiding the spread of disease and doctors furthering inequalities through avoidable actions and behavior (for example, skipping crucial steps in the physical examination of certain groups of people or not performing them altogether, overprescribing medication, or unethically prioritizing some patients over others, among others). Health emergencies normalize such wrongdoings in the sense that they become so usual and natural that people learn to ignore and adapt to them. But this normalization can erode faith in systems that govern public health, thereby necessitating a transformation.

The third and fourth circumstances are existential uncertainty and uncertainty about authority. Existential uncertainty relates to individuals dealing with mortality and health, as in the mental health crisis that was seen post-COVID-19 pandemic.<sup>10</sup> More importantly, it relates to the unease surrounding the probability that health systems will ever function well. Uncertainty about authority includes individuals questioning the authority of health experts, be it epidemiologists and doctors or WHO and national governments. Such uncertainty was on display during the recent pandemic, with some even calling for anarchist solutions to the health emergency.<sup>11</sup>

These circumstances are markers of health systems in need of a transformation and should give governments and societies strong reasons to consider drastic transformations of both national and global health systems. It is important to note that systems in need of transformation are not the same as systems that are momentarily affected by

an isolated act of war, armed conflict, or calamity. In such transitory calamities, there may be some pressing calls for the *normalization* of health—that is, for a health system to go back to what it was before the calamity, but the situation might not necessarily call for transformation. For transitioning health systems, going back to their “normal” is morally unacceptable.

So, what exactly must be transformed? In the circumstances of THJ, a moral demand for the just pursuit of transformation emerges because the mere repair or restoration of the status quo is morally unacceptable. But this demand goes beyond the transformation of material aspects associated with our health systems (e.g., health resources, health personnel, etc.). At a high level of abstraction, THJ demands that whatever contributes to the circumstances of THJ be transformed—that the circumstances of THJ come to an end. Thus, to end (or ameliorate) the circumstances of THJ, we must essentially transform how we relate to health providers, experts, authorities, institutions, and, of course, one another. Pursuing such transformation in a just manner requires a series of specific actions and an institutional framework. It will also require strengthening of the right to health. We now turn to presenting a skeletal structure of the THJ framework to then discuss the importance of the right to health for THJ.

### The structure of transitional health justice

Realizing THJ will involve rebuilding social trust in health institutions. It will also require efforts toward removing, at least to some extent, the distrust regarding the authority of health experts, governments, and other health-allied institutions on questions of health; but most importantly, it will require eliminating structural health inequalities that impede institutional reform. While transformation will likely bring about some permanent institutional changes, at least some of the practices

and institutional arrangements necessary for the pursuit of just transformation will have a more seasonal character; they will exist only up until the transition has taken place, as it were. Of course, in practice, it will rarely be clear when our health systems have transitioned—and the decision to do away with the transitional framework will not be a trivial one.

THJ has a narrower scope than TJ. As opposed to the latter, the goal of THJ is not the just pursuit of societal transformation but the just pursuit of transformation of our health systems. Yet, health is embedded in social relations, and some aspects of health can be said to even be *determined by* social conditions. Thus, the choices, compromises, and reforms made in the name of transformation must be sensitive to broader social issues that affect health. One such issue, which is salient in the circumstances of THJ, is the lack of trust in our health systems and authorities. A key part of transition will therefore involve building trust in the authority of national governments and national health institutions.

One way to do so is via the mediation of independent and autonomous health agencies—those not tied in any form to existing institutions that are regarded as untrustworthy by most members of a community. Such health agencies would be constituted of vetted and reputable health scientists, health economists, community health experts, other health professionals, and community representatives. National governments and state departments would have to liaise with these agencies to implement public health management initiatives in the transitional phase—or until stronger and trustworthy health authorities are established.

Building trust will also require reasonable checks and balances to be in place during the transitional phase. In addition to independent health agencies, it would be crucial to strengthen the corpus of health law (including health emergency law) in all jurisdictions to assist the just pursuit of trans-

formation of health systems. Here the judiciary can play an important role as an allied governing institution, particularly when it comes to challenging manifestly inadequate governmental action that leads to further erosion of trust and the furthering of inequality in a health system, as has been shown through previous positive experiences.<sup>12</sup>

In a world like ours, having witnessed inadequacies at every step of pandemic management, the building of trust—and the overall process of transformation—cannot simply be restricted to national authorities, law, and institutions. WHO is the main authority at the global scale, with some legal powers to respond to public health emergencies of international concern, but these powers are severely limited by state sovereignty.<sup>13</sup> Most of WHO's funding comes from donations by member states, and for this reason it has been accused of choosing diplomacy over transparency when dealing with some states. WHO does not have a guaranteed right of access in countries to investigate emerging outbreaks, and it cannot ensure compliance with its recommendations.<sup>14</sup> Part of the requirements during a transitional phase would be to strengthen WHO's ability to assist states in rebuilding their health systems. WHO is currently in negotiations to draft a convention dedicated to pandemic prevention, preparedness, and response.<sup>15</sup> But it remains to be seen if the convention would be able to eliminate some of the uncertainty regarding WHO's authority, strengthen the enforcement of its provisions, and include clear principles and institutional mechanisms for recovery and transformation.

Another core demand of THJ is the acknowledgment and redressal of mass-scale human rights violations that are markers of broken health systems. Traditionally, TJ frameworks rely on truth commissions to deal with past wrongs. Our THJ framework, however, breaks away from this tradition. Some violations of civil and political rights are justifiable on grounds of public emergency, but the more structurally rooted violations of economic

and social rights, like health rights, are usually not traceable to a single perpetrator. Truth commissions work when they preserve memory of past abuse and violations and promote accountability, but they can sometimes hinder health transformations because they can also increase distrust in health-related institutions, which is an essential marker of transitional health contexts and requires changing.

Bearing this in mind, we propose that transitioning health systems look at establishing “best practices commissions” (BPCs). These commissions would be tasked primarily with suggesting evidence-based practices that would best aid the transformation of a health system. They would also undertake some record-keeping and investigation of the causes and patterns of failings of the previous health system and human rights violations that took place during health emergencies. But their role would be limited to assessing the causes of failings and wrongdoings, and that would be prioritized over assigning responsibility or placing blame. In practical terms, the function of BPCs would be analogous to an ombudsperson tasked with overseeing community and national health registers, with a focus on suggesting best practices along the lines of the Good Clinical Practices.<sup>16</sup>

## Transitional health justice and the right to health

As mentioned before, the THJ framework aims at eliminating or ameliorating the circumstances of THJ, and the circumstances of THJ include the normalization of individual and collective wrongdoing. Some of these wrongdoings will inevitably amount to serious violations of the right to health, which suggests that an integral part of transformation involves measures to reassert, uphold, and strengthen the right to health. More than that, the right to health and the transitional health framework are mutually reinforcing—while transformation is often necessary to the realization

of the right, core demands of this right can guide health transformations.

There are, of course, multiple accounts of the right to health, each ascribing to it different grounds, scope, content, and correlative demands.<sup>17</sup> Thus, it should be expected that different accounts of the right to health will seek to guide transformation differently: the more capacious a conception of the right to health, the more robust its demands of institutional and social transformations from transitioning health systems will be. For brevity, we will not be presenting a full-fledged account of the right to health here. We will employ a legal characterization as a starting point to identify a few demands typically associated with the right to health and assess what these demands entail within a THJ framework.

One demand concerns the meaningful and effective participation of people in decision-making pertaining to their health.<sup>18</sup> Article 4 of the 1978 Declaration of Alma-Ata on primary health care states that “people have the right and duty to participate individually and collectively in the planning and implementation of their health care.”<sup>19</sup> Such participation was popular during the heyday of the HIV/AIDS movement in the 1990s, but public and stakeholder involvement remains limited in health-related policy and legislative decisions today.<sup>20</sup> This is evident even at the global level. Despite listing community engagement and inclusiveness as its guiding principles, the Zero Draft of the Pandemic Treaty provides limited channels for community or civil society participation.<sup>21</sup> Our proposed transitional framework has resources to uphold this demand. Community-driven BPCs that document the concerns of all stakeholders could be given competence as one of the official channels to engage in the domestic and international negotiation of policies and agreements related to health. People suffering the after-effects of health emergencies should be able to have a say in the decisions that affect their lives. As part of

their record-keeping and investigatory function, BPCs could collect and assess recommendations from the public and be the bridge between experts, individuals, communities, and national and global health institutions. Here we can see how the THJ framework and the right to health support each other: while the right to meaningful participation in health decisions supports the establishment of BPCs, BPCs can effectuate this right.

Another demand of the right to health is that of securing people's health in a nondiscriminatory manner and providing adequate accountability mechanisms for holding authorities answerable for their acts and omissions.<sup>22</sup> The principles of nondiscrimination, equality of treatment, and accountability align with, and aid in fulfilling, the primary demand of the THJ framework—that of building trust between people and their health institutions. This trust has repeatedly been tested by various health emergencies.<sup>23</sup> But when it comes to health reforms post-emergencies, most fail to address the mass-scale human rights violations that take place during emergencies, leading to further fragility of trust. The THJ framework aims at restoring and strengthening trust through, as mentioned above, independent and autonomous health agencies, stringent checks and balances, and a strengthened corpus of health law. It requires that a robust health rights framework be both central to, and dependent upon, justly transforming health systems.

When thinking about the right to health in transitioning contexts, we should not exclusively look at how its core demands shape the THJ's framework. We should also consider how a demand to eliminate the circumstances of THJ will impact our accounts of the right to health. The right to health is traditionally seen from a vertical standpoint, centering on the duties that states owe to right bearers.<sup>24</sup> However, if the elimination of the circumstances of THJ is part of the scope of the right to health—as we think it should be—then

any satisfactory account of this right must be more capacious and frame the right to health as imposing on individuals correlative health duties to one another, including duties to avoid normalizing individual wrongdoing during and after health emergencies. Examples of people prioritizing personal preferences over collective health interests were unfortunately myriad during the COVID-19 pandemic. The just pursuit of transformation—and the true realization of the right to health—will therefore require not only the transformation of institutions but also the transformation of our social relations more widely. Beyond rebuilding trust, the right to health should be seen as demanding that our transitional processes target the cultivation of virtues of compassion and solidarity and of social norms that prevent the dissemination of harmful health practices at both institutional and individual levels. How these can be cultivated is something that we cannot address in this contribution. We hope, however, to have conveyed the need to start a broader conversation about transitional health justice and its realization.

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## STUDENT ESSAY

# Locked Up and Left Behind: Addressing Cruel and Unusual Punishments among Senior Inmates during COVID-19 across US Prisons

SABBA SALEBAIGI

### Abstract

The COVID-19 pandemic has shed light on long-standing constitutional violations within the US correctional system, particularly affecting vulnerable populations such as senior inmates. By analyzing the impact of COVID-19 in prisons, the challenges faced in implementing preventive strategies, and the specific vulnerabilities of elderly prisoners, this paper identifies potential constitutional infringements experienced by senior inmates during the pandemic and the physical, mental, and social effects of the pandemic on this population. Specifically, this paper aims to bridge the fields of constitutional law, prison reform, elder law, and the COVID-19 pandemic by examining the impact of the pandemic on the rights of senior inmates under the US Constitution's Eighth Amendment protection against cruel and unusual punishment. The objective is to examine whether potential violations have occurred and propose actions to prevent violations in the future while ensuring accountability and redress if such violations occur. To address such violations, the paper emphasizes the need for increased sanitation measures and decarceration as preventive measures in future public health crises.

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## Introduction

Incarceration is intended to serve as punishment, deterrence, and rehabilitation for criminal acts. However, incarceration should not subject individuals to inhumane or degrading conditions. The US Constitution “does not mandate comfortable prisons, but neither does it permit inhumane ones.”<sup>1</sup> Despite such principles, US prisons have long been marked by human rights and constitutional violations, particularly for vulnerable populations such as seniors.<sup>2</sup> The COVID-19 pandemic has amplified these long-standing issues, highlighting the dire need for reform in the correctional system. The challenges of controlling airborne virus transmission within prisons have been demonstrated since the early 20th century, with instances such as tuberculosis outbreaks in New York prisons in 1903 and the Spanish flu outbreak at California’s San Quentin State Prison in 1918.<sup>3</sup> Despite this historical precedent, little was done a century later to slow the spread of COVID-19 in correctional facilities.<sup>4</sup> The virus was first reported in Wuhan, China, in December 2019.<sup>5</sup> By mid-March 2020, reports of inmates and staff infections in US prisons emerged.<sup>6</sup> By July 2020, the case rate in prison was 5.5 times higher than in the outside US population.<sup>7</sup> Overcrowding, poor ventilation and hygiene, and inadequate access to medical care make correctional facilities particularly vulnerable to diseases such as COVID-19.<sup>8</sup>

In this paper, I examine how the COVID-19 pandemic has impacted the health and rights of senior inmates in prison and explore what actions can be taken to mitigate such impacts in the future. To do so, I first examine the general impact of COVID-19 in prisons across the United States, the overall impact of the pandemic on inmates, and the various challenges faced by prisons in implementing prevention strategies. Second, I focus on the distinct susceptibilities of elderly prisoners that render them especially vulnerable in a pandemic

setting, as well as the mental and physical effects that COVID-19 has had on them. Third, I examine the potential human rights violations of senior inmates during the pandemic through the lens of the right to be free from cruel and unusual punishment under the Eighth Amendment to the US Constitution. Finally, I argue that in addition to addressing the past violations documented in this paper, prisons must take action to mitigate the risks faced by senior inmates during future public health crises. This should involve not only increased prevention measures and decarceration but also the provision of remedies to those who were impacted by past violations.

## How did COVID-19 impact prisons?

As of December 2021, the global tally of confirmed COVID-19 cases exceeded 287 million, with a staggering death toll of 5.4 million.<sup>9</sup> While the virus wreaked havoc across the world, its impact on the US prison system was particularly devastating. The COVID-19 pandemic hit prisons in the United States hard, with jails and correctional facilities accounting for a significant number of infections across the country.<sup>10</sup> Many people who are incarcerated have preexisting health conditions, making them more vulnerable to severe illness or death if infected with the virus.<sup>11</sup> As the aftermath of the pandemic continues to impact correctional facilities, it is vital to acknowledge the significant challenges faced by inmates, including limited access to testing and medical care, heightened fear of isolation and punishment, and the inadequacy of facilities. These challenges underscore the urgent need to address the well-being and human rights of incarcerated individuals, ensuring their access to health care, mental health support, and improved living conditions within prisons.

The transmission of COVID-19 within prisons was facilitated by various factors, including the in-

roduction of the disease through newly admitted or transferred inmates, inmates leaving the facility for court appearances or medical appointments, and the frequent rotation of prison staff.<sup>12</sup> The close living quarters in prisons created an environment conducive to the airborne transmission of the virus.<sup>13</sup> Since inmates and staff shared the same air, the virus found an easy pathway to propagate.<sup>14</sup> The Federal Bureau of Prisons implemented a COVID-19 action plan in March 2020, which aimed to restrict access to federal prisons and limit the movement of prisoners between facilities.<sup>15</sup> In spite of various efforts across the country, the virus swiftly and profoundly impacted prison environments. As of April 2020, a staggering 566 federal inmates had already tested positive for COVID-19, resulting in 24 fatalities.<sup>16</sup> The gravity of the situation escalated rapidly, with the tally of incarcerated individuals testing positive exceeding 32,000 by May 2020.<sup>17</sup>

The enormity of the crisis became increasingly evident as these figures consistently climbed. By September 2020, no fewer than 121,217 incarcerated individuals had tested positive for COVID-19.<sup>18</sup> By February 2021, the toll had surged to over 510,000 confirmed cases, with at least 2,200 reported deaths within US prisons.<sup>19</sup> It is important to note that these reported numbers likely underrepresent the actual extent of infections and fatalities, as limited testing and prisoners' reluctance to report symptoms due to fear of isolation contribute to an underestimation.<sup>20</sup> An illustrative example of this issue is the Marion Correction Institution in Ohio, a 2,500-capacity prison that at one point had 2,000 inmates who tested positive for COVID-19 following state-mandated mass testing.<sup>21</sup> These statistics highlight the rapid spread of COVID-19 within correctional facilities. While they do not provide specific information about the outcomes of inmates who contracted the virus, they underscore the pressing need for a comprehensive investigation into the conditions that facilitated such a swift infection rate among inmates.

Numerous correctional facilities across the United States have received considerable criticism due to their inadequate allocation of resources to prevent and manage COVID-19 outbreaks.<sup>22</sup> Prisons, known for their subpar hygiene conditions, often deny inmates sufficient access to essentials like soap and running water, rendering basic infection control practices such as regular hand washing nearly unfeasible.<sup>23</sup> The Centers for Disease Control and Prevention (CDC) has underscored the significance of practicing social distancing and enhancing sanitation to impede the transmission of COVID-19.<sup>24</sup>

Incarcerated individuals share confined spaces, encompassing cells, restrooms, washrooms, and dining halls, where maintaining the recommended physical distance is virtually unattainable.<sup>25</sup> Even single cells with solid doors can mimic shared dormitories if heating, ventilation, and air conditioning systems are not in compliance with standards, thereby exacerbating viral spread.<sup>26</sup> The cramped living quarters for inmates facilitated the spread of the virus, while frequent visits to communal spaces made it extremely challenging to implement quarantine measures such as social distancing.<sup>27</sup> Furthermore, the constant influx of staff in and out of the facility put inmates at a higher risk of exposure.<sup>28</sup> During the pandemic, prisons lacked sufficient alcohol-based sanitizers, which were essential for reducing transmission. The availability of alcohol-based solutions needed close monitoring to prevent potential stockpiling or misuse.<sup>29</sup>

In addition to its general recommendations, the CDC advocated for a multifaceted approach to combat COVID-19 within prison confines.<sup>30</sup> This encompassed the implementation of universal mask-wearing, an augmentation of ventilation systems, and the expansion of COVID-19 testing initiatives.<sup>31</sup> Paramount to this strategy was the introduction of masks for inmates and staff members alike, with heightened attention to ensuring proper fit for inmates.<sup>32</sup> However, there were insufficient

resources to address inmates' needs, and correctional staff were instructed to prioritize inmates at higher risk of contracting the virus when distributing masks.<sup>33</sup> This not only created a risk for inmates who did not receive appropriate personal protective equipment but also placed staff in a position of power in which they dictated who was more deserving of protection. Moreover, the universal adoption of mask-wearing, although ideal, faced pragmatic hurdles. The necessities of eating, bathing, and sleeping meant that prisoners periodically had to remove their masks, rendering a continuous mask-wearing regimen infeasible.<sup>34</sup>

A deficiency in proper ventilation plagues a substantial number of the nation's prisons, impeding the unobstructed circulation of fresh air and cultivating an environment that fosters the accumulation of airborne contaminants.<sup>35</sup> This insufficiency of fresh air results in infected individuals sharing common air space with susceptible inmates.<sup>36</sup> During the pandemic, diagnostic testing of inmates was limited due to the inadequate availability of tests nationwide.<sup>37</sup> Some prisons provided tests only to symptomatic inmates, disregarding the fact that 60% of COVID-19 cases are asymptomatic.<sup>38</sup> Test results were often not communicated to inmates, and inmates were transferred to different cells or prisons without knowledge of their COVID-19 status.<sup>39</sup> Inmates with inconclusive tests were sometimes isolated with those who tested positive, further exposing them to the virus.<sup>40</sup>

Evidence indicates that individuals over the age of 50, who account for over 10% of state prisoners and 12% of federal prisoners, face a significantly increased risk of life-threatening complications from COVID-19.<sup>41</sup> Moreover, accelerated aging in prison contributes to a higher likelihood of chronic illness, compounding the vulnerability of senior inmates.<sup>42</sup> These individuals already bear a heavy burden of chronic diseases such as diabetes and hypertension, rendering them more susceptible to severe COVID-19 infections.<sup>43</sup> Furthermore, the

overrepresentation of ethnic and racial minorities in the incarcerated population is a systemic issue within the criminal justice system.<sup>44</sup> This issue is relevant to our discussion of senior inmates because these systemic biases and disparities, along with barriers to quality health care and the confined living conditions in correctional facilities, also affect senior inmates and contribute to their higher prevalence of COVID-19 complications, hospitalizations, and fatalities.<sup>45</sup>

During the pandemic, prisoners faced significant challenges, particularly in accessing medical care. Many inmates delayed reporting symptoms out of fear, as they witnessed others being punished or isolated for seeking medical attention.<sup>46</sup> Solitary confinement was used as a disciplinary measure for noncompliance with COVID-19 protocols, leading to an estimated increase in the number of inmates in solitary confinement from 60,000 to 300,000 in June 2020.<sup>47</sup> The line between medical isolation and solitary confinement was blurred at most prisons, and inmates felt "like [they] were being literally punished for getting sick [with COVID-19]."<sup>48</sup> Moreover, there was a double standard between staff and inmates, with staff enforcing mask compliance and social distancing while not following these measures themselves.<sup>49</sup> Inmates who requested staff compliance were threatened with solitary confinement, causing frustration and fear.<sup>50</sup> Lack of staff compliance jeopardized inmates' health and safety, and staff wearing masks only during officials' visits created a false narrative of good conditions.<sup>51</sup> Staff's lack of cooperation heightened inmates' sense of unjustified restrictions, worsening the tense inmate-staff relationship.<sup>52</sup>

## How did COVID-19 impact inmates?

Imprisonment accelerates the aging process, causing incarcerated individuals to physically age faster than their non-incarcerated counterparts and develop health issues typically associated with indi-

viduals older than their actual age.<sup>53</sup> Studies suggest that each year of incarceration shortens a person's future life by two years, emphasizing the profound impact on senior inmates.<sup>54</sup> This phenomenon of accelerated aging is said to be due to a high number of environmental stressors that elderly inmates experience, such as bullying and sleep deprivation, along with insufficient access to proper health care.<sup>55</sup> Exposure to second-hand smoke, poor diet, and lack of exercise can further age an individual and jeopardize their health.<sup>56</sup> The introduction of the COVID-19 virus into prisons was detrimental to an already vulnerable population.

Prisons have long neglected the safety of older inmates and denied necessary accommodations to disabled individuals, including access to medication, prosthetic limbs, and hearing aids.<sup>57</sup> Unfortunately, the pandemic exacerbated these already concerning conditions.<sup>58</sup> The Americans with Disabilities Act, specifically Title II, prohibits discrimination against disabled inmates and mandates that prison officials provide reasonable accommodations for accessing programs and services.<sup>59</sup> The failure to provide detainees with visual or hearing impairments access to audio, large-print, or Braille materials regarding prison rules and policies not only increased survival risk but also led to increased disciplinary sanctions.<sup>60</sup> Furthermore, lockdown measures prevented inmates, particularly older or disabled individuals, from participating in rehabilitation programs, which put them at a disadvantage when it came to demonstrating the required qualities for parole or compassionate release.<sup>61</sup>

COVID-19 severely impacted inmates' mental health due to fear, vulnerability, and unhygienic living conditions in overcrowded prisons.<sup>62</sup> Regular routines, such as the recreational, social, and vocational outlets that helped residents cope while serving time prior to COVID-19, were largely eliminated, leaving inmates with even fewer resources to cope with the psychological effects of the pandem-

ic.<sup>63</sup> The COVID-19 prevention measures that were implemented, including social distancing, cancellation of visitations, and a limit on time spent outside one's cell, resulted in inmates being locked in their cells for extended periods, sometimes up to 23 hours or more each day.<sup>64</sup> This made it incredibly difficult for inmates to maintain a sense of connection with the outside world, particularly with family and friends.<sup>65</sup> The uncertainty surrounding COVID-19, including not knowing when lockdowns would end and when one could communicate with loved ones again, heightened inmates' anxiety and negatively affected their mental well-being.<sup>66</sup>

The exorbitant cost of communication during lockdowns left inmates feeling more isolated.<sup>67</sup> In one study, participants expressed the difficulty of separation and inability to connect with loved ones, with the loss of community connection described as traumatic.<sup>68</sup> Prisons on lockdown were described by residents as crazy, unorganized madhouses, with staff reacting with a panic and fear.<sup>69</sup> Noise levels were said to have increased as a result of prisoners becoming irritated during the 23-hour lock-ups.<sup>70</sup> Inmates shared that the "incessant, inescapable noise" contributed to self-harm and suicide.<sup>71</sup> Inmates received limited information about the severity of COVID-19 within their facilities, and they viewed this lack of information and restriction on communication with the outside world as deliberate manipulation to conceal the situation in their facilities from negative outside attention.<sup>72</sup>

During the pandemic, many prisons repurposed physical spaces, including ones that were previously unoccupied, for containment measures such as isolation and quarantine.<sup>73</sup> These spaces were characterized as unlivable, with buildings being moldy, rodent infested, and dilapidated.<sup>74</sup> Inmates described living conditions of sweltering heat with no air conditioning or drinkable water, no opportunity to shower or do laundry, and clogged sinks and toilets (or no toilets at all).<sup>75</sup> The lack of hot water meant that inmates' clothing and

bedding were not adequately cleaned.<sup>76</sup> Such conditions impacted the health of inmates and created harsh environments that were not conducive to recovery or rehabilitation.<sup>77</sup>

Several residents infected with COVID-19 were isolated and detailed the confiscation of all their property by staff and how they received no medical attention except for temperature checks.<sup>78</sup> The food quality in facilities declined as well.<sup>79</sup> Some inmates reported having only one hot meal each day and having to rely on cold sandwiches for months, while other inmates reported frequent food poisoning from undercooked meals or food covered in “rat urine & poop.”<sup>80</sup> Ordinarily, this can be considered a gross violation of one’s right to health because it is depriving them of general nutrition and a clean environment.<sup>81</sup> However, the vulnerability of senior inmates becomes more clear when we consider their preexisting physical frailty and the heightened need for improved access to food and medical care to maintain their strength and overall health.<sup>82</sup> In this context, not only is the right to health in jeopardy, but so is the right to be free from cruel and unusual punishment, as inmates depend on prison authorities to address their medical needs.<sup>83</sup>

### Was senior inmates’ Eighth Amendment right to be free from cruel and unusual punishment violated during the COVID-19 pandemic?

The Eighth Amendment to the US Constitution safeguards incarcerated individuals against cruel and unusual punishment, ensuring that they are not exposed to circumstances that pose a grave threat to their physical health or overall well-being.<sup>84</sup> Proving a breach of the Eighth Amendment requires demonstrating treatment that is so grossly inadequate, incompetent, or excessive that it shocks the conscience or violates fundamental fairness.<sup>85</sup> The Supreme Court’s rulings in *Estelle v. Gamble*

(1976), *Helling v. McKinney* (1993), and *Farmer v. Brennan* (1994) have established the deliberate indifference standard, protecting inmates from future harm and holding prison officials accountable for disregarding serious risks to inmate health and safety.<sup>86</sup> Deliberate indifference can arise with the “unnecessary and wanton infliction of pain” as per the Eighth Amendment.<sup>87</sup> A two-part test has been established to determine whether an incarcerated individual’s right to humane conditions of confinement has been violated under the Eighth Amendment.<sup>88</sup>

In order to raise an Eighth Amendment claim, an inmate must show first that they are or were incarcerated under conditions that pose a substantial risk of serious harm, such as deprivation of basic human needs (including medical care).<sup>89</sup> The high number of COVID-19 cases and deaths among senior inmates in prisons across the United States during the pandemic supports the assertion of a serious risk of harm to the older population, given their underlying health conditions.<sup>90</sup> Once this risk has been established, the inmate must demonstrate that prison officials acted or failed to act with deliberate indifference to the substantial risk of harm, equivalent to recklessly disregarding that risk.<sup>91</sup> An illustrative example of the implementation of this test can be observed in the case of *Banks v. Booths* (2020), where successful litigation regarding COVID-19 conditions in prison demonstrated how these legal standards can lead to immediate improvements in prison conditions.<sup>92</sup>

The protections guaranteed under the Eighth Amendment against cruel and unusual punishment encompass access to dental care, the assurance of adequate meals, and the provision of proper medical and mental health treatment.<sup>93</sup> The US Supreme Court has interpreted this language to mean not that prisons are obligated to meet all of the dental and medical needs of their inmates but rather that they must not be deliberately indifferent to the serious medical needs of prisoners.<sup>94</sup> Applying these rules

to the situation in prisons during the COVID-19 pandemic, it is clear that correctional facilities were obligated to undertake specific actions to safeguard inmates from transmittable viruses.<sup>95</sup> This includes the provision of reasonably adequate ventilation, sanitation, bedding, and hygienic materials.<sup>96</sup> Prisons across the country have justified their failure to implement these measures during the pandemic by pointing to significant constraints, including the rapid spread of the virus, concerns about public safety, and budget limitations.<sup>97</sup> While prisons had many challenges to navigate COVID-19, it is important to note that their actions may have infringed on the Eighth Amendment right to be free from cruel and unusual punishment. This understanding, however, does not diminish the fact that such infringements occurred.

Beyond the safeguards provided by the US Constitution, additional protection for inmates stems from international standards for human rights. The United Nations Standard Minimum Rules for the Treatment of Prisoners (known as the Mandela Rules) identify prolonged solitary confinement as a form of cruel, inhumane, and degrading treatment, often amounting to torture.<sup>98</sup> Solitary confinement should be strictly prohibited, especially when prisoners have mental or physical disabilities that would worsen under such conditions.<sup>99</sup> The Mandela Rules further assert that inmates should be entitled to health care standards on par with those available to the general community and must have access to essential services without any form of discrimination.<sup>100</sup> Moreover, health care personnel should not play a role in imposing disciplinary measures or other restrictive actions. Similar to the Mandela Rules, the International Covenant on Economic, Social and Cultural Rights requires that states respect the right to health by “refraining from denying or limiting equal access for all persons, including prisoners.”<sup>101</sup> However, it is important to note that as of November 2023, the United States has not ratified either the covenant or

the Mandela Rules. Consequently, these rules are considered advisory and function as international guidelines for the treatment of prisoners. Inmates cannot use the lack of compliance with these rules as grounds for litigation in US courts.<sup>102</sup> This situation of reduced legal avenues becomes especially problematic when considering that many senior inmates faced excessive isolation measures during the pandemic. These measures, implemented both as protective and reactive responses, potentially infringe upon their rights against cruel and unusual punishment.

Prolonged isolation can cause severe and lasting psychological and neurological damage, leading to higher suicide and self-harm rates compared to the general prison population.<sup>103</sup> In addition to the psychological harm that came from isolation and administrative segregation, many senior inmates were met with brute force and excessive violence as punishment for not obeying COVID-19 protocols.<sup>104</sup> Such behavior ordinarily cannot be condoned; however, within the context of a global pandemic in which most individuals’ bodies and minds were already weak, it is inexcusable. In an effort to mitigate human right violations, Penal Reform International suggests avoiding or minimizing blanket isolation for inmates who test positive, and instead conducting individualized medical assessments.<sup>105</sup>

While some argue that prisons took necessary measures to protect inmates and staff, such as isolation, limited movement, and vaccine distribution, the evidence shows that senior inmates were left vulnerable to the virus due to inadequate health care and a lack of access to vaccines.<sup>106</sup> The pandemic further strained an already overburdened health care system within prisons. Many prisons lack real hospitals and the capacity to provide the same standard of health care that is available in the community.<sup>107</sup> Some prisons even tried to save a few dollars by hiring medical professionals with questionable credentials, to the detriment of inmates.<sup>108</sup> Further, the prioritization of staff over inmates

for vaccination, despite higher case rates among inmates, neglected the vulnerability of senior inmates to severe illness.<sup>109</sup> This decision disregarded the obligation to provide equivalent medical care to prisoners as the general population and, more importantly, to the vulnerable population.<sup>110</sup> Failure to protect the health of senior inmates may constitute a violation of their right to be free from cruel and unusual punishment and cause irreparable constitutional injury to a vulnerable population.<sup>111</sup>

### Can US prisons mitigate future cruel and unusual punishments?

The COVID-19 pandemic has highlighted constitutional and human rights violations in US prisons, particularly among vulnerable populations such as senior inmates. These individuals faced a range of challenges during the pandemic, including social distancing and isolation, the suspension of prison visits, and reduced access to mental and physical health services.<sup>112</sup> To address these issues and mitigate their impact in the future, several measures can be implemented. Ensuring the provision of both individual and communal socially distant activities, such as outdoor exercise, virtual educational programs, reading materials, art and creative projects, and video conferencing with loved ones, can help maintain the mental and physical well-being of prisoners.<sup>113</sup> Additionally, clear and accessible communication about public health measures, particularly those related to COVID-19 prevention and safety protocols, should be tailored to the needs of disabled prisoners. This communication is crucial for their understanding of these measures and their compliance with them. Access to telephone and video calls with friends and family is essential for maintaining important relationships.<sup>114</sup> Comprehensive risk assessment, telepsychiatry services, and socially distant in-person mental health appointments can effectively address the mental health impacts of isolation.<sup>115</sup> Moreover, in terms of

mitigating the future transmission of viruses within prison facilities, implementing effective ventilation systems is essential.<sup>116</sup> Recommendations in this regard include practices such as opening windows, using portable air-cleaning devices, and ensuring healthy indoor air.<sup>117</sup> These measures collectively contribute to a safer and more humane environment within prisons, especially during times of crisis.

The pandemic highlights another crucial issue that requires urgent attention: the need for prison reform and a reduction in inmate populations. While some may argue for the construction of additional prisons to alleviate overcrowding, it is essential to consider alternative solutions that prioritize rehabilitation, diversion programs, and more humane conditions, which can ultimately lead to a safer and more just society. Conventional aims of criminal justice, such as deterrence, incapacitation, rehabilitation, and retribution, cannot be effectively achieved by incarcerating prisoners in conditions that expose them to severe and potentially deadly illnesses.<sup>118</sup> Efforts such as releasing offenders who would have been held for pretrial detention or issuing short sentences for nonviolent offenses can further help address the problem of overcrowding.<sup>119</sup> Prisons such as Clackamas (Oregon) and Kitsap (Washington) reduced their jail populations by 66% and 58%, respectively, during the pandemic, serving as examples of the feasibility of reducing prison populations during times of crisis.<sup>120</sup> In response to the health crisis in May 2020, the Federal Bureau of Prisons placed 4,700 inmates on home confinement and allowed them to continue their sentences under community supervision. It is unsurprising that it took a global pandemic to show the utility of home confinement and community sentences and the benefits they provide to both inmates and prisons. Creating available space in overcrowded facilities allows for the implementation of social distancing measures, enhanced cleaning protocols, and the adjustment

of other institutional practices.<sup>121</sup> These changes can help reduce the transmission of viruses among both inmates and staff.<sup>122</sup>

It is particularly concerning that it took a deadly pandemic for prisons to recognize the urgency of addressing overcrowding and potential human right violations, considering that these issues could have been mitigated from the outset by reducing the number of individuals admitted. Moreover, courts should recognize the existence of viable alternatives to imprisonment—such as restorative justice programs, community services, and probationary measures—that can better serve offenders while also relieving the population pressures on prisons. Prisons must acknowledge their role in these challenges and understand that decarceration, coupled with the thoughtful consideration of alternative sentencing options, offers the sole sustainable solution to underlying problems such as overcrowding and social distancing. Addressing the systemic issues that underlie these problems is paramount. By reducing the number of incarcerated individuals in the United States, we can protect inmates' constitutional and basic human rights and mitigate the transmission of deadly viruses such as COVID-19. Action is long overdue, and it is imperative that prisons reassess their policies and implement the necessary changes to ensure that justice is genuinely served.

## Conclusion

The harm inflicted on senior inmates in the name of criminal justice and public safety has pierced the veil of unconstitutional and life-threatening conditions for this population. We cannot continue to justify the unsafe living conditions and inadequate health care that have resulted in a disproportionate number of deaths and illnesses among this vulnerable population. We must urgently address these issues and ensure dignity and respect for senior inmates, despite their incarceration status. For those

senior inmates who are fortunate enough to finish their incarceration period, the stigma of incarceration alone is sufficient to hinder their prospects for a future life. Health complications from COVID-19 or other illnesses should not be additional burdens they face. While their likelihood of contracting the virus outside of prison would have still been probable, they were disproportionately exposed to the virus within such closed and cramped conditions. The comorbidities of age and health factors raise compelling substantive claims of cruel and unusual punishment for this population. The available data allow one to assume that prisoners did not receive the same standards of health care available to the community, which is a breach of rule 24 of the Mandela Rules.<sup>123</sup>

Regardless of the available legal protections in place to protect this community, relying solely on litigation is insufficient to address the overall health and human rights issues faced by inmates. While attempts have been made to seek legal remedies by invoking their Eighth Amendment rights in response to COVID-19-related issues in prisons, the judicial process often affords prisons generous opportunities to address inmates' concerns, which may fall short of fully protecting inmates from instances of cruel and unusual punishment.<sup>124</sup> Thus, systematic change is required to address the unlivable conditions that inmates, and particularly senior inmates, are subjected to, and resources and protections for them need to be increased in order to ensure adequate and humane care. Appropriate steps should also be taken toward decarceration and finding alternatives to incarceration for this demographic. This will require a coordinated effort between lawmakers, advocates, and community leaders to promote policies and programs that prioritize the health and well-being of our most vulnerable citizens. The courts have already conceded the challenges that the conditions of confinement have on the safety and health of the inmate population.<sup>125</sup> The chilling aftermath of

the COVID-19 pandemic should serve as a stark reminder of the urgent need to address these issues, recognizing that history is likely to repeat itself during the next airborne virus epidemic. It is our moral duty to learn from this experience and take proactive measures to protect the rights and health of inmates, rather than waiting for the next crisis to force our hand.

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## LETTER TO THE EDITOR

# Climate Change as a Risk Factor for Food Insecurity in Spain

JULIETTE DUFFY

In their recent paper “Food Security as a Social Determinant of Health: Tackling Inequalities in Primary Health Care in Spain,” *Mireia Campanera, Mercè Gasull, and Mabel Gracia-Arnaiz* explore the role that primary health centers play in addressing food insecurity in the Catalonia region of Spain and how food security is inextricably linked with the social determinants of health.<sup>1</sup> The paper highlights barriers to access to healthy, safe, and sufficient food, but it does not address one overriding confounding factor: climate change. In this letter, I illustrate the trickle-down effect that climate change has on food insecurity in Spain.<sup>2</sup>

There is widespread agreement that climate change is contributing to increased food insecurity around the globe.<sup>3</sup> The 2022 report of the *Lancet* Countdown states that extreme heat was the cause of an extra 98 million people reporting moderate to severe food insecurity in 2020 compared to 1981–2010.<sup>4</sup> Research in the Aragon region in Spain (neighboring the Catalonia region) indicates that this area can expect to see the highest maximum temperatures in Spain, as well as the greatest intensity of heat waves, with increasingly intense periods of drought in the future.<sup>5</sup> These regions of Spain should prioritize mitigation strategies that reduce greenhouse gas emissions to prevent the threat of intense heat waves and potential impacts that heat and drought may have on food security. The Intergovernmental Panel on Climate Change highlights that prioritizing the local production of fruits and vegetables in Spain, rather than importing produce, can reduce greenhouse gas emissions and promote food security.<sup>6</sup>

Climate change exacerbates social and health inequities.<sup>7</sup> Campanera et al. note that current socioeconomic strains are making food unaffordable for many families and individuals. Other research suggests that by 2035 food prices will have increased a further 60% in Spain; heat and decreased precipitation are reducing the quality and yield of harvests, increasing the price of fresh food and intermediate products along the food production chain.<sup>8</sup> Despite recommendations by primary health centers to eat healthy diets, this will have little effect if vulnerable patients cannot afford healthy food.

Climate-change-induced temperature increases have an impact on people with chronic disease and malnutrition; for example, temperature increases have a detrimental effect on the body mass index of people living in hot countries, in part because of the decrease in physical activity in hot climates.<sup>9</sup> With Spain’s increasing temperatures, higher levels of physical inactivity could compound the need identified by Campanera et al. to include food in the diagnosis, treatment, and prevention of disease.

The relationship between climate change and food insecurity in Spain cannot be ignored. Understand-

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ing the social determinants of health that influence food insecurity and being able to analyze this at the primary health care level may help prevent health problems. However, climate change risks must be factored into health, social, and food policies to protect and promote the right to food and health for people in Spain and elsewhere.

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## EDITORIAL

# Economic Inequality and the Right to Health: On Neoliberalism, Corporatization, and Coloniality

GILLIAN MACNAUGHTON AND A. KAYUM AHMED

The emergence of neoliberalism 50 years ago has led to a marked increase in economic inequality and an undermining of economic, social, and cultural rights. The papers in this special section examine the role of neoliberal policies in exacerbating economic inequality, while at the same time considering how these policies deliberately prevent efforts to progressively realize the right to health. Drawing on international human rights, several papers also propose actions to reduce economic inequality and create conditions favorable for realizing the right to health and human rights more generally.

The *Global Wealth Report 2022* “estimate[d] that the bottom 50% of adults in the global wealth distribution together accounted for less than 1% of total global wealth at the end of 2021. In contrast, the richest decile (top 10% of adults) own[ed] 82% of global wealth.”<sup>1</sup> Further, Oxfam reported in 2023 that globally, over the past two years, the wealthiest have become much wealthier, while at the same time, “poverty has increased for the first time in 25 years.”<sup>2</sup> Neoliberal policies have actively embraced free market capitalism and economic inequality and rejected ideas of solidarity by restructuring economies, privatizing, deregulating, reducing taxes on the wealthy, and transferring the obligations of states to private entities.<sup>3</sup>

All governments make political choices in allocating funding to and within the health sector. They decide whether to meet their right to health obligations as well as their international human rights duty to ask for or offer assistance to other states to meet their right to health obligations. COVID-19, especially until the rollout of vaccines, demonstrated the capacity of states to respond to crises when good health depended on health for all. Admittedly, some did much better than others at ensuring the economic protection of low- and middle-income populations, as well as equitable access to care and vaccination. But the global commitment to “build back better” now rings hollow, and attempts to respond to climate change using the same existential-crisis framing are few and far between. Overall, there has been a failure to respond to what should have been the most important lesson to come from the pandemic: good physical and mental health are fundamental to life and to our communities, and without good health, economies and societ-

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ies cannot thrive. In terms of human rights, if the right to health is not realized, nor will any other economic, social, cultural, civil, or political rights be truly fulfilled.

While there are numerous examples in which the right to health framework has successfully advanced policies to respect, protect, and fulfill the rights of marginalized groups, we recognize that the right to health is rarely invoked to address the root causes of economic inequality. Rather, the dominant interpretation of the right to health, accommodates—if not facilitates—the social atomization and market fetishism core to the neoliberal political project, which has increased economic inequality.

To address economic inequality and the right to health, states must change fiscal policies that remain focused on neoliberal goals such as those that promote unsustainable growth and ignore the plight of the majority and the planet. If universal good health had been afforded prominence, the health workforce would not be in its current precarious state, facing a projected global shortage of about 10 million workers by 2030, spread unequally, with the worst shortages expected in the lowest-income countries with the most need.<sup>4</sup> To fulfill an equal right to health, states must invest in health workers and in health infrastructure, and stop the egregious gouging of the health dollar by the private sector, especially in the for-profit health insurance and pharmaceutical sectors. Yet with few exceptions, the role of fiscal management in contributing to increased economic inequality and unequal access to health care and the social determinants of health has not been examined by right to health scholars.<sup>5</sup>

The papers in this special section address economic inequality and the right to health, examining health care systems and the social determinants of health in the context of neoliberalism and in light of the recent and current crises of gross economic inequality, austerity measures, climate change, and COVID-19.

## Neoliberalism and the right to health

Three of the papers examine the impact of neoliberalism on the right to health, considering the political dynamics of the post-COVID-19 context, the United Nations treaty bodies' consideration of private actors in health care systems, and the consequences of development finance institutions funding private for-profit health care with taxpayer funds from wealthy countries. In the first paper, Ted Schrecker argues that post-COVID-19, we have reached a “tipping point” in terms of economic inequality, making it more difficult, if not impossible, to realize health as a human right. He predicts, pessimistically, a gradual deterioration of tax-financed universal health care and greater health inequalities as the wealthy members of society are increasingly able to translate into policy their opposition to financing health care for those less well off. The post-COVID-19 era, he foresees, is likely to continue the “hegemony of neoliberal or market fundamentalist perspectives domestically and internationally” in continual detriment to the right to health.

Private actors form an important component of this neoliberal project, according to authors Rossella De Falco, Timothy Fish Hodgson, Matt McConnell, and A. Kayum Ahmed. In their paper, they survey statements from United Nations treaty bodies, the Special Rapporteurs on the right to health, and the African Commission on Human and Peoples' Rights concerning the involvement of private actors and the right to health. Like Schrecker, they believe that the “commercialization of health care systems still does not appear to have reached its zenith.” Nonetheless, they argue that several normative developments, including growing skepticism of the compatibility of private actors in health care with the right to health, present opportunities for treaty bodies to interpret the right to health to require inequality-reducing measures. In this respect, they suggest several ways for treaty bodies to increase their efforts to reduce

commercialization and economic inequality toward realizing the right to health.

In the third paper, Anna Marriott, Anjela Taneja, and Linda Oduor-Noah examine whether a sample of European development finance institutions and the International Finance Corporation are meeting their obligations regarding the right to health. The authors find that more than 50% of these entities' investments in health have gone to the private sector, which is not well regulated or held accountable for realizing the right to health. They conclude that this investment approach is placing significant barriers for many people to access quality, affordable health services and thereby limits the realization of the fundamental right to health for all. Based on this analysis, the authors recommend that high-income governments and the World Bank not fund any future for-profit private health care projects through development finance institutions unless various steps are taken, including strengthening these institutions' approach to human rights due diligence through greater transparency, nondiscrimination, monitoring, and accountability.

### The right to health as a redistributive project

Four papers examine the redistributive potential of human rights, focusing on social protection, universal health care, the conception of equality in human rights law, and climate change. First, for Joo-Young Lee, economic inequality is a key social determinant of health, and social protection is essential for ensuring an adequate standard of living while simultaneously reducing economic inequality. The COVID-19 pandemic highlighted "the need for a robust social protection system, including income protection, family and child support, and health care"; however, there remain large gaps globally. In this context, Lee revisits international human rights law, maintaining that it offers a normative

foundation for a transformative social protection system. More specifically, she looks to both the right to social security and the International Labour Organization's Social Protection Floors in Recommendation No. 202 to provide "a firm normative basis for the requirement of comprehensive universal coverage for protection against social risks."

Second, Anja Rudiger argues compellingly in her paper that advocates for the right to health should embrace universal health care as "a redistributive project" that can contribute to advancing not only the right to health but also serve as a mechanism to reduce economic inequality. She contrasts the market-based health care system in the United States with a truly universal health care system, focusing on (1) who pays for it?, (2) who has ownership of it?, and (3) who governs it? While she recognizes that traditional human rights advocates may resist the ideas of redistribution, public ownership, and co-governance, she argues that greater economic equality through such measures must be at the heart of efforts to realize the right to health for all.

According to Michael Marcondes Smith, economic policies—such as austerity measures—that concentrate wealth and increase economic inequalities often have negative impacts on human rights. Yet austerity measures are justified on the basis of supporting growth and trickle-down economics, which would ostensibly eventually result in the realization of human rights. Marcondes Smith maintains that the general assumption that human rights may be sidelined and postponed while economic inequality increases suggests a problematic conception of equality in human rights law. In his paper, he critically examines the way this assumption informs the exclusion of distributive considerations from the scope of equality within human rights law. He proposes a reinterpretation of equality in human rights that "may take on a distributive function in combating policies of wealth concentration such as austerity."

Thalia Viveros-Uehara's paper on climate change and economic inequality draws on the human rights framework "to chart a more transformative course toward a distributive, corrective, and procedural balance" that advances the socioeconomic conditions of marginalized groups. Viveros-Uehara recommends that in addition to addressing climate mitigation (such as reducing greenhouse gas emissions), we must also address climate adaptation (such as building more resilient health care systems). She provides an overview of actions by international organizations, domestic courts, civil society, and research communities to show that almost all their attention is focused on mitigation. She argues that instead we must focus greater attention on "the urgent provision of accessible, acceptable, quality, and resilient health care" for those most at risk of health impacts flowing from the climate crisis.

### Intellectual property and inequality

Two papers in this special section reflect on the intellectual property regime as a mechanism that contributes to economic inequality. Thomas Pogge's paper critiques the current intellectual property regime—the patent system governed globally by the World Trade Organization—referring to it as "a toxic regime for rewarding important pharmaceutical innovations, one that persistently harms and kills millions of people around the world." In particular, Pogge explains how this system increases economic inequality and indeed is supported by economic inequality. In response, he proposes a Health Impact Fund to complement the patent system, whereby inventors of important new medicines would be rewarded based on the extent to which their medicine has improved health. Rather than limiting medicines to those who can afford them and thereby allowing diseases to continue to spread among populations, the Health Impact Fund would encourage inventors to address diseases

among the poor, as they would be compensated for doing so. Such a system for remuneration of research on medicines would greatly reduce economic and health inequalities and contribute to realizing the right to health for all.

Luciano Bottini Filho suggests the need for a more comprehensive approach to manage scarcity in health care. In his paper, he examines various areas underemployed as part of the state obligation to maximize resources—as required by article 2 of the International Covenant on Economic, Social and Cultural Rights—and identifies a range of legal determinants of scarcity that can be used to positively influence the availability and affordability of health technologies aside from intellectual property (patent) laws. In particular, he recommends that states adopt complementary policies such as direct price control, price negotiation and contractual mechanisms, competition laws, and public-private partnerships. While scholars have written extensively about the impacts of patents on the right to health, Filho introduces new avenues to explore in law.

### Reimagining the right to health

The papers in this special section have led us to conclude that under a neoliberal organization of the global economy, which privileges the maximization of private interests over the realization of rights and collective well-being, economic inequality will soar and the right to health for all will remain unrealized.

The World Health Organization has attempted to expand on the social determinants of health by including the commercial determinants of health. As it explains:

*The social determinants of health are the conditions in which people are born, grow, work, live, and age, the systems put in place to deal with illness, and the wider set of forces and systems shaping the conditions of daily life ... Commercial determinants*

*of health are a key social determinant, and refer to the conditions, actions and omissions by commercial actors that affect health.<sup>6</sup>*

The *Lancet's* 2023 series on the commercial determinants of health recognizes the damaging effects of neoliberalism on the realization of the right to health.<sup>7</sup> Rethinking and regulating corporate practices could potentially move us closer to addressing the underlying structural flaws baked into the neoliberal world order. At the same time, the *Lancet's* conception of the commercial determinants of health is limited to for-profit actors and does not address the harmful practices of other private entities operating within a market logic exactly as a commercial entity would, such as non-profit hospitals and health insurance companies in the United States and private foundations globally.

One emergent idea that we offer as a provocation is to consider reconstituting the right to health as a “decolonial option.” For Walter Mignolo, decolonial options derive from acts of “epistemic disobedience,” or delinking from Euro-American constructions of universal knowledge centered on capitalism, patriarchy, and white supremacy.<sup>8</sup> Furthermore, epistemic disobedience requires engaging with knowledge and ideas that have traditionally been marginalized by Western modernity, such as Indigenous knowledge systems.

Instead of merely defending people living in poverty through inadequate social protection floors, or reducing inequality inadequately through the Sustainable Development Goals, human rights must work toward dismantling the violence of the neoliberal architecture that reproduces poverty and inequality.<sup>9</sup> The papers in this special section open various avenues to advance this cause.

By delinking from the principles of neoliberal ideology—such as self-interested individualism, wealth accumulation, and economic inequality—and linking with marginalized epistemologies and peoples, human rights can begin a process

of regeneration. The right to health continues to serve as a valuable framework for challenging the profit-centered approach to health. Its evolution in response to the commercial determinants of health should also be supported. But given that the right to health remains open to corporate capture, some fundamental shifts are urgently needed. We argue that the right to health must be explicitly decolonial for the right to health to serve as a framework for global health equity.<sup>10</sup> This shift toward decoloniality will contribute to dismantling the neoliberal logic that underpins the global health architecture.

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# The COVID-19 Pandemic as a Tipping Point: What Future for the Right to Health?

TED SCHRECKER

## Abstract

“Building back better” post-pandemic, as advocated by the Organisation for Economic Co-operation and Development, could advance the realization of health as a human right. However, the COVID-19 pandemic is more likely to represent a tipping point into a new and even more unequal normal, nationally and internationally, that represents a hostile environment for building back better. This paper begins with a brief explanation of the tipping point concept. It goes on to describe the mechanisms by which the pandemic and many responses to it have increased inequality, and then identifies three political dynamics that are inimical to realizing health as a human right even in formal democracies, two of them material (related to the unequal distribution of resources within societies and in the global economy) and one ideational (the continued hegemony of neoliberal ideas about the proper limits of public policy). Observations about the unequal future and what it means for health conclude the paper.

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## Introduction

In June 2020, the Organisation for Economic Co-operation and Development, a group of the world's high-income countries and some middle-income ones, called for "building back better" post-pandemic, in terms of a decarbonized and more sustainable economy.<sup>1</sup> The rhetoric was subsequently embraced by the US president.<sup>2</sup> It is certainly possible, in the sense of not being precluded by such constraints as the laws of thermodynamics, that such efforts to build back better could also reduce inequalities in access to preconditions for realizing the right to health: the social determinants of health.<sup>3</sup> The authoritative interpretation of the right to health emphasizes that it "embraces a wide range of socioeconomic factors that promote conditions in which people can lead a healthy life, and extends to the underlying determinants of health, such as food and nutrition, housing, access to safe and potable water and adequate sanitation, safe and healthy working conditions, and a healthy environment."<sup>4</sup> Despite officially expressed interest in building back better, the COVID-19 pandemic and its knock-on effects will be understood in retrospect as a tipping point into a new and more unequal normal that is even less hospitable to realizing the right to health than the pre-pandemic world. This prediction is grounded in three political dynamics, two of them material (related to the unequal distribution of resources within societies and in the global economy) and one ideational (the continued hegemony of neoliberal ideas about the proper limits of public policy, and the associated limits to political agendas).<sup>5</sup>

The tipping point concept has been widely invoked, sometimes imprecisely and at other times with considerable rigor. It is most familiar from discussions of global environmental change. Leading climate change researcher Timothy Lenton explains that tipping points "occur when there is strongly self-amplifying (mathematically positive) feedback within a system such that a small per-

turbation can trigger a large response from the system, sending it into a qualitatively different future state."<sup>6</sup> Stated more colloquially, "sometimes little things can make a big difference," or at least a disproportionate difference, "to the state and/or fate of a system."<sup>7</sup> Researchers now anticipate that continued atmospheric warming is likely to lead to a number of such tipping points, instantiated by the potential effects of continued loss of tropical rain forests.<sup>8</sup> Such forests generate a substantial proportion of their own rain: in other words, much of the water that falls as rain in a rain forest is the product of evapotranspiration within the forest itself.<sup>9</sup> "Self-amplified forest loss" as a consequence both of human activity (forest clearance) and reduced oceanic moisture inflows may lead to a tipping point followed by accelerated forest dieback and the transformation of the rain forest into savannah or steppe.<sup>10</sup> This will, among other consequences, accelerate climate change as the forest no longer provides a carbon sink. Such oversimplification would make professional climate researchers blanch, but it suffices to suggest the relevance of the tipping point concept to understanding the post-pandemic world.

When the tipping point concept is used to understand social change rather than change in natural systems, tipping points must also be understood as occurring when new path dependencies arise, as the consequences of past policy choices cross a threshold beyond which certain future directions become prohibitively difficult or impossible to pursue. This can happen either as the magnification or acceleration of existing trends qualitatively changes distributions of resources or when the basic structure of institutions changes. (Adoption of formulae for amending constitutions is an example of the latter category.) In some situations, "tectonic policies" may be designed to create path dependencies, as with British Prime Minister Thatcher's privatization of council housing, in the hope of creating a new cohort of Conservative-lean-

ing homeowners.<sup>11</sup> The tipping point envisioned here operates through political processes by way of various channels associated with increased economic inequality. As in the case of climate tipping points, we cannot anticipate many of the details of the new normal, but we can anticipate some of its key characteristics.

### The landscape of inequality: Before and during the pandemic

The COVID-19 pandemic occurred against a background of rising economic inequality associated with (roughly) post-1980 globalization, during which global gross domestic product more than tripled. Although substantial reductions in absolute poverty occurred, primarily in China, between 1980 and 2016 the top 1% of the global income distribution captured 27% of the entire value of global growth, while the global bottom half of the income distribution captured just 12%. More recent income inequality data are available, but the earlier data have been used in order to avoid the effects of temporary wage supports during the early stages of the pandemic. (The top 1% of the global distribution is defined by a household before-tax income for two adults and two children of more than US\$300,000 in 2008, so approximately US\$422,000 in 2023 dollars.)<sup>12</sup> Many countries also saw drastic increases in within-country income inequality.<sup>13</sup>

The pandemic and many responses to it magnified existing trends of increasing inequalities in the underlying social determinants of health and thereby compromised possibilities for realizing the right to health in several ways.<sup>14</sup> Populations such as poorly paid frontline service workers who were unable to work from home were and are more likely to be infected; they also often relied on public transport, associated with another set of exposures because of the proximity of other passengers. Many workers whose jobs were not considered essential by the jurisdiction in question

were disproportionately vulnerable to the economic effects of lockdown-related job loss, and often to economic losses associated with illness given dramatic variation across the high-income world in entitlement to sickness pay.<sup>15</sup> “[I]mmune systems weakened by long-term exposures to adverse living and environmental conditions” made people both more susceptible to infection and vulnerable to severe illness.<sup>16</sup> Preexisting conditions and comorbidities such as diabetes and obesity, which themselves exhibit a socioeconomic gradient, likewise made people more vulnerable to severe illness once infected. Finally, increased transmission was associated with such socially patterned variables as crowded or multigenerational housing, which rendered social distancing impossible while often magnifying work-related exposures and vulnerabilities. The actuarially convenient cull of elderly care home residents, especially during the first year of the pandemic, must also be noted as reflecting the tacitly accepted disposability of that population in many countries.<sup>17</sup> Although the cited source warns against direct comparisons among countries, because of differences in how data were collected, the individual national figures are powerful indictments in themselves.

Part way through the pandemic, the trajectory anticipated in this paper would have seemed improbable in some country contexts. Stimulus and furlough programs transferred resources to people deprived of livelihoods by lockdowns and cushioned the collapse of many economic sectors; in the highly unequal United States, the effect was to reduce poverty as officially defined to a degree that would never have been attained under less extreme circumstances.<sup>18</sup> The US Federal Reserve’s annual survey of households in 2021 found the highest levels of several indicators of financial well-being since the survey began in 2013, although this was before the cost-of-living crisis started to bite in 2022.<sup>19</sup> However, these measures and outcomes were temporary, as emphasized by the headline

of a May 2023 *New York Times* story—“The U.S. Built a European-Style Welfare State. It’s Largely Over”—indicating that at least in that country, such policies merely created a short-term interruption of a longer-term trend of increasing income inequality.<sup>20</sup> On the other hand, in the UK the prevalence of destitution soared by more than 60% between 2019 and 2022.<sup>21</sup>

Outside the high-income world, a grim prognosis manifested earlier. Stimulus programs were confined to relatively affluent polities with the fiscal capacity and autonomy to undertake them. International Monetary Fund (IMF) figures published in October 2021 illustrated the scale of this issue, with advanced economies (as classified by the IMF) having deployed far more extensive spending and investment and forgone far more revenue than so-called emerging market countries and, in particular, low-income countries.<sup>22</sup> Many low-income countries were facing impending debt crises even before the pandemic.<sup>23</sup> Sixty-four low- and middle-income countries spent more on servicing their public debt than on public health care in the last pre-pandemic year of 2019, and 25 countries spent more than 20% of total government revenues on debt servicing in 2022.<sup>24</sup> Citing the 2019 figure, in January 2023 the American Public Health Association called on the IMF, World Bank, and G20 “to eliminate debt for the poorest countries and expand fiscal space for public financing of health services and public health programs.”<sup>25</sup>

Although comparative national data on wealth are less reliable than income data, it is generally accepted that wealth inequalities are not only greater than income inequalities but were likewise growing pre-pandemic, notably because of labor’s declining share of national income as a consequence of globalization.<sup>26</sup> Worldwide, the indispensable *World Inequality Report 2022* observed that “between 2021 and 2019, the wealth of the top 0.001% grew by 14%, while average global wealth is estimated to have risen by just 1%. At the top of the top, global billion-

aire wealth increased by more than 50% between 2019 and 2021.”<sup>27</sup> A broader pattern of increasing wealth among the already wealthy was driven by asset purchase programs (otherwise known as quantitative easing) by central banks that were massively expanded in response to the pandemic.<sup>28</sup> According to the *Global Wealth Reports*, the number of US dollar millionaires worldwide rose from 46.8 million in mid-2019, the last pre-pandemic year, to 62.5 million in 2021, and the number of ultra-high-net-worth individuals (those with a net worth of more than US\$50 million) rose by 21% in 2021 alone.<sup>29</sup> Share prices have since become more volatile, but the temporary nature of pandemic-era social supports makes it clear that even when these are effective, the greatest damage will be suffered at the lower levels of the economic distribution.

As the effects of expansionary fiscal policies that were intended to counteract the destructive consequences of lockdowns combined with ultra-low interest rates, many countries saw a rapid increase in housing prices (both purchase prices and rents).<sup>30</sup> A widespread housing affordability crisis already existed pre-pandemic, consequent to the financialization of housing and leading in many places to the “double precarity” of housing and employment, with both direct and indirect effects on health.<sup>31</sup> The crisis was proximally driven by price increases that were extraordinary in historical perspective, but distally by the entry of major corporate investors into housing markets.<sup>32</sup> Across the European Union, house prices rose 10% between the fourth quarter of 2020 and the fourth quarter of 2021, with considerably higher increases in some countries.<sup>33</sup> In the UK, average sale prices increased by 18.5% between the end of 2019 and the end of 2021, along with rising private sector rents—leading one researcher to warn in 2021 that “the UK [was] sleepwalking into a potential evictions crisis” that has now materialized.<sup>34</sup> In Canada, as households sought more space in the suburbs, between 2019 and 2021 house prices increased by an aver-

age of just under 20% to over 45%, depending on distance from downtown, in the country's 15 major census metropolitan areas.<sup>35</sup> City center housing did not become more affordable; rather, stratospheric downtown prices spread to suburbs, further worsening access to employment and transport for households with limited resources.

As in many other contexts, “crisis talk” must be qualified by recognition that all invocations of crisis—indeed, whether particular features of the post-pandemic world manifest as crisis or opportunity—depend on aspects of social situation such as class, gender, racialized status, and place. Housing is a case in point because of how housing wealth contributes to inequality. Before the pandemic, one team of researchers had concluded that “sustained inflation of property values ... has fundamentally shifted the social class structure, from a logic that was structured around employment towards one that is organized around participation in asset ownership and appreciation.”<sup>36</sup> In the United States, the flip side of housing unaffordability was an increase of US\$6 trillion in housing wealth, which disproportionately benefited the already well-off.<sup>37</sup> There as elsewhere, there will be knock-on effects on inequality as this wealth is transferred intergenerationally.<sup>38</sup> In another dimension of financialization, income-seeking investors accounted for 24% of US single-family home sales in 2021, driving up rents as a consequence, and for 30% of all Canadian residential purchases in the first three months of 2023.<sup>39</sup>

### The political economy of post-pandemic possibilities

Changing distributions of income and wealth are central to political analysis of prospects for realizing health as a human right. Two explicitly equity-oriented blueprints for building back better actually predate the pandemic but can inform understandings of the post-pandemic context. In

2019, the United Nations Conference on Trade and Development (UNCTAD) called for a global Green New Deal that included raising labor's share of incomes, raising additional revenue to support fiscal stimuli, and expanding public investment in clean transport and energy systems and sustainable food production.<sup>40</sup> Doing so, UNCTAD argued, would require a range of innovative policy instruments, notably including public banking, to which it devoted an entire chapter of that year's *Trade and Development Report*. Also in 2019, British researchers published a prize-winning UK-focused proposal for “incentivizing an ethical economics” featuring such directions as raising additional tax revenue to invest in sustainable growth and offering universal care provision in old age—a “new social contract” and “new intergenerational contract.”<sup>41</sup> Importantly in view of the argument made here, both analyses emphasized the need to improve the progressivity of taxation in order to fund the initiatives they proposed.

Realizing the right to health requires first of all access to a variety of material prerequisites, on a basis that does not depend on individuals' or households' economic situation. Indeed, the idea of health as a human right, and of economic and social rights more generally, draws its power from its challenge to the norms of the marketplace, in which claims to the requisites for health must be asserted based on the claimant's purchasing power, even as that marketplace has penetrated multiple new areas of human existence and interaction.<sup>42</sup> Background research for the World Health Organization's Commission on Social Determinants of Health identified the “three Rs”—rights, redistribution, and regulation—as essential to reducing the inequality of health outcomes that was the commission's focus.<sup>43</sup> Necessary policy instruments are available, as shown in the preceding paragraph; it is the politics of redistribution that are problematic. Whether redistribution is direct, as through pro-

gressive taxation and social protection spending, or indirect, as when regulations limit the power of commercial actors, it has both winners and (often powerful and well-resourced) losers. The essence of the tipping point represented by the pandemic is that in many jurisdictions, increased inequality in the distribution of resources necessary to shape political outcomes is creating barriers to realizing the right to health that may well be insurmountable.

Even in the shrinking number of functioning formal democracies, at least three relevant dynamics are at play. The discussion that follows is necessarily what economists describe as stylized. The dynamics in question will be mediated by the structure of national and subnational political institutions, by such variables as the extent of trade union representation, and, in the case of many low- and middle-income countries, by the country's relations with its external creditors. My choice of examples is necessarily selective, since the universe of relevant datasets and research is impossible to canvass in a paper of this length. Comparative country-specific inquiry will be very useful.

The first dynamic is the growing influence of super-rich individuals and corporations on policy choices, as a consequence of both their deployment of financial resources to influence electoral outcomes and their global mobility: the ability to shift residence and investment to jurisdictions with more favorable policy environments.<sup>44</sup> As early as 2001, the former director of the IMF's Fiscal Affairs Department identified "fiscal termites" that chew away at the foundations of national governments' abilities to raise revenues in order to meet their domestic policy objectives, by way of interjurisdictional tax competition.<sup>45</sup> A sociologist who trained as a financial planner for the ultra-wealthy concluded based on extensive interviews that "many countries are already more receptive and accessible to wealth managers, who are acting on behalf of the world's richest people, than they are to elected representatives from their own govern-

ments ... [T]he high-net-worth individuals of the world are largely ungoverned, and ungovernable." In a provocative analogy, she continued, "What this is doing to the Westphalian host system is similar in some respects to what e-commerce has done to bricks-and-mortar business, destroying it in a race to the bottom."<sup>46</sup> Transnational corporations are recording a growing share of their profits in tax havens; this is especially true of intellectual property-intensive growth industries such as technology and pharmaceuticals, in which opportunities for tax avoidance are abundant.<sup>47</sup>

The second is the domestic influence of a broader stratum of the affluent, whether we think in terms of the archetypal 1% or a larger cohort that includes (for example) millions of homeowners enriched by pandemic-era increases in property prices, who often constitute a decisive political plurality except in tenant-majority urban settings. A policy analyst later to serve in the US Clinton administration described a "secession of the successful" in which the affluent have less and less need for services provided in the public realm and become increasingly committed to resisting the taxes necessary to finance them.<sup>48</sup> Sometimes, the impulse to secede takes more concrete form: in 2023, Georgia's legislature rejected the attempt by Atlanta's affluent Buckhead neighborhood to form a separate municipality, taking with it 40% of the city's property tax revenues.<sup>49</sup> Pre-pandemic political science research from multiple, mostly high-income democracies found

*remarkably strong and consistent evidence of substantial disparities in responsiveness to the preferences of affluent and poor people. Insofar as policy-makers respond to public preferences, they seem to respond primarily or even entirely to the preferences of affluent people. Indeed ... the influence attributed to poor citizens is not just less than that attributed to affluent citizens, but consistently negative.*<sup>50</sup>

This finding is especially instructive as a coun-

terweight to the claim that political leaders will respond to electorates' "demands" for particular policies.

To illustrate the value of this analysis, consider the disappearance of wealth taxation from political agendas. Early in the COVID-19 pandemic, even before the full extent of its effects on wealth concentration became evident, UNCTAD argued that "[in] light of the further increase in inequality resulting from this crisis the case for a wealth tax seems irrefutable."<sup>51</sup> Even the editors of the *Financial Times* conceded that wealth taxes would "have to be in the [policy] mix."<sup>52</sup> More recently, silence on this point has been deafening, including on the part of parties on the electoral left, although economists such as the 2023 winner of the American Economic Association's John Bates Clark Medal have convincingly refuted claims about the difficulty of implementing wealth taxation.<sup>53</sup> In Canada, where one 2021 poll indicated that 79% of respondents favored a wealth tax, the Liberal finance minister has been categorical in rejecting even more modest measures such as changing the preferred tax treatment of capital gains, which overwhelmingly accrue to the affluent.<sup>54</sup> In the UK, a probable future Labour finance minister unequivocally rejected wealth taxes and higher top marginal income tax rates.<sup>55</sup>

Post-pandemic increases in the ratio of high-income countries' debt to their gross domestic product, combined with rising interest rates that increase the cost of borrowing, augur expanded conflicts between obligations related to the right to health and resistance to raising the necessary revenue. The debt crisis issue outside of the high-income world has already been identified, and leading researchers warn of a "coming austerity shock" in many low- and middle-income countries in the absence of extensive debt cancellation.<sup>56</sup> The effect will be to replicate and deepen the well-documented destructive effects of pre-pandemic austerity on economic and social rights, and of past structural adjustment conditionalities attached to debt

restructuring loans by the World Bank and IMF.<sup>57</sup> (In 2022, Ghana's finance minister said, "We have forgotten how difficult and tenacious that master from Washington was." The following year, Ghana entered its 17th IMF debt restructuring program.<sup>58</sup>) The austerity shock will probably increase both within-country economic inequality, by way of further cuts in social protection and health care, and inequality among countries, should it lead to slower growth in those economies that are most in need of it. It is possible to envision a range of alternative approaches, as articulated by the United Nations Independent Expert on the effects of foreign debt.<sup>59</sup> However, these would probably create losses for both foreign private lenders and domestic debtor-country elites who benefit from the use of foreign loans to socialize the cost of their own accumulation of fortunes.<sup>60</sup> Leading authorities on capital flight from Africa note that the value of capital flight from 30 countries over the period 1970–2015 is several times the value of their external debt in 2015 and that "some of these debts fueled the accumulation of capital flight abroad through the 'revolving door' and various mechanisms of embezzlement of public funds by politicians."<sup>61</sup> Further, an initiative to address debt crises in a way that does not invite future repetitions might need to include net direct transfers from wealthy countries to poorer ones, against a background in which, between 2000 and 2017, the overall pattern of annual financial flows was consistently from "developing and transition" economies to developed ones, occasionally approaching US\$1 trillion, even before accounting for an estimate of illicit financial flows.<sup>62</sup>

The third dynamic is ideational: the continuing hegemony of neoliberal or market fundamentalist perspectives domestically and internationally. In 1995, a multidisciplinary panel of social scientists described neoliberalism after the election of the Thatcher, Reagan, and Kohl governments as "the central ideological force in the Western world."<sup>63</sup>

Much more recently, the introduction to a study of politics in 50 countries, many with data going back half a century, noted “the transformation of global ideology toward the liberalization of the economy, the sacralization of private property, the decline of progressive taxation, and more generally the abandonment of any perspective supporting the transformation of the economic system and the supersession of capitalism.”<sup>64</sup> This hegemony is not unrelated to material interests. According to one leading historian, “A transatlantic network of sympathetic businessmen and fundraisers, journalists and politicians, policy experts and academics grew and spread neoliberal ideas between the 1940s and the 1970s”; more recent support has, if anything, intensified.<sup>65</sup> Innovation scholar Mariana Mazzucato argues compellingly that this “dominant economic paradigm” is especially inadequate and inappropriate to address the challenges of building back better post-pandemic while addressing climate change.<sup>66</sup> In a newly unequal age, barriers to the migration of these insights into the policy mainstream are formidable, buttressing persistent hostility toward equity-oriented policy innovation that one think-tank has called “zombie neoliberalism.”<sup>67</sup> Simply put, the ideational end point of the material dynamics explicated here is that policies necessary to build back better can become unthinkable. When this process was much less advanced, historian of science Donna Haraway referred to it as “losing effective social imaginaries.”<sup>68</sup>

Readers may regard the preceding discussion as too pessimistic, pointing to such trends as headline wage settlements for unionized workers and social policy initiatives like Scotland’s £25/week payment for each child in a family on benefits.<sup>69</sup> As welcome as such developments are, it could be pointed out (for example) that unionized workers are a minority in many jurisdictions, while the ranks of workers in the “gig economy” are swelling; that Scotland is still unlikely to meet its own child

poverty reduction targets; and that these examples are of limited relevance to the differential accumulation of wealth and the concentration of resources and influence at the top of the economic distribution.<sup>70</sup> More generally, the tipping point argument does not imply a linear and undifferentiated trajectory of increased inequality and deprivation but rather a longer-term trend: the difference between weather and climate, as it were.

### Two further observations and a conclusion

First, Beveridge-style, tax-financed health systems have historically been major contributors to reducing health inequalities related to economic situation and realizing a rights-based approach to health care access. They will probably be among the early casualties of the tipping point, gradually deteriorating into residual services for users unable to afford private provision or insurance. Those users may be quite numerous, but they lack political resources. As Robert Evans, the magnificently acerbic dean of Canadian health economists, observed, “[A] well-functioning modern health system requires the transfer, through taxation, of a very significant amount of money from the healthy and wealthy to the care of the unhealthy and unwealthy.”<sup>71</sup> Britain’s National Health Service (NHS) and Canada’s provincial and territorial systems of public health insurance are two of the most conspicuous examples of Beveridge systems, with Canadian national policy nominally committed to avoiding the emergence of a parallel private tier that has always existed in Britain. Arguments that these systems are unsustainable are code for saying that the richest members of those societies do not want to pay for the care of those others perceived as undeserving, and they are increasingly able to translate that preference into policy outcomes. Predictably, publicly financed health care in both countries is in potentially terminal crisis as this is

written, because of failure both to supply needed funding in the short term and to plan for future workforce needs and finance the necessary training. (In June 2023, NHS England finally released a 15-year workforce plan.<sup>72</sup> Analysis by the Institute for Fiscal Studies pointed out the formidable revenue requirements it implied, underscoring its political implausibility, especially if needed revenues were to be raised in ways that preserved the redistributive effect identified by Evans.<sup>73</sup>)

Second, territorial distinctions between core and periphery, or developed and developing countries, increasingly fail to reflect the disparate living conditions of people sharing national borders but little else. Development scholar William Robinson has argued that globalization necessitates a shift to “social” rather than “territorial cartography” in which, for example, “a global division of labour suggests differential participation in global production according to social standing and not necessarily geographic location.”<sup>74</sup> A striking illustration of the importance of social cartography for understanding new dimensions of inequality related to the right to health involves the fact that more than a million people in the United States, many in affluent cities, now lack connections to running water.<sup>75</sup> The authors of a recent ethnographic study of three US cities hard hit by the pandemic note that in the case of Detroit, which saw a drastic increase in water shutoffs after the city’s bankruptcy led to raised prices for service, “the water situation erodes perceived notions about the U.S. as a high-income, or ‘developed’ context, bringing traditionally ‘global’ health concerns to the heart of an iconic American city.”<sup>76</sup> Similar situations are likely to multiply in future.

The normative urgency of a human rights perspective on health as a challenge to the marketplace thus increases, even as its political viability declines. In an apparent concession to this maldistribution of political influence, the UK’s opposition Labour Party has tried to lower expectations of change,

its leader using the language of unaffordability, wooing private equity magnates and “constantly calculating which of the people desperately awaiting his government he can afford to ignore because they have no powerful advocates,” as *Guardian* columnist Nesrine Malik has put it.<sup>77</sup> For a darker glimpse of the probable pattern of allegiances in a world of deepening inequality, consider a pre-pandemic study of São Paulo, notoriously one of the world’s most unequal cities and the site of an iconic and widely reproduced 2004 aerial image showing the juxtaposition of ostentatious wealth and extreme poverty.<sup>78</sup> Urban anthropologist Teresa Caldeira began her book *City of Walls* with excerpts from an interview with a former teacher who was married to a real estate agent: an archetypal middle-class couple. The teacher lamented the decline of her neighborhood and said of her husband, “When he sees a *cortiço*, a favela, he says that a bottle of kerosene and a match would solve everything within a minute.”<sup>79</sup> In the more unequal post-pandemic world, such perspectives are likely to become increasingly mainstream, and the economically precarious more likely to be criminalized than recognized as holders of rights. Multiple manifestations, notably including the criminalization of homelessness, are already conspicuous in the United States.<sup>80</sup> Again, comparative inquiry and documentation will be valuable. The last word of Albert Camus’s famous essay on suicide is “hope,” but it is difficult to sustain in these times.

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# Assessing the Human Rights Framework on Private Health Care Actors and Economic Inequality

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## Abstract

Private actors' involvement in health care financing, provision, and governance contributes to economic inequality. This paper provides an overview of emerging normative trends regarding private actors' involvement in health care by reviewing and critically analyzing international and regional human rights standards on the right to the highest attainable standard of physical and mental health. Specifically, we survey statements from United Nations human rights treaty bodies and recent jurisprudence of the African Commission on Human and Peoples' Rights that discuss private actors' involvement in health care. We then identify strengths and weaknesses of the current international human rights law framework to address the human rights and inequality impacts of private health care actors, before concluding with a series of recommendations to further develop existing standards.

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## Introduction

Over the last 40 years, the involvement of private actors in health care has steadily grown in most countries, albeit at different paces, for different reasons, and in varying social, political, and economic contexts.<sup>1</sup> Such private health care actors include providers (e.g., hospitals and clinics), insurance companies and sickness funds that finance health care services, and private suppliers of health care goods, such as pharmaceutical companies and medical equipment manufacturers.

In several high-income countries, private actors' role in health care began to grow in the late 1970s and early 1980s as a part of broader neoliberal policy reforms that aimed to diminish the role of the state and expand that of the market, particularly in the provision of social services.<sup>2</sup> In many low- and middle-income countries, this liberalization of the health sector, which increased private actors' involvement, was largely driven by conditionalities attached to development aid and economic stability loans, as international and regional banking systems similarly pursued policies that viewed health care as a private good.<sup>3</sup>

Often short of full-scale sectoral privatization, private sector involvement in health has taken a variety of intermediate shapes, including contracting and subcontracting, public-private partnerships, and various private-in-public arrangements, such as private wards in public hospitals. In this paper, these various ways in which market mechanisms have spread within health systems through privatization, liberalization, and deregulation are referred to as commercialization, an umbrella term emphasizing the market logic across these processes.<sup>4</sup>

The utility and social impact of health care commercialization is hotly contested by academics, public health experts, economists, and human rights practitioners.<sup>5</sup> Advocates for private health care markets argue that the private sector is more efficient, less bureaucratic, and more cost-effective than the public counterparts and may improve

health care outcomes and quality of care.<sup>6</sup> Critics, meanwhile, typically argue that claims of improved health care outcomes are either exaggerated or false and that higher private sector involvement results in unfair, fragmented, and expensive health care systems.<sup>7</sup>

However, significant evidence suggests that health care commercialization deepens vertical, economic-based inequalities in access to health care services and medicines. In the United States, for example, a recent study found that the privatization of 258 hospitals between 2000 and 2018 resulted in a reduction in the number of low-income Medicaid patients treated, because such patients are less profitable than other groups due to lower public reimbursement rates.<sup>8</sup> A recent quantitative analysis of private health clinics in Kenya over 2012–2020 also found a positive association between relative income and the quality of health care received.<sup>9</sup> Similar pro-rich inequalities in the utilization of private medical insurance and services have been found in Ireland, Mongolia, and Nepal, among others.<sup>10</sup> Consistent with these trends, some traditional public health institutions have recently issued statements critical of health care commercialization. In 2023, the *Lancet*, a pre-eminent general medical journal, published a series of articles on the commercial determinants of health and how “a substantial group of commercial actors are escalating avoidable levels of ill health, planetary damage, and inequity.”<sup>11</sup>

Some of the most consistent critics of health care commercialization, however, have been non-governmental human rights organizations, which have increasingly raised concerns about the impacts of health care commercialization on human rights across the world, including notably in countries such as India, Italy, Kenya, Lesotho, Nigeria, South Africa, Uganda, and the United States.<sup>12</sup> In part, this focus reflects the key role that international human rights law can play in addressing commercialization, economic inequality, and the right to

health. In fact, under international human rights law, even when private actors are involved in health care, states retain a primary obligation to ensure the realization of the right to the highest attainable standard of physical and mental health (the right to health), which is enshrined in article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR).<sup>13</sup>

In its General Comment 14, the Committee on Economic, Social and Cultural Rights (CESCR) further clarifies that this right includes “the provision of equal and timely access to basic preventive, curative, rehabilitative health services and health education.”<sup>14</sup> According to a report by former Special Rapporteur on the right to health Paul Hunt, the entitlement to universal health care services encompasses states’ duty to ensure that “disadvantaged individuals and communities enjoy, in practice, the same access as those who are more advantaged.”<sup>15</sup> Importantly, the United Nations Guiding Principles on Business and Human Rights detail states’ duty to *respect*, *protect*, and *fulfill* human rights, including when third parties are involved in health care, as well as the corporate responsibility to respect human rights.<sup>16</sup> While the framework on *protecting* human rights from third-party abuses is more developed than that which governs private health care provision’s involvement in *fulfilling* the right to health, the latter requires urgent scrutiny.<sup>17</sup> In fact, private actors’ involvement in health care is increasingly part of long-term development strategies, particularly in several low- and middle-income countries.<sup>18</sup>

Beyond the ICESCR, which had been ratified or acceded to by 171 states at the time of writing, many other human rights treaties, as well as more than 100 constitutions around the world, contain right to health provisions.<sup>19</sup> Nonetheless, there remains little human rights-based research and scholarship on the right to health and private health care actors, especially in comparison to fields such

as education and water.<sup>20</sup> However, there are the following important exceptions:

- Former Special Rapporteur on the right to health Anand Grover has noted that “privatization of health care often results in ... increased inequity in the accessibility of health care and greater out-of-pocket expenditures.”<sup>21</sup>
- In the context of access to vaccines, the current Special Rapporteur on the right to health, Tlaleng Mofokeng, has indicated that “the benefit of industry and private companies cannot be prioritized over the rights to life and health of billions” and has more generally noted that she is considering “an examination of the role played by the privatization of health-care services—including public-private partnerships, financial aid and philanthropy—in attaining universal health coverage.”<sup>22</sup>
- Scholar Audrey Chapman states that the private provision of health care, in which she includes private health insurance, can have negative impacts on the right to health because it makes accountability more complex, burdens underfunded public entities with regulatory and monitoring responsibilities, negatively impacts equality and discrimination, and undermines social solidarity.<sup>23</sup>
- Scholar Eduardo Arenas Catalán, in a more recent and dynamic analysis of the right to health, focuses on the inherent incompatibility of “solidarity” with the commercialization of health care, arguing that widespread understandings of the right to health presently reflect “acquiescence of the commercial logic around which healthcare services have been organized under the influx of neoliberalism.”<sup>24</sup>
- Scholars Antenor Halo De Wolf and Brigit Toebes conceptualize a human rights impact assessment framework for health care privat-

ization, or commercialization, plans.<sup>25</sup> Toebes further applies such a framework to the case study of the Netherlands.<sup>26</sup>

- Scholar Sarah Hawkes and others have investigated the little attention to human rights in the context of public-private partnerships in health.<sup>27</sup>
- Human rights mechanisms and scholars have explored how the private interests of pharmaceutical companies impinge on access to medicines.<sup>28</sup>
- Recently developed expert principles on “Human Rights and Public Health Emergencies” strongly stress the need for the effective regulation of private health care actors at all stages in the preparation for, prevention of, response to, and recovery from health emergencies such as pandemics.<sup>29</sup>

In this paper, we aim to make a modest contribution to this body of human rights-based scholarship on the right to health, private health care actors, and economic inequality in accessing health care services. After defining private actors in health care, we analyze normative trends at the international level relating to states’ obligation to realize the right to health where private actors are involved in financing, providing, or supplying health care goods and services. We focus on health-related statements of United Nations human rights treaty bodies, which are the institutions mandated to authoritatively interpret and monitor the implementation of human rights treaties. Results compare the recent work of treaty bodies with recent jurisprudence of the African Commission on Human and Peoples’ Rights on the provision of public services and social rights. Drawing from this survey of health-related statements, our conclusions raise a series of questions that should be addressed through further normative development.

## Methodology

This paper is based on a systematic review of treaty bodies’ statements on private actors’ involvement in health care produced between 1990 and 2023. First, we analyze general comments issued by treaty bodies to review their normative interpretations of the right to health, including how they evolved over time. Second, we analyze crosscutting normative trends in treaty bodies’ concluding observations, which are recommendations issued after their periodic review of states’ efforts to implement human rights treaties.<sup>30</sup> Such concluding observations were qualitatively coded based on normative indicators related to the right to health and private actors. Each extract could be associated to multiple codes due to the interconnectedness of the right to health framework. From this comparative analysis, we draw empirical conclusions on how treaty bodies interpret the right to health when private health care actors are involved, with a special focus on economic inequality within countries.

Data for this analysis were retrieved from a publicly available database collecting treaty bodies’ statements on private actors in health care, which is compiled and routinely updated by the nongovernmental organization Global Initiative for Economic Social and Cultural Rights (GI-ESCR).<sup>31</sup> As of June 2023, this database included 55 extracts from the concluding observations of the following treaty bodies:

- Committee on Economic, Social and Cultural Rights (CESCR)
- Committee on the Rights of the Child (CRC)
- Committee on the Rights of Persons with Disabilities (CRPD)
- Committee on the Elimination of Discrimination against Women (CEDAW)
- Committee against Torture (CAT)

- Committee on the Elimination of Racial Discrimination (CERD)

To complement this analysis, we also reviewed treaty bodies' general comments, recommendations, and open statements, which we retrieved through complementary search. Likewise, we reviewed relevant reports of United Nations Special Rapporteurs on the right to health. At the regional level, we reviewed recent relevant developments at the African Commission.

### Defining private health care actors' involvement in health care

While there is no universal definition of private health care actors, previous human rights scholarship on this topic provides a useful guide.<sup>32</sup> In this paper, we understand private actors as nonstate entities that might be either individuals or institutions, whether formal or informal. Private actors in health care include "faith-based and other nongovernmental non-profit organizations and individual health-care entrepreneurs, both formal and informal, to private for-profit firms and corporations."<sup>33</sup>

Health care actors can perform three functions: *financing* health care; *providing* health care; and *supplying* medical goods, such as pharmaceuticals, equipment, and technologies.

- We define health care *financing* as the act of providing funds for health care, which can happen through general taxation, insurance contributions, out-of-pocket payments, or forms of donation, including international assistance. Private actors involved in health care financing are frequently private insurers, which might be for-profit companies as well as nonprofit sickness funds.<sup>34</sup>
- We define health care *provision* as the act of delivering health care services, from prevention to treatment and rehabilitation. Private health

care providers may encompass a range of health professionals (e.g., individual doctors, nurses, or psychologists) and health facilities (e.g., hospitals, clinics, nurseries, and pharmacies).

- Finally, we understand private health care *suppliers* as entities that are involved in researching, developing, and manufacturing therapeutics, vaccines, and other drugs, as well as medical devices, equipment, and technology. Examples of such private actors are pharmaceutical and medical devices companies.

These private actors participate in the financing, provision, and supply of health care in different ways. They also have different reasons for participating in health care, including commercial and noncommercial goals.<sup>35</sup> These different motives have fundamental implications for the organization of health systems, and health policy scholars normally distinguish health care systems based on the relative role played by the *state*, the *market*, and *societal or nongovernmental actors* in health care.<sup>36</sup> Following this reasoning, Table 1 summarizes a typology of these health care actors, of which an earlier version was published by GI-ESCR.<sup>37</sup>

### Treaty body statements on private actors and the right to health

#### *Overview of relevant general comments and recommendations*

Treaty bodies' general comments have consistently regarded the role of private actors as, at the very least, nominally compatible with the right to health. CESCR's General Comment 3, published in 1990, notes that ICESCR "neither requires nor precludes any particular form of government or economic system ... provided only that it is democratic and that all human rights are thereby respected."<sup>38</sup>

In General Comment 14, published in 2000, CESCR echoes this economic agnosticism, explaining that ICESCR places a duty on state parties to

fulfill the right to health through “the provision of a public, private or mixed health insurance system which is affordable for all.”<sup>39</sup> However, in this same general comment, the committee also highlights the special risks posed by private entities involved in health care, noting that states’ obligation to protect the right to health under ICESCR requires that “the privatization of the health sector does not constitute a threat to the availability, accessibility, acceptability and quality of health facilities, goods and services.”<sup>40</sup>

More recently, in its 2017 General Comment 24, CESCR stresses, along similar lines, that “privatization is not per se prohibited by the Covenant,” but simultaneously notes that private actors involved in sectors such as health should be “subject to strict regulations that impose on them so-called ‘public service obligations.’”<sup>41</sup> In the specific context of health care, General Comment 24 further adds that “private health-care providers should be prohibited from denying access to affordable and adequate services, treatments or information.”<sup>42</sup>

As a result, while CESCR has consistently reiterated an agnostic position toward private entities’ involvement in health care, it has appeared to grow increasingly skeptical of market mechanisms to deliver the right to health. For example, later in

General Comment 24, CESCR expresses concern that

*goods and services that are necessary for the enjoyment of basic economic, social and cultural rights may become less affordable as a result of such goods and services being provided by the private sector, or that quality may be sacrificed for the sake of increasing profits.*<sup>43</sup>

Other treaty bodies have similarly had to grapple with the role of the private sector in the realization of the right to health, as expressed within their mandates. For example, CRC’s 2013 General Comment 16 on state obligations regarding the impact of the business sector on children’s rights, which is grounded in a recognition “that the business sector’s impact on children’s rights has grown in past decades because of factors such as ... outsourcing and privatizing of State functions that affect the enjoyment of human rights,” provides a comprehensive framework for state parties to ensure “that the activities and operations of business enterprises do not adversely impact on children’s rights,” including the right to health.<sup>44</sup>

Consistent with this trend toward greater skepticism of market actors, in May 2023, CERD released the first draft of its General Recommen-

TABLE 1. Typology of health care actors

Role	Private commercial actor	Private societal or noncommercial	Public
Financing	For-profit insurance companies Philanthropic corporations	Nonprofit sickness funds Philanthropic foundations	Governments
Provision	For-profit hospitals, clinics, nurseries, pharmacies Individual businesses Nonprofit providers operating under a market logic	Nongovernmental health care providers Faith-based health care providers	Public hospitals and clinics Public pharmacies Public prevention departments Public health departments
Supplying	Pharmaceutical companies Manufacturing companies Suppliers of medical equipment	Networks facilitating pharmaceutical research and development through open science, donations, knowledge sharing Nongovernmental organizations	Public pharmaceutical enterprises Public research institutes, including universities Public manufacturers

ation 37 on racial discrimination in the enjoyment of the right to health, which lists “privatisation and commercialisation” as potential causes of racial discrimination and includes a dedicated section on “private actors.”<sup>45</sup> While subject to change, this draft language endorses “mandatory human rights due diligence regimes” and more overtly recommends that

States should adopt regulation[s] ensuring that private business enterprises, private health-care facilities, insurance and pharmaceutical companies, manufacturers of health-related goods and equipment and other relevant organizations comply with the principle of equality and non-discrimination in the right to health.<sup>46</sup>

It is noteworthy that the report of the Special Rapporteur on the right to health on “Racism and the Right to Health” alludes to similar concerns.<sup>47</sup> Similarly, in its General Comment 22 on the right to sexual and reproductive health, CESCR emphasizes that states should refrain from retrogressive measures, including “legal and policy changes that reduce oversight by States of the obligation of private actors to respect the right of individuals to access sexual and reproductive health services.”<sup>48</sup>

This skepticism of private entities’ involvement in health care has been further cemented in treaty bodies’ general comments and recommendations over the past two decades. Their concluding observations during this period, presented in the following sections, provide additional context about the drivers of this concern and evince emerging normative trends with respect to private health care actors’ position within the right to health framework.

### *Concluding observations and the absence of a per se prohibition against privatization: A changing position?*

While privatization may not be per se prohibited under ICESCR, concluding observations from the

CESCR and other treaty bodies suggest that, at least insofar as individuals lack access to public health care options and depending on circumstances, private actors may largely be ill-suited to deliver the goods and services essential to the right to health.

For example, in 2013, CESCR noted with concern that the decline in public health spending in Egypt had resulted in a “fragmented and increasingly privatized health-care system” that had resulted in “a large percentage of the population, particularly those in vulnerable situations, being excluded from health insurance and deprived of access to health facilities, goods and services.”<sup>49</sup> Voicing concerns relating to economic equality, CESCR suggested in a 2023 concluding observation on El Salvador that the country’s shrinking public health care sector had increased economic segregation:

*Access to health services is limited owing to the lack of financial means allocated by the State party to the public sector, and by the preference for a private-sector approach to the management, financing and provision of services, to the detriment of those who are unable to pay for such services.*<sup>50</sup>

Recent concluding observations from other treaty bodies similarly reflect what may be a stricter scrutiny of private actors’ involvement in health care where individuals lack robust public health care. For example, in a 2022 concluding observation to Cyprus, CRC stated that it is “seriously concerned” about the “lack of access to public health care, including early detection and rehabilitation, forcing parents to cover the costs of private healthcare services.”<sup>51</sup> Concerning Bahrain, CRC also emphasized its concern about “the increasing trends towards the privatization” of the health and education sectors, and “the potentially negative consequences this may have on the enjoyment of economic, social and cultural rights by all children.”<sup>52</sup> For its part, CEDAW noted in its 2022 concluding observation on Türkiye that the lack of public options for safe

abortion “compels many women to resort to expensive private clinics or unsafe abortion.”<sup>53</sup>

Overall, the number of concluding observations including language on private actors in health care has grown over time, as shown in Figure 1. In 2022, for example, there were 13 concluding observations that mention private actors in health care, which is more than the total number of mentions between 1999 and 2012.

As shown in Figure 2, CESCR published the plurality of the concluding observations touching on private health care actors during 1999–2022, accounting for 24 of the 55 identified. However, other treaty bodies also increased their work on private health care actors between 2013 and 2022.

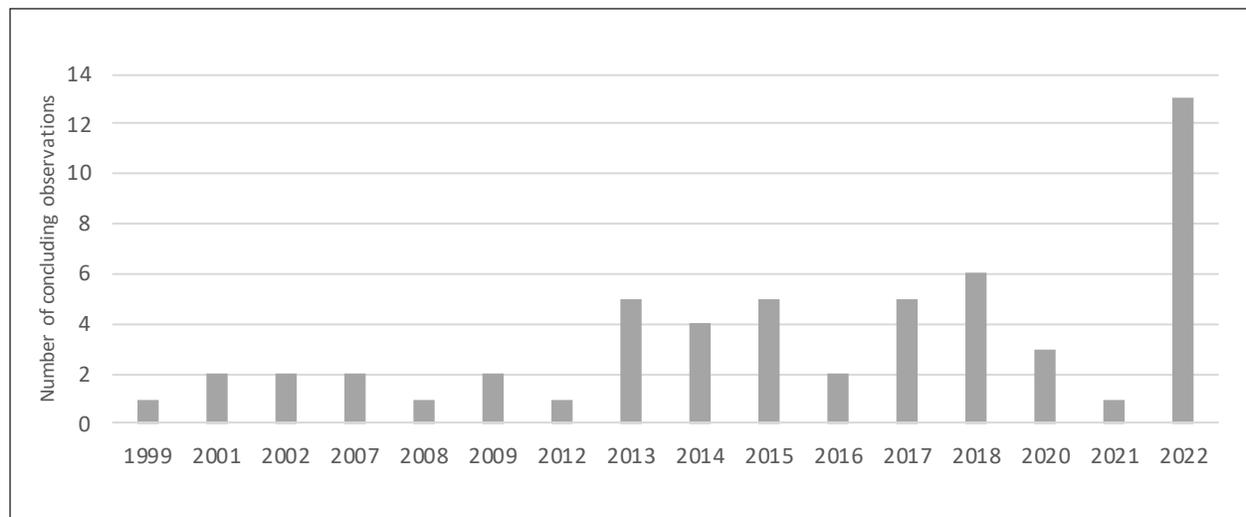
The concluding observations analyzed often refer to health care services in general, focusing on access to such services for the whole population or a specific group (e.g., women, persons with disabilities, children, or migrants). Only four focus on mental health care specifically, and nine on sexual and reproductive rights.

### *Concluding observations on nondiscrimination and equality*

Of the 55 concluding observations in our sample, only 5 focus on vertical inequalities due to differences in wealth or income, while 29 mention inequality between groups on grounds such as gender, poverty, citizenship status, disability, and age.

With regard to such vertical inequalities, the CRC commented in a few cases that expensive private medical services might increase vertical inequalities among children, including recommending that Sri Lanka “combat ... expensive private medical care, with a view to ensuring that each child has equal access to quality public health care.”<sup>54</sup> Likewise, it stated that it was “deeply concerned that children do not enjoy equal access to quality health care owing to the high cost of health care ... , and in part to the domination of the health sector by the private sector” in the case of Lebanon.<sup>55</sup> In Vietnam, the CESCR expressed concern to the government about “the health protection divide in the society and ... the adverse impact of privatization on the affordability of health care.”<sup>56</sup>

FIGURE 1. Number of treaty bodies’ concluding observations mentioning private actors in health care



Source: Own elaboration on the basis of data available in Global Initiative for Economic, Social and Cultural Rights, “Compendium of United Nations Human Rights Treaty Bodies’ Statements on Private Actors in Healthcare,” <https://gi-escr.org/en/our-work/on-the-ground/un-continues-to-raise-concerns-on-private-actors-in-healthcare>, (July 2023).

These observations are linked to concerns regarding “economic and social status” as a basis for discrimination, which CESCR specifies in General Comment 20 on nondiscrimination in economic, social, and cultural rights.<sup>57</sup>

Treaty bodies also discussed differences between public and private health sectors as problematic per se. In 2015, CRC noted with concern “the difference in quality between public and private health-care services” in Chile.<sup>58</sup> Similarly, CESCR recommended that Ireland introduce “a common waiting list for treatment in publicly funded hospitals for privately and publicly insured patients.”<sup>59</sup> This resonates with Gillian MacNaughton’s definition of one-to-one equality, or positive equality, regardless of status, which can have positive impacts on reducing economic inequalities in accessing health care.<sup>60</sup>

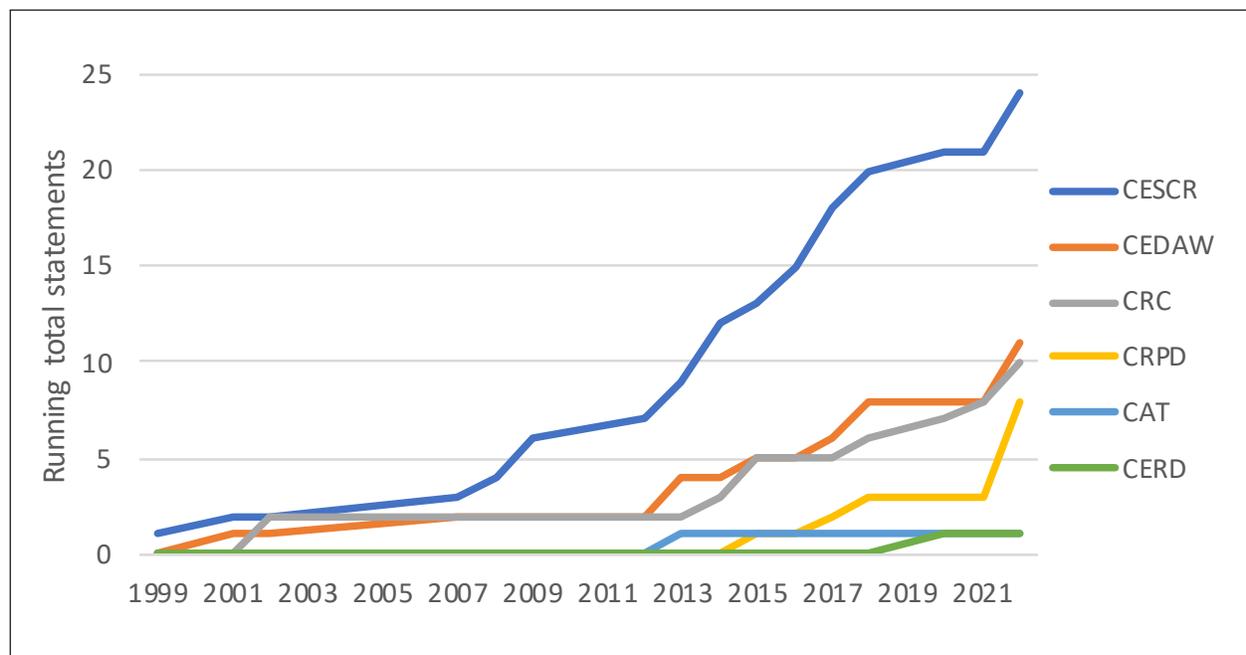
Treaty bodies’ statements addressing hori-

zontal inequality and private health care are more specific and frequent than those addressing vertical inequality. For instance, CESCR recommended that Croatia “carefully review the probable effects of its plans to privatize portions of the national health-care system on the most disadvantaged and marginalized sectors of society, including ... those living in poverty.”<sup>61</sup>

*Concluding observations on the availability, accessibility, acceptability, and quality of health care*

Treaty bodies have frequently raised concerns regarding the effects that private health care actors have on the availability, accessibility, acceptability, and quality of health care—a series of standards commonly referred to as the AAAQ framework.<sup>62</sup> We found that 22 out of 55 statements apply the AAAQ framework’s language to analyze privatiza-

FIGURE 2. Running total statements on private actors in health care by treaty bodies (1999–2022)



Source: Own elaboration on the basis of data available in Global Initiative for Economic, Social and Cultural Rights, “Compendium of United Nations Human Rights Treaty Bodies’ Statements on Private Actors in Healthcare,” <https://gi-escr.org/en/our-work/on-the-ground/un-continues-to-raise-concerns-on-private-actors-in-healthcare>, (July 2023).

tion of health care, either as a stand-alone challenge or as part of a broader range of concerns.

Among these observations, a few raise an economic inequality dimension. CESCR, for example, stated that “the Committee is also concerned that the gradual privatization of health care risks making it less accessible and affordable” in Poland and expressed concerns about “the adverse impact of privatization on the affordability of health care” in Vietnam, without referring to a specific marginalized group.<sup>63</sup> More commonly and directly, treaty bodies look at how privatization impacts the AAAQ framework in the context of specific groups. For instance, CEDAW raised concerns to Cyprus regarding “the insufficient availability of abortion services in public hospitals and the high cost of such services in private clinics.”<sup>64</sup>

### *Concluding observations on monitoring and regulating*

Treaty bodies frequently emphasize states’ obligations to monitor and regulate private providers, with 21 out of 55 statements in our sample focusing entirely on this or otherwise including this aspect.

The practice of these treaty bodies is in line with the Guiding Principles on Business and Human Rights, which highlight states’ duty to *protect* human rights, including states’ obligations to provide remedies to victims of corporate abuse and adopt a “legal framework requiring business entities to exercise human rights due diligence,” so as to “identify, prevent and mitigate the risks of violations” of the right to health.<sup>65</sup>

In its 2008 concluding observations on India, for example, the CESCR recommended that the government “provide information on the measures to regulate the private health-care sector.”<sup>66</sup> CRC, for its part, recommended in 2015 that Brazil “establish a systematic monitoring mechanism for private care institutions, with a view to ensuring compliance with minimum quality standards.”<sup>67</sup> That same year, CEDAW noted with concern the

“insufficient monitoring of private health-care providers” in Lebanon.<sup>68</sup>

Importantly, treaty bodies’ statements suggest that one way that states can monitor privatization plans is to conduct preemptive impact assessments.<sup>69</sup> For example, in 2009, CESCR recommended to Tajikistan that it “ensure that any public-private partnership has no negative impact on the affordability of medical services, particularly for the most disadvantaged persons.”<sup>70</sup>

### *Concluding observations on public budgets*

In nine statements, treaty bodies address the linkage between available resources and private actors in health care, also addressing whether including private actors in health care is an appropriate way to fulfill the right to health.<sup>71</sup> For example, in 2014, CESCR recommended to Lebanon that the government “review whether the practice of contracting out the delivery of basic services to private actors constitutes an optimal use of available resources” and noted that it “finds it regrettable that the health budget is insufficient to provide adequate coverage for the entire population, thereby favoring the private provision of health-care services” in Guatemala.<sup>72</sup>

Treaty bodies have also started to analyze the balance between public and private health care from a budget perspective. For example, CEDAW recommended to India that it take measures to “balance the roles of public and private health providers in order to maximize resources and the reach of health services.”<sup>73</sup> However, treaty bodies have missed opportunities to unpack the economic inequality implications of such observations. A partial exception is when the CESCR noted that, in Korea, “disadvantaged and marginalized individuals do not have adequate access to medical services in privately run hospitals, which constitute 90 per cent of all hospitals,” and urged the state party to “increase expenditure for health care and to take all appropriate measures to ensure universal ac-

cess to health care, at prices that are affordable to everyone.”<sup>74</sup>

## Recent innovations from the African Commission on Human and Peoples’ Rights

The African Commission has recently made statements that both affirm a right to public health care services and go further than treaty bodies with respect to calling for more limited private actor involvement in health care.

In 2019, the African Commission issued a resolution affirming that African states are “the duty bearers for the protection and fulfillment of economic, social and cultural rights, in particular the rights to health and education without discrimination, for which quality public services are essential.”<sup>75</sup> Building on this resolution, in 2022, the commission issued its General Comment 7, acknowledging that “many commercial actors have pursued profit-seeking strategies that make services [like health care] more inaccessible to large segments of the population” and that “increasingly commercial interests in Africa are transforming social services into private commodities.”<sup>76</sup> The commission called on states to ensure “equal and democratic involvement of all members of the community or society in their design, organization, governance, financing, delivery and monitoring of social services, in the exclusive pursuit of the public interest.”<sup>77</sup> Moreover, the commission indicated that when “private social service providers are unable or unwilling to comply with standards and regulations,” states should require them to “cease their operations.”<sup>78</sup>

## Conclusions and recommendations

The commercialization of health care systems still does not appear to have reached its zenith. The right to health framework under international law

provides a powerful tool to address the adverse impacts that private health care actors, especially commercial ones, have on economic inequality and access to health care.

However, while this paper has highlighted several important normative developments, including a growing skepticism of the compatibility and compliance of private actors with the right to health framework and concrete guidelines, such as preemptive human rights impact assessments, there remain significant opportunities for these bodies to advance, formalize, and regularize inequality-reducing interpretations of states’ right to health obligations relating to the private sector. Below, we specify the gaps in treaty bodies’ analyses and suggest some potential ways to address them.

First, human rights institutions should use a more consistent typology when discussing private actors in health care, going beyond the binary public-private divide. Building on previous work, this paper presents a potential typology that could be used in this context, including by paying attention to whether the actor is financing, providing, or supplying medical goods for health care, and whether the actor is a commercial or noncommercial entity.

Second, treaty bodies should examine more comprehensively the ways through which commercial mechanisms lead to an inefficient allocation of resources within health systems. For example, they might promote over-investment in more-profitable medical services, such as expensive curative care, to the detriment of, and underinvestment in, preventative and other less-profitable services that benefit a larger population, such as prevention, family medicine, and urgent care.<sup>79</sup>

Third, treaty bodies should expand their work on public budgets, private actors, and economic inequality. For instance, while the CESCR recently expressed concerns “about reports that referrals from public health-care providers to private health-care providers increase the health-care costs borne by the State party” and recommended that the

state of Palestine “strengthen its public health-care system with a view to lowering expenses linked to referrals to private health-care providers,” it missed an opportunity to elaborate on the economic inequality implications of this predicament.<sup>80</sup> It is also worth questioning why the state obligation to realize the right to health within the “maximum of its available resources” often focuses exclusively on financial resources instead of considering the full range of available or potentially available resources (human, financial, technological, infrastructural, etc.). Arguably, the resources available should also include those under the control of private actors who typically control access to a range of key infrastructural, human, technological, and financial resources at the direct expense of the availability of such resources in the public sector.

Finally, treaty bodies should expand their work on the link between private sector involvement in health care and vertical inequality. Most treaty body recommendations to states are still concentrated on the traditional human rights concern of horizontal inequalities, including discrimination on the basis of poverty. Very little consideration is undertaken of the dynamics between public and private health care provision as potentially problematic from an economic inequality point of view. Treaty bodies have an opportunity to investigate the systemic impacts of health care commercialization on a range of issues, including social solidarity; spatial and other inequalities; and the quality, price, and availability of health services and products. This could be analyzed in the context of highly unequal societies to produce findings on the impact of different health systems on such inequality.<sup>81</sup> This would assist in answering the central question about to what degree, if at all, economic segmentation in health care access, often associated with commercialization, is consistent with international human rights law.

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# Are Development Finance Institutions Meeting Their Human Rights Obligations in Health?

ANNA MARRIOTT, ANJELA TANEJA, AND LINDA ODUOR-NOAH

## Abstract

The right to the highest attainable standard of health is a fundamental right of every human being without distinction as to race, religion, political belief, or economic or social condition.<sup>1</sup> Spent wisely, aid and other forms of government spending are essential for attaining this right, as well as driving development. However, taxpayer funds from high-income governments such as the UK, France, and Germany are increasingly being funneled through development finance institutions (DFIs) toward multi-million-dollar investments in for-profit health care corporations in low- and middle-income countries. This contributes to the corporatization and financialization of health care in these contexts and is implicated in profiteering and exploitation, the denial of treatment to those who cannot afford it, and a range of human rights abuses—all with little or no accountability. This paper examines the human rights obligations of a sample of European DFIs and the International Finance Corporation, drawing on the “availability, accessibility, acceptability, and quality” right to health framework. We find that this investment approach is not only limiting the realization of the fundamental right to health for all but also placing significant barriers to accessing quality, affordable health services.<sup>2</sup>

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## Introduction

The COVID-19 pandemic has increased economic inequality worldwide, with the poorest people hit hardest. As a result of the pandemic, poverty has increased for the first time in 25 years. The pandemic saw a new billionaire created every 30 hours, with their wealth rising more in the first 24 months of the crisis than in the preceding 23 years combined. Oxfam's 2022 Commitment to Reducing Inequality Index shows that the world's governments failed to mitigate this dangerous rise in inequality.<sup>3</sup> Concurrently, the health care market is projected to grow at an annual growth rate of 10.4% and is anticipated to reach a market volume of US\$85.95 billion by 2027.<sup>4</sup> However, half the world's population continues to be denied access to essential health care largely due to health care costs, and every second 60 people suffer catastrophic and impoverishing costs by having to pay out of pocket for health care.<sup>5</sup> According to the World Bank and World Health Organization, catastrophic health expenditure occurs when an individual spends more than 10% of their income on health-related expenses.<sup>6</sup>

Ensuring that everyone everywhere can realize their fundamental right to the highest attainable standard of health requires enabling people to access quality, affordable health services without financial hardship.<sup>7</sup> A substantial body of evidence exists showing that this cause is hampered by the growth of for-profit private health care providers, which exacerbates inequitable access to health care services, including by increasing the life-expectancy gap between rich and poor people.<sup>8</sup>

This paper examines the body of health care investments made by European development finance institutions (DFIs) and the World Bank Group's private sector development arm, the International Finance Corporation (IFC). DFIs are wholly or majority government-owned institutions and, with the exception of the European Investment Bank, support only private sector development. They do so in health through grants, loans, guaran-

tees, equity investment, lending through financial intermediaries, and blended instruments such as public-private partnerships.<sup>9</sup> Our analysis focuses on DFIs' support to private health care providers (and not the entire health portfolio, which includes investments in the pharmaceutical and other sectors). We seek to understand the extent to which the realization of article 12 of the International Covenant on Economic, Social and Cultural Rights is compromised by this support.<sup>10</sup> This analysis is important given the growing focus of international development institutions, including the World Bank Group, on private sector solutions, especially the mobilization of private capital, to address development challenges, including in the delivery of public services.<sup>11</sup>

## Methodology

This paper examines whether IFC and a sample of European DFIs are meeting their obligations regarding the realization of the right to health. We use the availability, accessibility, acceptability, and quality (AAAQ) framework to interrogate the human rights impact of their investments. To make this assessment, we draw on the findings of two Oxfam reports that were also written by us, the authors of this paper—namely, *Sick Development* and *First, Do No Harm*.<sup>12</sup> The following methodologies were used in the development of the two reports: For the *Sick Development* report, a comprehensive portfolio analysis of health investments into for-profit health companies across all low- and middle-income countries was compiled for four European DFIs from 2010 to 2022 using DFI websites, the websites of financial intermediaries, and broader online searches. The DFIs in question included the UK's British International Investment (formerly Commonwealth Development Corporation); Germany's Deutsche Investitions- und Entwicklungsgesellschaft; France's Proparco; the European Investment Bank; and the World Bank

Group's IFC, where its financing for health overlapped with the others.

Data were cross-checked against IFC's project portal to identify where IFC co-invests alongside the European DFIs in health care. Health care provider companies were further investigated for their affordability, accessibility, and any information related to patients' rights via desk-based research (including company websites, academic literature, and media searches) and direct inquiries. The authors of the report also utilized Oxfam's global network of staff, partners, and contacts to seek further information about health care providers where possible.<sup>13</sup> Primary research involving individual and focus group interviews with key stakeholders (including patients, carers, and community health workers) was also conducted in two states in India, the country with the highest concentration of DFI investments in health care. Second, for the *First, Do No Harm* report, data were collected from IFC's project portals for all IFC health care advisory and investment (direct and indirect) projects in India between 1997 and 2022. This was followed up with desk-based research and interviews with key stakeholders.<sup>14</sup>

### DFIs in health care: Human rights law

The ultimate obligation to protect and fulfill the right to health lies with the state.<sup>15</sup> However, the International Covenant on Economic, Social and Cultural Rights and the United Nations Guiding Principles on Business and Human Rights place clear expectations on businesses to abide by international treaties and covenants. For instance, the United Nations Guiding Principles on Business and Human Rights note that businesses should "avoid causing or contributing to adverse human rights consequences and addressing their impact when they occur" and should ensure access to remedy for human rights abuses.<sup>16</sup> Principles 11 to 17 set forth several expectations in this regard, requiring

that businesses establish appropriate policies and processes to communicate their commitments and human rights expectations of entities that they engage with. Businesses also have ongoing obligations to undertake human rights due diligence "in order to identify, prevent, mitigate and account for how they address their adverse human rights impacts."<sup>17</sup> Due diligence should be an ongoing exercise as a business evolves. DFIs have, however, previously been criticized for categorizing human rights only as part of a compliance or risk management agenda, as opposed to part of broader efforts to improve their positive impact, including the realization of human rights.<sup>18</sup> We view the spirit of the law as meaning that their obligations are much broader than mere risk assessment.

The obligations of private actors can be further understood in light of General Comment 14 of the United Nations Committee on Economic, Social and Cultural Rights, which states that "private business all have responsibilities regarding the realization of the right to health" and outlines the AAAQ framework, which provides a summary of essential elements of the right to health and is a useful basis for assessing actions toward the fulfillment of the right.<sup>19</sup> General Comment 14 also warns that "financing towards private actors can be a retrogressive step if it leads to negative outcomes, either in terms of substantive health outcomes or in terms of procedural obligations, such as transparency, participation, and accountability," and that retrogressive measures are broadly impermissible.<sup>20</sup>

Similarly, General Comment 24 of the Committee on Economic, Social and Cultural Rights states that all business activities and entities, "whether they operate transnationally, or their activities are purely domestic, whether they are fully privately owned or State-owned, and regardless of their size, sector, location, ownership and structure" are also required to respect covenant rights.<sup>21</sup> Moreover, the general comment states that "private health-care providers should be prohibited from

denying access to affordable and adequate services, treatments or information.”<sup>22</sup> General Comment 24 also grants states the latitude to impose regulations that ensure that private actors assume “public service obligations.” States may therefore adopt legislation or measures to ensure that private actors deliver on “equal access to health care and health-related services provided by third parties.”<sup>23</sup>

The onus is on the state to regulate private actors in order to ensure that these provisions are upheld, including ensuring that the provision of services by non-state actors is reviewed and aligned or adapted to prevailing needs. Private actors should also make efforts to assess their contributions to health inequality and social segregation more broadly. Given the vast sums of money that governments are channeling through DFIs into private health care provision, it is clear that DFIs have a responsibility to ensure that these companies abide by the AAAQ framework and, at a minimum, do no harm.

Other applicable principles are found in the United Nations Guiding Principles on Human Rights Impact Assessments of Trade and Investment Agreements, which outline the obligation of states—and, by extension, DFIs—to ensure that the necessary safeguard clauses are inserted into investment agreements to enable states and business entities to abide by their human rights obligations.<sup>24</sup> The principles further note that “business

enterprises may be perceived as being ‘complicit’ in the acts of another party where, for example, they are seen to benefit from an abuse committed by that party.”<sup>25</sup> The principles set forth the expectation that businesses will undertake due diligence actions, including ex ante and ex post human rights impact assessments to assess “the potential impacts of the trade and investment agreement on human rights outcomes and on the capacity of States (and non-State actors, where relevant) to meet their human rights obligations, as well as on the capacity of individuals to enjoy their rights.”<sup>26</sup>

### Sick development: Examining DFI investments in health care

The authors of the two reports referenced in this paper found that 358 direct and indirect investments in private health companies in low- and middle-income countries were made by the four European DFIs between 2010 and 2022.<sup>27</sup> Together, these four DFIs invested at least US\$2.4 billion directly in health and indirectly via health-specific financial intermediaries (see Tables 1 and 2). Eighty-one percent of their health investments were made via financial intermediaries, but the total value of these investments is impossible to calculate from the data available. Of the total investments, 56% were in for-profit hospitals or other private health care provider companies. Similarly, IFC has directly

TABLE 1. Direct investments in health (including public-private partnerships)

DFI	Number of investments	US\$ value
UK’s British International Investment	12*	\$712.53m
Germany’s Deutsche Investigations- und Entwicklungsgesellschaft	25†	\$489.5m‡
European Investment Bank	3	\$357m
France’s Proparco	27	\$597m
<b>Total</b>	<b>67</b>	<b>\$2.2bn</b>

\* Includes one investment in a nonprofit drug purchasing mechanism.

† In slides provided by Deutsche Investigations- und Entwicklungsgesellschaft to Oxfam, the institution had 21 active direct investments in 2022. Oxfam’s data cover the period 2010–2022.

‡ Four out of 25 are missing investment values.

invested US\$523 million in private health care companies in India since it began funding the sector in 1997.<sup>28</sup> A full review of IFC’s health portfolio was beyond the scope of the reports in question; however, widescale co-investment was identified by IFC (both directly and indirectly) in at least 42 of the same financial intermediaries and 112 of the same private health care company beneficiaries that are supported by the four European DFIs.

### Do DFI investments violate the right to access health care services?

Accessibility to health has four overlapping dimensions: nondiscrimination, physical accessibility, economic accessibility, and information accessibility. Human rights law emphasizes protection for vulnerable groups, with conventions stating that “health facilities, goods and services must be accessible to all, especially the most vulnerable or marginalized sections of the population ... without discrimination on any of the prohibited grounds.”<sup>29</sup> States are encouraged to adopt regulations that will address any discriminatory risk or actions, including by non-state entities, and to adopt “relatively low-cost targeted programmes and strategies to target and eliminate health-related discrimination, even in times of severe resource constraints.”<sup>30</sup> There is also an expectation that “health facilities,

goods and services must be within safe physical reach for all sections of the population, especially vulnerable or marginalized groups ... including in rural areas.”<sup>31</sup> A recent report by the Office of the United Nations High Commissioner for Human Rights, however, notes that while DFIs’ environmental and social safeguard policies have improved, insufficient attention is paid to the human rights of service users, including access to or affordability of services and the failure to address the limits of consumer protection policies in particular contexts.<sup>32</sup>

Given the above, we sought to understand the extent to which DFIs’ investments and support to private health care facilities enhance the availability and accessibility of health care.

#### *Failure to improve access and availability of health care facilities in areas with the biggest health care gaps*

While all but one of the five DFIs reviewed state that they aim to reach disadvantaged populations and to improve the affordability and quality of health care, the private health care facilities they fund are predominantly located in cities where private health care provision is available in greater volume than rural areas. In India, for example, IFC is investing in high-end urban hospitals and clinics concentrated in highly populated urban areas where profits can be generated. This is despite poor rural

TABLE 2. Indirect investments in health via health-specific financial intermediaries

DFI	Number of health sector financial intermediaries	US\$ invested in health sector
UK’s British International Investment	4	\$130.2m*
Germany’s Deutsche Investigations- und Entwicklungsgesellschaft	6	\$55m†
European Investment Bank	2	\$29.4m
France’s Proparco	6	\$74.4m
<b>Total</b>	<b>18</b>	<b>\$289m</b>

\* Includes one investment called MEMG Manipal, which British International Investment told Oxfam is a direct investment. However, in order to capture the sub-investments made via this investment, we categorize it here as a health intermediary, while noting the institution’s guidance to the contrary. This amount also includes two investments in the Medical Credit Fund, which the institution clarified is a loan facility and not a private equity fund.

† Three out of six are missing investment values.

populations suffering the greatest access gaps. Only 4.2% of IFC direct-investee hospitals are in smaller habitations (known as Tier III cities), and of the 144 hospitals listed on the corporate websites of these chains, only one describes itself as being in a rural area.<sup>33</sup> Only 13.9% of the hospitals are in the 10 states ranked lowest in terms of the overall performance of the health system based on the Annual Health Index 2021.<sup>34</sup> One partial exception is the IFC investee Apollo, which expanded its operations to Tier III cities through its Apollo Clinics and Reach Hospitals. However, as evidenced by a report by the German development agency GIZ, high consultation fees mean its services remain unaffordable to average patients visiting these clinics.<sup>35</sup>

### *Health care services that are inaccessible and unaffordable*

According to General Comment 14, economic accessibility requires that

*health facilities, goods and services must be affordable for all. Payment for health-care services, as well as services related to the underlying determinants of health, has to be based on the principle of equity ... Equity demands that poorer households should not be disproportionately burdened with health expenses as compared to richer households.*<sup>36</sup>

Emphasis is also given to health care services not becoming less affordable or of lower quality in a bid to enhance profits. An increase in provision by private actors should not make health care services “conditional on the ability to pay.”<sup>37</sup> Additionally, emergency or life-saving treatment cannot be denied on the grounds of one’s inability to pay.

The evidence suggests that DFIs are falling short across all these requirements by directing development resources to hospitals that are unaffordable to patients on low incomes and that deny services, including emergency care, to those unable to pay. As one example, countries have committed

to reducing maternal mortality as part of the Sustainable Development Goals, but so far there has been little improvement.<sup>38</sup> Research into the fees charged for maternity services by all of the European DFI-funded private hospitals, where these were available (in 49% of the 224 private health care facilities identified), showed that the average starting cost of an uncomplicated vaginal birth amounts to over one year’s income for an average earner in the bottom 40%, and the cost of a cesarean birth amounts to over two years’ income for the same person. For an average earner in the bottom 10%, the starting cost for an uncomplicated vaginal birth at a DFI-funded private hospital rises to over nine years’ income, and over 16 years’ income for a cesarean birth.<sup>39</sup>

Data from Nigeria illustrate this further: Nigeria has the fourth-worst maternal mortality rate in the world, with approximately 90% of the poorest women giving birth on their own without a midwife or other medical professional.<sup>40</sup> Hygeia, a Nigerian-based health care company, has received at least 11 direct and indirect investments from Germany’s and France’s DFIs, the European Investment Bank, and IFC since 1999.<sup>41</sup> The company’s website states that it provides health care at “affordable rates,” but its hospitals are located in exclusive districts where childbirth costs start at the equivalent of nine months’ income for the poorest 50% of Nigerians.

Elsewhere, but similarly, at the height of the pandemic, when the need for accessible and affordable hospital care was most acute, several DFI-funded private hospitals either refused emergency treatment to COVID-19 patients or exploited the crisis by escalating charges. For example, the DFI-funded Maputo private hospital charged an upfront deposit of US\$10,000 for COVID-19 treatment and care. In Uganda, Nakasero Hospital in Kampala reportedly charged US\$1,900 per day for a COVID-19 bed in intensive care.<sup>42</sup> Lastly, in India, national legislation dictates that patients have a right to receive emergency medical care

even if they cannot pay for it. The authors in *First, Do No Harm*, however, documented at least eight emergency cases where patients were reportedly turned away by DFI-funded CARE Hospitals and Narayana Health.<sup>43</sup>

*False faith in health insurance mitigating gaps in access*

DFIs often point to the potential role of health insurance in equalizing access to the private health care they fund. The World Bank Group, for example, argues that health insurance expands “affordable, quality health care and creates a mass market for lower-income populations” specifically.<sup>44</sup> The new strategy of the British DFI, British International Investment, also states that for all of the new private hospital investments it makes, it will ensure that a significant proportion of users are on government payment schemes.<sup>45</sup> This theory assumes that these schemes currently work for people living in poverty. In most low- and middle-income countries, however, these assumptions do not hold.<sup>46</sup> In India, for example, 80% of people lack government or private health insurance to cover regular and emergency medical spending.<sup>47</sup> Furthermore, merely having insurance does not guarantee the ability to benefit from it. Narayana Health and CARE Hospitals have both been DFI funded and are officially registered providers in the Chhattisgarh and Odisha government-funded health insurance schemes that aim to reduce the financial burden of accessing health care for poor and vulnerable groups.<sup>48</sup> Both hospitals are required to provide free health care to eligible members and their families, but patients interviewed in *Sick Development* were blocked from using their cards at both of these hospitals without justification. The patients suffered catastrophic financial consequences as a result.

For example, 73-year-old Hammond stated, “The staff told us not to bring the card because it was of no use here. They told me it was for survey purposes and was not used for treatment.” This

led to Hammond spending 30% of his total pension income at CARE Hospitals—which is above the threshold deemed catastrophic by the World Health Organization.<sup>49</sup> A different patient, Robert, had to mortgage his family’s plot of land and take out three private loans to pay for tests and treatments associated with his heart surgery at CARE Hospitals that should have been covered by his government insurance card but was rejected. After repayments, Robert was left with just 1,300 rupees (US\$16) per month to support himself and his family. Stakeholder and focus group interviews revealed that the denial and selective use of government insurance cards was commonplace at these DFI-funded hospitals, especially for tribal people and patients on low incomes.<sup>50</sup>

*Inability to demonstrate improved access, especially for marginalized populations*

DFIs claim that their health investments improve access to health services for patients.<sup>51</sup> However, they provide no supportive impact evidence. For example, after over 25 years of advisory and investment projects on health care in India, IFC has still not disclosed any evaluation or published development results or outcomes, nor has it shared any baseline data or anticipated impact frameworks.<sup>52</sup> As a result, it is not possible to carry out any objective assessment of whether or how women or marginalized communities benefit from or are impacted by its investment projects. In its own evaluations, the World Bank Group’s Independent Evaluation Group has highlighted the systemic challenges and issues with IFC’s health portfolio, stating that IFC does not adequately prioritize quality and equity when investing and monitoring impact.<sup>53</sup> Similarly, there was no disclosed evidence from the European DFIs of any comprehensive impact evaluation or any meaningful and substantiated impact data in relation to health care access for people on low incomes, or for women and girls.<sup>54</sup>

## Are DFIs helping improve the acceptability and quality of health care?

The drive to maximize income and profit can increase the risk of unethical, exploitative, extractive, and, in some cases, dangerous and harmful behavior on the part of hospitals that lower both the acceptability and quality of care.<sup>55</sup> We therefore set out to assess the extent to which patients' rights were being upheld in DFI-supported hospitals, especially given the weak regulatory contexts in which such investments are made.

Patients' rights are rooted in the United Nations Universal Declaration of Human Rights and often find local expression through patients' rights charters, laws, regulations, and other instruments that doctors and hospitals are bound by. Some DFIs have further domesticated these principles—for example, IFC provides a set of voluntary guidelines that investees can opt into in order to promote quality, patient safety, and ethics in service delivery known as the Ethical Principles in Health Care.<sup>56</sup> Despite these laws and guidelines, we find significant gaps in how these principles are enforced. For instance, in IFC's case, the authors in *First, Do No Harm* could not identify a single project information window on the IFC portal that addresses the status of patients' rights at its investee hospitals in India. There is also no information available to the public about IFC's outreach to patients' rights groups, health worker unions, or the public health movement.<sup>57</sup>

Our evidence shows that abuses within the DFI-funded private hospitals are widespread and that DFIs appear largely unresponsive to them, even in contexts where such practices frequently occur or receive widespread media attention. A large number of these alleged and confirmed abuses violate both international conventions and national laws. For example, in India, we found over 70 reported patients' rights violations that have been adjudicated and whose convictions have been upheld by national regulators against IFC-sup-

ported corporate hospitals. The violations include overcharging, denial of health care, price rigging, fraud and financial conflict of interest, medical negligence, and refusal to provide free health care to patients living in poverty despite this being a condition under which free or subsidized land was allotted to these hospitals.<sup>58</sup> Some more detailed examples of the alleged and confirmed patients' rights violations perpetrated by the DFI-funded private hospitals in question included the following:

- *Refusal to treat patients or offer emergency treatment.* In India, national legislation dictates that patients have a right to receive emergency medical care even if they cannot pay for it. However, the author in *Sick Development* documented at least eight emergency cases where patients were reportedly turned away by CARE Hospitals and Narayana Health.<sup>59</sup>
- *Patient detentions and retention of the bodies of deceased patients due to unpaid hospital bills.* We identified up to 37 cases of alleged and confirmed patient detentions (including babies and a secondary school student) at the DFI-funded Nairobi Women's Hospital in Kenya. Many of the DFI investments in this hospital came a year after the hospital director had made public the hospital's policy of detaining patients who could not pay.<sup>60</sup>
- *Failure to obtain consent while undertaking medical procedures.*<sup>61</sup>
- *From a patients' rights perspective, unrealistically high frequency of billing, unnecessary treatments, and unreasonable charges for basic items* such as protective gloves and hand sanitizer.<sup>62</sup> In India, it was found that fees charged to patients who sought care at DFI-funded hospitals in our sample ranged from between three and a half months to 14 years' worth of wages for an average earner. The authors in *First, Do No Harm* questioned the high cost of accessing treatment and medicines

at DFI-funded hospitals in India: one medical and sales representative stated in response that the average markup on medicines at private hospitals was around 50% but could be more than five times the purchase cost. The Competition Commission of India is undertaking an inquiry into inflated drug pricing in three of the biggest corporate hospital chains in the country, including several that are financed by IFC. The commission's four-year investigation has so far concluded that the hospital chains have been abusing their dominance in the market by overcharging patients for both services and medical products.<sup>63</sup>

Additionally and according to human rights law, including the Guiding Principles on Business and Human Rights, businesses are required to undertake human rights due diligence to “identify, prevent and mitigate the risks of violations of Covenant rights, to avoid such rights being abused, and to account for the negative impacts caused or contributed to by their decisions and operations and those of entities they control.”<sup>64</sup> In response, IFC has established performance standards and an environmental and social risk mitigation system.<sup>65</sup> This system requires IFC-supported hospitals to follow applicable standards. Compared to other DFIs, IFC's environmental, social, and corporate governance frameworks are relatively mature, with the environmental and social risk assessment system having undergone several reviews.<sup>66</sup> It is therefore considered to be a benchmark or industry standard.

Yet, the above evidence shows that there are significant weaknesses therein that need to be tackled. For instance, all IFC investments in hospitals and clinics have an “environment and social review summary” information page in which environmental and social action plans should be listed. However, review of these pages for health care investments showed no updates on action plans,

or information on levels of compliance. The actual risks identified and any “progress in practice” also remained largely undisclosed. Further, we were unable to ascertain whether appropriate actions had been taken by IFC to resolve any identified risks.<sup>67</sup> Lastly, in *First, Do No Harm*, the authors found that environmental and social risk assessments inadequately capture the potential negative impacts of profit-driven health care actors on the larger health care system, including the potential to undermine government health care capacity via brain drain or to drive up health care access inequality.

The evidence collected, together with the absence of disclosed data, is a clear indication of gaps in environmental and social risk systems, which highlights the dangerous inadequacy of due diligence, oversight, and monitoring mechanisms for DFI investments.

### Does absence of effective remedy make DFIs party to ongoing rights abuses?

The right to redress and effective remedy for harm where violations have occurred is a core tenet of international human rights law.<sup>68</sup> It holds that business enterprises have a responsibility to ensure that individuals and communities who have experienced human rights violations as a result of their activities have access to remedy by providing for or cooperating in remedial action.<sup>69</sup> DFIs share this same responsibility and should not exit a project before remedy has been provided.<sup>70</sup>

The evidence strongly indicates inadequate DFI oversight and governance of their health care portfolios, which has increased the risk of harm, as well as a remedy gap, which has been observed by way of the following: Some of the DFIs in question, such as the UK's British International Investment, lack independent grievance mechanisms; none of the interviewees who had experienced harm were aware of the DFI investments in the private hospitals concerned or of the grievance or account-

ability mechanisms available to them; and some DFIs, such as IFC, stand accused of failing to act even where non-compliance has been identified by their accountability mechanisms.<sup>71</sup> Human rights abuses and violations at DFI-funded hospitals are well documented, including in the press. However, none of the DFIs have publicly acknowledged these abuses and deficits prior to the outlined investigations, even in cases where their investee hospitals have been publicly held to account by a court of law. There is nothing that gives confidence that concrete and systematic scrutiny of investments is in place.

These shortcomings in accountability are discernible in relation to direct health care investments, but are further amplified for the majority of DFI health care investments because they are made indirectly via financial intermediaries.<sup>72</sup> Respondents—including patients, duty bearers, and community members—were found to be unaware of the role, responsibilities, and impact of financial intermediaries in the provision of their health care services and were also uninformed of any grievance or accountability mechanisms available to them and how to engage them.<sup>73</sup>

## Conclusion

Our collective experience with the COVID-19 pandemic provided unfortunate truths and a stark reminder of the injustices and impacts of global health inequity on the right to health. In order to strengthen health systems, efforts must be ramped up to reduce these gaps. To do so, clear and substantive action will be needed to stem trends toward investments in for-profit health care that worsens health disparities, particularly in low-income countries. Governments are responsible for deploying development funds in a manner that will ensure that their investments enhance the accessibility, affordability, and quality of health care services, including via their development finance institutions. We find, however, that DFIs are failing

to anticipate, prevent, or respond to the risks to health care equity and to patients' rights presented by their investments in profit-seeking health care providers. The DFI model of investing in health care, especially via financial intermediaries, has proven dangerously flawed in upholding human rights in health care and incapable of delivering safe investments in contexts of inadequate government health care regulation.

On the basis of the evidence collected, we recommend that high-income governments and the World Bank Group not fund any future for-profit health care programs, projects, or providers, directly or indirectly, through DFIs unless and until the following steps are taken:

- Urgently commission an independent evaluation of existing and historic DFI health care funding, with a priority focus on the impact of DFIs on advancing universal health coverage, and the protection and promotion of patients' rights.
- Require that DFIs provide demonstrable evidence of positive impact on advancing health equity and the protection of human rights.
- Ensure full transparency for all existing investments and advisory services, including all investments made through financial intermediaries, and fully monitor and disclose evidence on impact.
- Strengthen DFIs' approach to human rights due diligence and ensure that independent accountability and grievance mechanisms are appropriately implemented.
- Take action to remedy any harms resulting from their investments, including violations of human and patients' rights.

Human rights bodies, including the Human Rights Council, must be more cognizant of the risks described above and explicitly examine the impact that DFIs have on the realization of the right to

health. They should:

- Strengthen the integration of patients' rights within human rights frameworks, ensure adherence to these frameworks by multilateral and bilateral organizations, and develop guiding principles for corporate businesses active in direct patient services to protect against any human rights abuse.
- Review DFI operations in health and make recommendations to strengthen the impact of their investments on the right to health.

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# Economic Inequality, Social Determinants of Health, and the Right to Social Security

JOO-YOUNG LEE

## Abstract

This paper discusses economic inequality as a key social determinant of health. It highlights the potentially transformative role of social protection systems in addressing economic inequality and health inequalities. How to finance social protection and how to distribute benefits among people are key questions in the pursuit of a transformative social protection system that can adequately tackle economic inequalities. This paper argues that a human rights approach can provide a normative orientation in the political process that decides the distribution of burdens and benefits in relation to social protection, calling for an assessment of its impact on socioeconomic inequalities and on disadvantaged groups of people. While the right to social security is at the center of a human rights approach to social protection, the rights to health, education, housing, and work also provide important normative elements for social protection. A human rights-based social protection system requires comprehensive protection for major social risks and challenges throughout the life cycle; universal access to quality services such as health, education, child care, and services for older people or people with disabilities; and a progressive financing mechanism. In this regard, the International Labour Organization's Social Protection Floors Recommendation No. 202 provides strong guidance on the implementation of the right to social security for all.

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## Introduction

In the midst of the COVID-19 pandemic, United Nations (UN) Secretary-General António Guterres called for a new social contract and a global new deal in order to address rising inequalities and rebuild solidarity and trust among people.<sup>1</sup> The Secretary-General's report *Our Common Agenda* stressed social protection as a key element of the renewed social contract that ensures conditions for all to an adequate standard of living.<sup>2</sup> Tackling economic inequalities was on the global agenda even before the COVID-19 pandemic.<sup>3</sup> However, the pandemic revealed the link between the unequal distribution of health and socioeconomic inequalities in severe ways, highlighting the urgency of a holistic approach to tackle such inequalities.<sup>4</sup> While remote working may have enabled people to keep their jobs and protect their health, there was inequality in access to remote work, with those in high-paid jobs enjoying greater access than those in low- and middle-skilled jobs.<sup>5</sup> Further, people with limited access to health information, vaccines, and essential care were disproportionately affected by the pandemic. And workers in the informal economy and those in so-called flexible and temporary forms of employment were more affected by the loss of jobs and income. While comprehensive and progressively funded social protection policies and programs helped ameliorate the socioeconomic impacts of the pandemic and mitigate an increase in economic inequality, social protection systems in many countries have long been underfunded and have shown gaps in the availability, accessibility, and adequacy of benefits.<sup>6</sup>

This paper examines how to unlock the transformative potential of a comprehensive human rights-based social protection system to address economic inequality and health inequalities. It begins with a discussion of economic inequality as a major social determinant of health, clearly illustrated by the COVID-19 pandemic and its consequences. It turns to social protection as a “structural driver”

of the transformation of economic inequality, and the large gaps in social protection that pose challenges to building and extending social protection. It considers a human rights approach to social protection, which includes the right to social security and its normative content, along with the rights to health, education, and housing. The International Labour Organization's (ILO) Social Protection Floors Recommendation No. 202 is highlighted as a human rights-based guide to social security. This paper addresses the key question of whether social protection can address both poverty and economic inequalities and discusses the disparate impacts of different forms of social protection schemes on this question. It examines the key elements of transformative social protection and concludes by underscoring the importance of progressive financing of social protection and equitable access to social security benefits in order to build a more equitable society.

## Socioeconomic status as a social determinant of health

In 1980, the *Report of the Working Group on Inequalities in Health* (also known as the *Black Report*), published by the UK Department of Health and Social Security, demonstrated the unequal distribution of ill health and death among the population of Britain and argued that socioeconomic circumstances such as income, education, housing, diet, employment, and conditions of work were key factors in health inequalities.<sup>7</sup>

In 2008, the World Health Organization Commission on Social Determinants of Health report *Closing the Gap in a Generation* took a view that health inequities were largely attributable to inequalities in the distribution of power, income, goods, and services, as well as the consequent disparities in people's living conditions, such as “their access to health care, schools, and education, their conditions of work and leisure, their homes, com-

munities, towns, or cities.<sup>78</sup> The report called for improving the conditions of daily life and addressing the inequitable distribution of power, money, and resources with a view to achieving equality in health.<sup>9</sup> Guaranteeing fair employment and decent work and building a universal and comprehensive social protection are among 12 goals to that end.<sup>10</sup>

### *Socioeconomic inequalities and health inequalities during the COVID-19 pandemic*

The COVID-19 pandemic shows yet another example of the links between the unequal distribution of health and socioeconomic inequalities. An association between socioeconomic inequalities and noncommunicable diseases has already been well documented.<sup>11</sup> Increasing evidence has been emerging, highlighting the association of socioeconomic deprivation with COVID-19 in its incidence, severity, and mortality. Studies in the United States, India, England, Switzerland, France, and Colombia have shown that people with lower socioeconomic conditions tend to have a higher risk of infection, resulting in wider health inequalities.<sup>12</sup> Undoubtedly, socioeconomic conditions are not the only factor, though.

Clare Bambra et al. suggest that the concept of a “syndemic” is useful in understanding the multiple types of vulnerability of marginalized groups, including people living with greater socioeconomic deprivation during the COVID-19 pandemic.<sup>13</sup> A syndemic refers to a situation where “risk factors or comorbidities are intertwined, interactive and cumulative, adversely exacerbating the disease burden and additively increasing its negative effects.”<sup>14</sup> According to this concept, the overall health of people with higher socioeconomic deprivation was more severely affected by COVID-19 than that of the least deprived, due to a synergistic combination of unequal distribution of chronic diseases, inequalities in working and living conditions, limited access to social protection, and unequal access to health care services. People working in essential

services sectors (such as food, cleaning, health care, delivery, and public services), people working in informal economies, and people in a precarious form of employment had a greater risk of exposure to infection because they were likely to continue to commute and work in person.<sup>15</sup> Overcrowded and poor-quality housing conditions also contributed to increasing the risk of infection.<sup>16</sup> In addition, limited access to quality health care and health information during the pandemic may have contributed to more adverse outcomes among people with disadvantaged socioeconomic backgrounds.<sup>17</sup> Moreover, marginalized groups, including people with greater socioeconomic deprivation, tend to have higher rates of underlying health conditions that increase the severity and mortality of COVID-19 compared to the least deprived; this, in turn, is an outcome of socioeconomic inequalities.<sup>18</sup>

### *Worsening economic inequalities during the health crisis*

Many countries implemented various measures to contain the pandemic, including travel restrictions, the closure of schools and workplaces, restrictions on gatherings, and shelter-in-place orders. Again, the impacts of those measures and subsequent economic recessions were not evenly distributed among people. The ILO estimated that pandemic-related restrictions and economic recessions caused an unprecedented loss of 255 million full-time jobs worldwide in 2020, which was about four times greater than during the global financial crisis in 2009.<sup>19</sup> The job losses affected workers with lower skills more than those with higher skills.<sup>20</sup> Micro and small enterprises and informal workers were also hit harder by the crisis.<sup>21</sup> While the disruption to the labor market affected both men and women, women’s employment fell by 5%, compared with 3.9% for men, and the increase in unpaid work, such as child care and housework, fell disproportionately on women.<sup>22</sup> The rate of decline in employment among young people was 2.5 times greater than

that among adult workers.<sup>23</sup> Moreover, the unequal disruption to education during the pandemic is expected to have longer-term negative impacts on jobs, wages, and skills development, creating new inequalities among cohorts of children and young people.<sup>24</sup>

These uneven impacts of the crisis aggravated existing economic inequalities and generated new ones. According to Oxfam, the richest 1% reaped about 63% of new wealth created between 2020 and 2021, which is six times more than the total new wealth gained by people in the bottom 90%.<sup>25</sup> The World Bank announced that the COVID-19 pandemic in 2020 appeared to have caused the largest single-year increase in global inequality and the largest increase in global poverty since World War II, putting 71 million more people in extreme poverty compared to the previous year.<sup>26</sup> In July 2023, a group of leading economists, including Joseph Stiglitz, Jayati Ghosh, and Thomas Piketty, called on the UN and the World Bank to do more to combat rising extreme inequality, highlighting that “following the COVID-19 pandemic and now the global cost of living crisis, inequalities have worsened, by many measures.”<sup>27</sup>

### Social protection: Key instrument for reshaping economic inequality

Rising economic inequality is not inevitable and is an outcome of political choices about how far inequality can be tolerated. Unequal living and working conditions that are closely linked with health inequalities are in fact the consequences of a combination of policies, economic arrangements, and politics.<sup>28</sup> In discussing the social determinants of health, the Commission on Social Determinants of Health also highlights tackling “these structural drivers” of socioeconomic conditions as one of the three principles of action to achieve health equity.<sup>29</sup> Social protection is indeed among the key structural drivers that determine economic inequalities

and in turn health inequalities, by way of reshaping the distribution of power, money, and resources.

### *Global call for social protection systems in the post-pandemic context*

The pandemic has highlighted more than ever the need for a robust social protection system, including income protection, family and child support, and health care. It is evident that emergency measures are necessary to alleviate the impacts on vulnerable groups of people during health, economic, or natural crises. However, without a comprehensive pre-crisis social protection system, such measures are unlikely to respond adequately to the crisis in a timely manner. The UN High Commissioner for Human Rights has noted that “countries that had invested in quality public services through universal and comprehensive healthcare and social protection system have proven to be more resilient.”<sup>30</sup>

For example, during the pandemic, sick leave and sickness benefits played an important role in protecting individuals, their families, and the public, as well as ensuring income security in the event of ill health. Unemployment benefits were critical in protecting individuals from poverty and vulnerability during the economic recession. Affordable, good-quality child care and education are critical for closing the gaps in children’s development and future earnings. Access to affordable, quality health care certainly had an impact on health inequalities during the pandemic.<sup>31</sup> As the UN Secretary-General stressed, “countries which had comprehensive social protection systems in place prior to the crisis, which was the case only for a minority of States, were able to quickly organize necessary support by scaling up or adapting operation.”<sup>32</sup> Luxembourg was such an example, where the existing strong unemployment benefit was well equipped to protect individuals from income loss against unemployment and short-time work, thus mitigating an increase in income inequality.<sup>33</sup> The

changes made to the scheme during the pandemic were mainly aimed at simplifying a procedure to speed up the cash flow and expanding eligibility for the scheme.<sup>34</sup>

It is therefore unsurprising that not only the UN Secretary-General but also other international organizations emphasized social protection in their recommendations for recovering from the COVID-19 crisis.<sup>35</sup> In a global call to action for a human-centered recovery, the ILO reminded all countries of its call to achieve universal social protection, along with the specific measures to promote quality employment, ensuring that an economic and social recovery is fully inclusive, sustainable, and resilient.<sup>36</sup> The World Bank also stressed the need for universal social protection systems, highlighting the role of social protection in providing safeguards against the shocks of the crisis and reducing inequalities, especially for poor and vulnerable people.<sup>37</sup> UNICEF, jointly with the ILO, called on countries to expedite progress toward universal social protection.<sup>38</sup>

### *Concepts of social protection*

It is only in recent decades that the term “social protection” came into wide use in both developing and developed countries.<sup>39</sup> The ILO began its standard-setting work on social security before World War II, and the Universal Declaration of Human Rights of 1948 embodied the right to social security. However, social security had long been viewed as pertaining exclusively to high-income countries.<sup>40</sup> Beginning in the 1980s, the World Bank and the International Monetary Fund started supporting “social safety nets,” a more limited range of targeted programs, for developing countries, mainly to mitigate the adverse effects of structural adjustments on vulnerable groups of people.<sup>41</sup> However, globalization, accompanied by increased inequality and economic volatility, required the development of national policies and programs of a permanent and comprehensive nature in order to protect peo-

ple from vulnerability, risks, and deprivation.<sup>42</sup> In this context, social protection has gained global attention as a means to combat poverty and reduce inequality. As a result, social protection systems have become an essential part of the 2030 Agenda for Sustainable Development (for instance, see Targets 1.3, 5.4, and 10.4).

There is no uniformly accepted definition or form of social protection. The ILO uses “social protection” and “social security” interchangeably and defines social protection in broad terms as “the set of policies and programmes designed to reduce and prevent poverty and vulnerability across the life cycle.”<sup>33</sup> The main areas of social protection include “child and family benefits, maternity protection, unemployment support, employment injury benefits, sickness benefits, health protection, old-age benefits, disability benefits and survivors’ benefits.”<sup>34</sup> Each of these areas can be funded either from contributions or through general taxation, or a combination of both.

### *Large gaps in social protection*

Despite the significant progress in building and extending social protection in many parts of the world over the last two decades, large gaps remain. According to the ILO, more than half of humanity, as many as 4.1 billion people, are left unprotected, with only 46.9% of the global population effectively covered by at least one social protection benefit (excluding health care and sickness benefits).<sup>45</sup> Only 26.4% of children worldwide receive social protection benefits.<sup>46</sup> Among the working-age global population, only 30.6% are legally covered by “comprehensive social security systems including a full range of benefits from child and family benefits to old-age pension.”<sup>47</sup> The gap is particularly wide for unemployment benefits, which only 18.6% of the world’s unemployed effectively receive.<sup>48</sup> Only about 39% of the world’s working-age population is legally entitled to income security by way of paid sick leave, sickness benefits, or a combina-

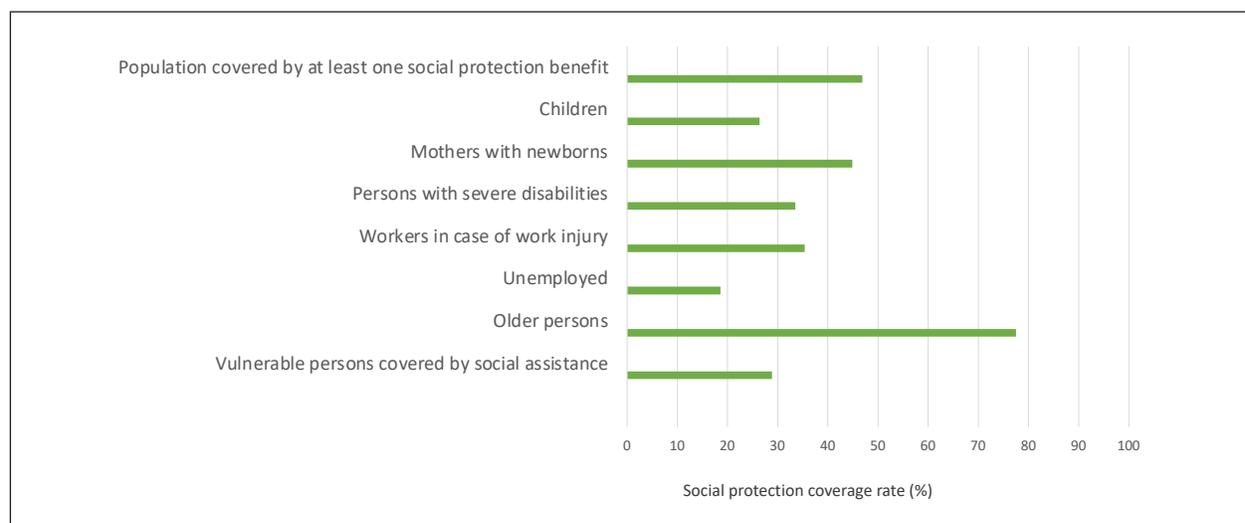
tion of both.<sup>49</sup> Income protection during sickness effectively covers only a third of the working-age population across the world. (See Figure 1.)

The ILO has identified three major challenges in closing persistent gaps in social protection coverage. First, the high levels of informal labor and the growth of so-called flexible forms of work are a key impediment.<sup>50</sup> People making their living in the informal economy account for more than 60% of the global employed population, and the majority of them do not have access to adequate income protection and health care.<sup>51</sup> Since the classical social protection system was initially premised on standard forms of employment, many individuals in part-time, temporary, self-employed, or so-called new forms of employment tend to have limited or no access to social protection, depending on the relevant national policy and legal framework.<sup>52</sup> This issue is cross-cutting across other key areas of gaps. Second, migrant workers and forcibly displaced persons and their families often experience dual challenges in access to social protection because many countries do not guarantee equal treatment

between nationals and non-nationals in social protection, and many migrants work in the economic sector characterized by lower social protection.<sup>53</sup> Third, women continue to enjoy lower levels of social protection than their male counterparts, which is the result of “the persistent patterns of inequality” in the world of work—that is, women’s “higher levels of part-time and temporary work and of informal employment (especially informal self-employment), gender pay gaps and a disproportionately high share of unpaid care work.”<sup>54</sup>

In addition to legal barriers to social protection, there are also practical barriers that prevent individuals from accessing social security benefits that they are legally eligible for. The Special Rapporteur on extreme poverty and human rights, Olivier De Schutter, considers that non-take-up is prevalent.<sup>55</sup> Although it is difficult to track the exact trend of this phenomenon due to the lack of monitoring by governments, the existing study on member states of the European Union indicates that the rate is over 40% for all social benefits considered.<sup>56</sup> The prevalence of non-take-up may be linked with a

FIGURE 1. Effective social protection coverage, global estimates, by population group (2020 or latest available year)



Source: International Labour Organization, World Social Protection Database, reproduced from International Labour Organization, *World Social Protection Report 2020–22: Social Protection at the Crossroads* (Geneva: International Labour Organization, 2021), p. 46.

number of factors, such as “a lack of awareness of the benefits themselves (especially due to language and literacy barriers), lack of information about eligibility criteria, difficulties with completing application forms, low amount or unpredictable disbursements and stigmatization when engaging with public administrations.”<sup>57</sup> De Schutter stresses that whatever the reasons are, “non-take-up is a failure of the social protection system, not of the individual,” and significantly limits the impact of the social protection system on the reduction of poverty and inequalities.<sup>58</sup> Overcoming these legal and practical barriers is crucial to ensure access to social security for all individuals.

### A human rights approach to social protection

In this context, it is important to revisit a human rights approach to social protection. First, the right to social security is recognized in major human rights instruments, including articles 22 and 25 of the Universal Declaration of Human Rights and article 9 of the International Covenant on Economic, Social and Cultural Rights (ICESCR).<sup>59</sup> The right to social security aims at guaranteeing human dignity for all persons in the circumstances of social risks and challenges across the life cycle, and it provides a firm normative basis for the requirement of comprehensive universal coverage for protection against social risks. Second, international human rights law also recognizes the rights to health, education, housing, water and sanitation, and family protection, and requires that goods and services necessary for the realization of these rights be made accessible and economically affordable for all.<sup>60</sup> Third, state parties’ obligation to take steps, to the maximum of their available resources, with a view to achieving progressively the full realization of economic, social, and cultural rights under the ICESCR (article 2(1)) requires them to review the manner in which social protection is funded and

to pursue progressive financing of social protection based on income and wealth. Furthermore, the rights to work and to just and favorable working conditions require broader socioeconomic policies that increase opportunities for decent work and ensure equal pay for work of equal value, which should be an essential companion to social protection systems.<sup>61</sup> Since the right to social security should be at the center of a social protection system, the section below elaborates on the right, along with the concept of the maximum available resources in the ICESCR, drawing on the Committee on Economic, Social and Cultural Rights’ General Comment 19 and its concluding observations.

### *The right to social security as a human right*

Social protection (social security) systems that states adopt to ensure the right to social security may vary depending on the national context. Nonetheless, state parties to the ICESCR must integrate key elements of the right to social security, which are described by the Committee on Economic, Social and Cultural Rights in General Comment 19.<sup>62</sup>

First, the right to social security requires comprehensive protection against all major social risks and challenges across the life cycle and therefore entails, among other things, protection from “(a) lack of work-related income caused by sickness, disability, maternity, employment injury, unemployment, old age, or death of a family member; (b) unaffordable access to health care; [and] (c) insufficient family support, particularly for children and adult dependents.”<sup>63</sup> Second, benefits, whether in cash or in kind, must be adequate in amount and duration so that everyone can realize their rights to family protection, to an adequate standard of living, and to health.<sup>64</sup> Third, state parties should ensure the accessibility of social protection in terms of coverage (everyone, including the most disadvantaged and marginalized groups, should have access to social security without discrimination); eligibility (conditions for benefits must be reason-

able, proportionate, and transparent); affordability (in the case of contributory system); participation and information (the social protection system must be designed and administered in a manner that ensures access to information, participation, and accountability); and physical access.<sup>65</sup> In particular, the right to social security calls for attention to groups who are largely marginalized or excluded from traditional social security systems—for example, women who shoulder the disproportionate burden of unpaid care work; part-time, casual, self-employed, and home workers; informal workers; Indigenous peoples and ethnic minorities; and migrant and undocumented workers.<sup>66</sup> Essentially, the right to social security requires a comprehensive social protection system that ensures the universality of coverage and the availability and adequacy of benefits that can provide effective protection in the event of social risks and contingencies, with particular attention to the most marginalized groups.

The systems may involve a mix of contributory schemes (social insurance) and non-contributory tax-funded schemes, including a universal benefit for everyone who experiences a particular risk or social assistance targeted for those in a situation of need.<sup>67</sup> What is important is to ensure that these social security schemes are progressively financed and redistribute resources and services equitably in favor of persons in lower income brackets and other disadvantaged groups. This interpretation can derive from the obligation of state parties under the ICESCR to take measures, to the maximum of their available resources, to make progress in realizing the right to social security. In this way, as the Committee on Economic, Social and Cultural Rights notes, “social security, through its redistributive character, plays an important role in poverty reduction and alleviation, preventing social exclusion and promoting social inclusion.”<sup>68</sup> In relation to the concept of the maximum of available resources, the committee has increasingly recommended that state parties enhance the progressivity of their fis-

cal and tax policies and increase budget allocations in areas such as social security, health care, and education.<sup>69</sup> Along the same line, a more focused examination may be necessary for the issue of financing the right to social security.

### *The ILO’s Social Protection Floors Recommendation*

The Social Protection Floors Recommendation (No. 202), adopted in 2012 by ILO member states together with representatives of workers and employers, was a significant step toward implementing a comprehensive human rights-based social protection system. The recommendation clearly articulates the right to social security and key elements of human rights approaches as guiding principles. Principles that states should apply in the fields of social protection include the universality of protection; entitlements based on legislation; the adequacy of benefits; nondiscrimination, gender equality, and responsiveness to special needs; social inclusion, including of persons in the informal economy; respect for the rights and dignity of people; solidarity in financing; financial, fiscal, and economic sustainability with due regard to social justice and equity; and coherence with social, economic, and employment policies.<sup>70</sup>

Since the ILO’s founding in 1919, social security has been an important part of the organization. The Declaration of Philadelphia, which became part of the ILO Constitution, recognizes the “solemn obligation of the International Labour Organization to ... achieve,” among others, “the extension of social security measures to provide a basic income to all in need of such protection and comprehensive medical care,” as well as “provision for child welfare and maternity protection.” The ILO social security standards provided guidance on the establishment of social security systems. However, the early social security standards, including the 1952 Social Security (Minimum Standards) Convention (No. 102), were biased toward male bread-winners working under

the full-time, standard employment model, which reflected the conditions of developed countries when the convention was drafted.<sup>71</sup> As a result, they did not provide adequate guidance on social protection gaps for those in the informal economy, those in non-standard forms of employment, and women.

Recommendation No. 202 intends to “provide states with a guideline for eliminating these and other gaps in the implementation of the right to social security.”<sup>72</sup> It encourages states to build social protection floors that guarantee basic social security, which entails access to essential health care, including maternity care, that meets the criteria of availability, accessibility, acceptability, and quality; basic income security for children, at least providing access to nutrition, education, care, and any other necessary goods and services; basic income security for persons of working age who are unable to earn sufficient income, in particular in cases of sickness, unemployment, maternity, and disability; and basic income security for older persons.<sup>73</sup> These social protection floors are in effect the minimum essential levels of the right to social security that states are required to implement as a priority.<sup>74</sup> Through these social protection floors, (1) all people living in a country should have access to a nationally defined set of essential health care services; (2) all children should be ensured basic income security so as to access to nutrition, education, and health care; (3) people of working age should have income protection in case of ill health, insufficient income, and unemployment; and (4) people in old age and with disability should have income protection for a life with dignity.

The guarantee of social protection floors would significantly contribute to addressing the large gaps in social security and combatting poverty. However, this concept of social protection floors is likely to have limited effects on reducing economic inequalities, and, as suggested by Beth Goldblatt, “retains a minimalist approach to rights that fails to challenge the underlying systemic inequalities

of the international economic system.”<sup>75</sup> Therefore, it is of critical importance that social protection floors be complemented by social security schemes that provide adequate levels of protection for a large segment of the population, including the middle class, as well as progressive financing. In this respect, Recommendation No. 202 does not stop at social protection floors. States are further called on to “seek to provide higher levels of protection as many as possible, ... and as soon as possible,” which concretizes states’ obligations to take steps progressively toward the full realization of the right to social security.<sup>76</sup> Importantly, Recommendation No. 202 sets out “solidarity in financing while seeking to achieve an optimal balance between the responsibilities and interests among those who finance and benefit from social security schemes” as one of the principles.<sup>77</sup> According to the ILO, solidarity financing entails “vertical redistribution from high-to lower-income households ... through progressive personal income tax rates or contribution rates that are proportional to income,” as well as “horizontal redistribution, for instance between healthy and sick persons, men and women, younger and older persons or families with and without children.”<sup>78</sup>

## Social protection and economic inequality

### *Differing impacts of social protection systems on economic inequality*

It is commendable that reducing inequality has been identified as one of the Sustainable Development Goals and that social protection has been explicitly recommended as a vital policy to achieve this. It is also encouraging that international organizations, including the World Bank, emphasize universal social protection. However, it should be noted that social protection does not necessarily lead to a decrease in economic inequality.

In many developing countries, social protection has focused largely on targeted programs,

namely safety nets for people living in poverty and other vulnerable situations.<sup>79</sup> Under this approach, “social policies were conceived of primarily as residual interventions to address market failures or to assist those adversely affected by crisis or unable to benefit from growth.”<sup>80</sup> Such targeted social protection programs have a positive impact on alleviating extreme poverty to a certain extent, but their impact on economic inequality is not clear. An assessment of social protection systems in Latin America from 2003 to 2013 found that targeted programs contributed to reducing poverty but were less effective in reducing income inequality than universal social protection programs.<sup>81</sup> It suggested that the impact of redistribution was largest in countries with comprehensive social protection systems encompassing universal access to health and education, high social spending, and progressive benefits.<sup>82</sup>

In 2010, a study by the UN Research Institute for Social Development compared the impact on poverty and inequality of the three welfare state regime models in developed countries—that is, conservative, liberal, and social democratic—employing Gøsta Esping-Andersen’s typology of welfare states.<sup>83</sup> It found that the rates of both poverty and income inequality were most significantly reduced in countries where “a wider range of health, education and care services, as well as social protection benefits and transfers, are provided publicly and universally by the state on the basis of citizenship or residence.”<sup>84</sup> An earlier study on the redistributive effects of welfare state institutions among developed countries also suggested that poverty and inequality can be more effectively reduced with universalist (encompassing) approaches to social protection than with low-income targeting.<sup>85</sup>

The funding model is another critical factor that shapes a social protection system’s impact on economic inequality. Social protection systems are typically funded through a mix of social insurance contributions and taxes. Progressivity in mobiliz-

ing resources and distributing benefits, whether through contributions or non-contributions, is imperative for enhancing the transformative potential of social protection to address economic inequality. For instance, if revenue for social protection mainly comes from value-added tax, with marginal support from income taxes, it can significantly limit the redistributive effects of social protection.<sup>86</sup> Similarly, if public expenditure is mainly allocated toward subsidizing social protection schemes linked to formal sector employment, instead of social assistance or essential social services, it can sustain or even exacerbate economic inequality.

Social insurance schemes funded through contributions by employers and workers also continue to be an important means of financing that seeks to pool and redistribute risks and benefits within and between generations.<sup>87</sup> Health care can be designed to have an equitable distribution effect, with funding mainly generated from contributions. For example, individuals and employers are required to contribute to health care based on their income and wealth, but health care services are made accessible to all people in society, irrespective of their ability to contribute.<sup>88</sup>

A caveat should be made to the suggestion that a social protection system funded primarily by general taxation can ensure an adequate standard of living for all and reduce economic inequality. The World Bank, which used to promote a targeted safety net approach in developing countries, has become an advocate of a universal basic income. The 2019 *World Development Report* proposed expanding social assistance (e.g., through a guaranteed minimum income, a mandated savings and insurance plan, and privately managed individual savings) and reducing social insurance, arguing that the social insurance model is ill-suited in the context of growing non-standard employment and large informal economies.<sup>89</sup> The ILO has expressed concern that this proposal for “‘minimum social insurance’, achieved through cuts to employers’

contributions, would result in increased levels of inequality and endanger the sustainability of social protection systems.<sup>90</sup> A universal minimum guarantee of social protection is a good thing. But if it is coupled with a weakening of the public social insurance system and a growing dependence on private insurance, it can lead to a social protection system that coexists with rising inequality. Closing the wide social protection gaps resulting from the substantial informal economy would require a two-track approach that integrates both contributory and non-contributory systems.<sup>91</sup> One track involves encouraging the transition of informal workers to the formal economy through the creation of more decent job opportunities, and extending social insurance schemes to those workers. Simultaneously, a universal minimum social protection should provide basic income security and access to social services for all, including those who engage in the informal economy.

### *The transformative potential of social protection in reducing economic inequality*

Meeting the objective of expanding social protection to decrease economic inequality, as adopted in the Sustainable Development Goals, necessitates a transformative approach to social protection.<sup>92</sup> Human rights can provide a normative ground for the pursuit of a transformative social protection system that can address economic inequalities. Katja Hujo suggests that “universal and adequate social protection schemes that are progressively financed redistribute risks, income and resources in ways which favour groups with lower incomes, status, or other disadvantages, leading to more equitable social outcomes and empowerment while also fostering cross-class coalitions.”<sup>93</sup> Goldblatt stresses that “progressive taxation that increases with income alongside generous social security transfers, usually to those in need, play a key role in reducing economic inequality, in addition to measures such as minimum wages and the provision of

goods and services such as health care and housing.”<sup>94</sup> Furthermore, identifying and addressing the structural conditions that give rise to poverty and inequality is required for social protection to be transformative.<sup>95</sup>

In essence, the transformative potential of social protection systems in reducing economic inequality can be enhanced if social protection is based on human rights, particularly the right to social security, as well as the rights to health and education, which require (1) comprehensive universal coverage for protection against social risks; (2) universal access to quality social services, such as health care, education, child care, and services for older people or people with disabilities; and (3) the progressive financing of social protection based on income and wealth, whether it is contributory or non-contributory. Moreover, social protection measures must be accompanied by wider social and economic policies, since relying solely on a social protection system is inadequate.

### Conclusion

Economic inequality is a key social determinant of health. This paper has highlighted the central importance of social protection in ensuring an adequate standard of living for all and reducing economic inequality. International human rights law provides a normative foundation for a transformative social protection system. While the right to social security is at the center of this human rights-based approach to social protection, the rights to health, education, housing, and water and sanitation should also be an important part. Not all forms of social protection, however, tackle both poverty and economic inequality. This paper has discussed the key components of a human rights-based social protection framework that can reshape the distribution of resources and benefits toward a more equal society. These components include comprehensive protection for major social risks

and challenges throughout the life cycle; universal access to basic quality services such as health, education, child care, and services for older people or people with disabilities; and a progressive financing mechanism, whether contributory, noncontributory, or of another form. The ILO Social Protection Floors Recommendation No. 202 provides concrete guidance for the realization of the transformative potential of social protection.

Political processes at the national level are what ultimately determine the mobilization of revenue, expenditure allocation, financing mechanisms for social protection, and the design of social security schemes. A major challenge that lies with those processes is that they are “often dominated by elite groups,” and the outcome thereof may not lead to a human rights-based social protection system.<sup>96</sup> In fact, in more unequal societies, due to existing unequal power relations, it is more difficult to have social protection systems that can tackle economic inequalities.<sup>97</sup> A human rights approach can contribute to this struggle for equality by requiring that the impact of any social protection decision on socioeconomic inequalities and on disadvantaged groups be taken into account. It is also important to recognize that building a fairer and more inclusive society also requires addressing the ex ante situation of market income inequalities and creating fair opportunities, and not only ex post redistribution through social protection.<sup>98</sup> In this regard, a human rights approach to social protection has to be closely linked to the rights to work and decent working conditions.

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## PERSPECTIVE

# The Equity Effect of Universal Health Care

ANJA RUDIGER

For well over a century, the politics of universal health care have shaped the development of modern welfare states and their ability to manage economic inequality. Whether governments adopt universal health care in response to workers' struggles, capitalist labor demand, or other factors, universal health care tends to advance economic redistribution.<sup>1</sup> This equity effect of universal health care is often overlooked, including in the human rights field.<sup>2</sup> Although right to health standards are clear on states' obligation to finance health care equitably, along with providing universal access to quality health facilities, goods, and services, the distributional impact of a universal system has received less consideration.<sup>3</sup> I propose that right to health advocates embrace universal health care as a redistributive project that can help advance not only the right to health but also economic equality. Both are deeply intertwined.

The United States presents a prime example. It is one of the most unequal wealthy countries, where resources are concentrated in the hands of a few while millions struggle to access basic economic and social rights. The top 10% of US households own approximately 70% of the total wealth, and the typical white family is about ten times wealthier than the typical Black family.<sup>4</sup> Life expectancy and health outcomes are below average, compared to other OECD countries, yet health expenditure is the highest.<sup>5</sup> Despite spending twice as much per capita on health as Canada or France, the pre-COVID-19 mortality rate from treatable causes was over a third higher in the United States than in Canada and twice as high as in France.<sup>6</sup> While poor and unequal health outcomes point to health system failures, economic and social structures are key underlying factors. The pandemic brought this into sharp focus: COVID-19 mortality has been positively associated with country-level income inequality.<sup>7</sup> The United States has among the highest COVID-19 mortality rate in the world, disproportionately affecting Black, Indigenous, and low-income populations.<sup>8</sup> Economic and social inequalities drive much of this unconscionable toll on human lives. A large body of research confirms that societies with greater income inequality have poorer health outcomes.<sup>9</sup>

But if economic inequality is at the root of poor health outcomes, does the health care system matter? It does. Inequalities are maintained and reproduced by the systems and institutions that organize

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our lives. In the United States, these are racialized, commodified systems that control access to human rights according to factors such as income, wealth, race, and gender. The largest of these systems is market-based health care, controlled by a powerful medical industrial complex. At 18.3% of GDP in 2021, the US health sector has a greater share of the economy than in comparable countries, whose average is less than 12% of GDP.<sup>10</sup> Shifting the US health care system out of the market and toward universal public provision and public financing would catalyze structural economic changes and facilitate the decommodification of other economic and social rights.

Fifteen years ago, at the beginning of the Obama presidency, I wrote in these pages about emerging US advocacy efforts to treat health care as a right and a public good, rather than a commodity.<sup>11</sup> A growing number of right to health advocates had been pushing for free and equal access to care for all. Our vision centered the right of everyone to get the health care they need, when and where needed, financed publicly through progressive taxation. The focus on the right to care, rather than a right to coverage, revealed and responded to the layers of inequity and control produced by intermediaries, from insurance companies to employers. Unfortunately, Obama's signature reform, the Affordable Care Act of 2010, took a different approach. It established private insurance "marketplaces," thereby entrenching the hold of insurance companies on people's access to care. An increase in households covered by insurance was nullified by deductibles, user fees, and claim denials, leaving two-thirds of insured people struggling to access care.<sup>12</sup>

As advocates shifted their attention to state-level reforms, I shared Vermont's "Healthcare Is a Human Right" campaign's financing proposal, a progressive tax mix that would have reduced wage disparities and raised the incomes of all but the wealthiest households.<sup>13</sup> The campaign spearheaded a narrative shift, subsequently popularized

by Senator Bernie Sanders. His two presentational runs centered on health care as a human right and a lever for advancing economic equality.

When the COVID-19 pandemic exposed shocking gaps in preventive and primary care, and stark inequities in access and outcomes, the days of market-based health care seemed to be numbered. Universal health care, it was estimated, could have saved 212,000 lives in 2020 alone.<sup>14</sup> Today, however, market-based US health care continues to be a global flagship for the neoliberal economic model and its entrenched inequities.

The tentacles of economic neoliberalism reach deep into health systems around the world. While the United States is unique among its peers in refusing to provide universal access to health care, many universal health systems, conceived at the height of the welfare state era, are under intense pressure from privatization and prolonged resource deprivation.

Where do human rights advocates go from here? Below, I offer three guiding questions, addressing health care financing, delivery, and governance, to promote a shift in approach. While I focus on US conditions, these questions can be applied to any system exposed to capitalist market imperatives.

## 1. Who pays?

The concept of "single payer" has long served as a stand-in for the goal of universal health coverage in the United States. It describes the consolidation of all payers—private, public, and employers—into one government payer, primarily to increase efficiency and generate savings for coverage expansion. Hence, the key question for single-payer advocates is "How much does it cost?" While countless studies have confirmed that a universal health system will cost less than the fragmented, exorbitantly expensive market-based system, neither aggregate nor average savings are particularly meaningful to lower-income families that are disproportionately

burdened by health care costs.<sup>15</sup> By shifting the question to “who pays,” we can identify and prioritize the distributional effects of various financing models.

Market-based health care, anchored by the for-profit insurance industry, is financed regressively, primarily through premiums and user fees. This produces an inverse correlation between household income and household health care expenditure, resulting in lower-income people spending a greater income share on health care than the wealthy. This is not merely a reflection of existing income disparities but a regressive effect of the financing design and payment mechanisms. Although much of US health care is already publicly subsidized, the flow of public funds is largely obscured. For-profit companies have all but taken over the two main public programs, Medicaid and Medicare, which primarily serve poor people and those aged 65 or older, respectively. The majority of Medicaid recipients are enrolled in so-called managed care organizations, with five publicly traded for-profit companies accounting for half of all enrollment.<sup>16</sup> Similarly, over half of all Medicare beneficiaries have bought private “Medicare Advantage” plans, which generate the highest profit margins in the industry through strategies such as limiting provider networks and requiring prior authorization for accessing certain types of care.<sup>17</sup> In addition to public programs, the single largest federal tax expenditure is the tax exclusion for employer-sponsored health insurance, which costs more than US\$300 billion annually.<sup>18</sup> It benefits high-earning taxpayers the most, providing them with a net subsidy for their insurance coverage.<sup>19</sup> Additionally, the effect of financial risk protection generated by the insurance model is regressive, as it is of greater value to wealthier households.

In contrast, a universal, publicly financed health care system that provides free access at the point of care generates both aggregate savings and redistributive impacts. It flips who pays for health

care: those who make more pay more. How big this equity effect is depends on the progressivity of the financing design. For example, the Medicare for All Act, introduced by Senator Sanders in 2017, could sharply reduce health care payments for families in the bottom 80% of income, while removing subsidies for the top 20% of earners.<sup>20</sup> This would also narrow racial and gender income gaps, since people of color and women are overrepresented among lower-income groups. According to a set of financing proposals—not entailed in the bill—middle-income families would pay, on average, an estimated 2.6% to 14% less for health care than in the current system, while high-income households would pay 3.9% to 5.6% more (depending on their current insurance status).<sup>21</sup> Several state-level universal health care proposals, introduced in the past decade, illustrate similar redistributive effects. By ensuring that top earners contribute according to their means, publicly financed systems can deliver significant financial relief to low- and middle-income families and narrow the income gap. Questioning “who pays” will allow right to health advocates to achieve the maximum redistributive effect within a framework of adequate and equitable revenue generation.

## 2. Who has ownership?

The ownership of hospitals, specialist clinics, physicians’ practices, pharmaceutical companies, and other health care facilities has rarely been questioned in the United States—until the recent wave of corporate mergers, private equity takeovers, and hospital closures. Private equity firms have spent around US\$750 billion over the last decade acquiring and consolidating health care facilities, leading to higher prices and worse health outcomes.<sup>22</sup> The pharmaceutical industry is failing to produce essential medicines, prioritizing more profitable drugs. Amid the rapid corporatization of

both for-profit and nonprofit health facilities, the longtime advocacy demand of “publicly financed, privately delivered” health care has been overtaken by the dynamics of advanced capitalism. Insurance companies are no longer the only profiteers jeopardizing people’s access to care. By raising the question of public ownership alongside public financing, we can begin to talk about a national health service, with public hospitals, publicly employed doctors, and publicly owned pharmaceutical facilities.

In a country built on a racialized system of property ownership, nationalizing health care is not going to be an easy feat. The logic of private ownership drives economic, racial, and gender inequities and substitutes for the missing welfare state. When government fails to provide public goods to meet everyone’s needs, private property becomes the route to economic security, albeit a route largely blocked for many, especially people of color and women. Those identifying as property owners and consumers, not rights holders, tend to limit their expectations of government to the maintenance of functioning markets.

What would it take to transform market-based health care, undergirded by the private property regime, into a publicly owned and operated system that provides health care as a public good? Some US advocates are looking to the Veterans Affairs health system as a model, a publicly funded, owned, and operated system that is lauded for its quality health outcomes.<sup>23</sup> They have crunched the numbers on a federal buy-out of investor-owned health facilities.<sup>24</sup> The question of “how we seize ownership of health care assets from the corporations that have come to dominate them” is bold but necessary.<sup>25</sup> It underscores the need for a broad-based popular movement, united through human rights.

### 3. Who governs?

In an era of concentrated corporate power and democratic decline, the governance question takes

on new urgency. It is not acceptable that corporate actors make decisions about health care affordability, accessibility, availability, and quality. Although dependent on public funding, these corporations use their market power to circumvent regulations and evade accountability. Limited consumer and patient rights cannot counterbalance the rights of shareholders to reap profits from what should be an essential public service.

But the system, at least in the United States, may be eroding from within. The extreme pressures of market-driven health care are pushing both health care workers and “consumers” to question the legitimacy of corporate rule. The financial bottom line determines care provision even in nonprofit facilities.<sup>26</sup> Across the system, doctors and nurses are flagging their “moral injury” as they are forced to put profits over patients.<sup>27</sup> People are encountering the limits of their consumer rights when high-level decisions cause them to lose access to vital services, such as reproductive care. At the same time that faceless investors and stock market algorithms tighten their grip on health governance, health care reemerges as a moral claim—and a human right.

The human rights framework empowers all of us to participate in the decisions that affect our lives. But to exercise this power, we will need to reshape democratic governance to become both inclusive and meaningful. People systematically excluded from decision-making must gain a seat at the table. The right to participation must extend to co-creation, co-governance, and co-ownership of public services and infrastructure. This propels us into the realm of economic democracy, the rebalancing of power in the economic sphere. In health care, which depends on a centralized funding pool to cross-subsidize different levels of need, new governance models may have to strike a balance between system-wide and community-level decision-making, mindful that all decisions have racialized and gendered impacts. If we elevate hu-

man rights principles as guardrails for governance, we obtain a basic framework for the democratization of health care.

Human rights advocates may point out that international right to health standards do not prescribe redistribution, public ownership, or co-governance. But these standards do obligate us to make progress toward a clear and compelling outcome. Change starts with the desired result: if everyone—not just the wealthy and otherwise privileged—is to enjoy the highest attainable standard of health, the pursuit of economic equality must be at the heart of our efforts.

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# Equality Restricted: The Problematic Compatibility between Austerity Measures and Human Rights Law

MICHAEL G. MARCONDES SMITH

## Abstract

Economic policies that concentrate wealth and aggravate socioeconomic inequalities often have negative impacts on human rights. For example, evidence points to the unequal impact of austerity measures—such as the defunding and privatizing of health care—on already disadvantaged groups and individuals. Despite its detrimental impacts, austerity often appears as a necessary evil in times when difficult choices must be made. Justified through arguments of trickle-down economics to support growth, the realization of human rights is postponed. Human rights are sidelined as guidelines that inform rather than limit such measures. The assumption that wealth concentration and the consequent reduction of human rights standards may be justified suggests a problematic conception of equality in human rights law. In this paper, I critically examine the way that this assumption informs the exclusion of distributive considerations from the scope of equality within human rights law. I identify and evaluate the emerging interpretations of equality beyond the legal-technical notion of equal treatment and the prohibition of discrimination and the extent to which equality in human rights may take on a distributive function in combating policies of wealth concentration such as austerity.

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## Introduction

Times of economic crisis present policy makers with difficult choices. Austerity measures are policies aimed at alleviating an economic crisis through the rearrangement of public spending. The element of choice lies in the election of what is to be prioritized in the expenditure, and what is to be considered less essential or productive. Characteristics of austerity measures are the reduction of welfare benefits and the stalling, and often retrogression, of the realization of human rights.<sup>1</sup> Socioeconomic rights such as the right to health are particularly targeted as excessive burdens on state expenditure.<sup>2</sup> Attacks on health care through defunding or privatization are thus employed within an argument for efficiency and necessity.<sup>3</sup> For example, austerity measures in Spain “shifted certain health costs on to individuals,” impacting most harshly the most vulnerable.<sup>4</sup> Similar experiences in the United Kingdom, Portugal, Ireland, and Italy further demonstrate the economic and health-related failures of austerity measures.<sup>5</sup> In prioritizing economic revitalization, public expenditures on health, social protection, and welfare benefits in general are sacrificed. Following neoliberal ideologies, private enterprises are prioritized in reestablishing economic productivity, resulting in the concentration of capital in the hands of these entities, the impoverishment of the working class, and a consequent increase in socioeconomic inequality.<sup>6</sup>

Despite the ideological underpinnings of austerity measures, human rights law approaches them through a neutral lens. The compatibility between austerity and human rights law is assessed with a view to the relevant standards imposed by the legal framework, best dealt with under the scope of economic, social, and cultural rights. Although resource allocation and distribution is required for the progressive realization of these rights, human rights law adopts a neutral stance concerning the economic model and strategies to be adopted.<sup>7</sup> While setbacks in the protection, respect for, and

fulfillment of human rights may trigger the responsibility of states and other actors, austerity per se is not necessarily incompatible with human rights law, as space remains open for its justification.<sup>8</sup> Scrutiny of austerity measures is therefore carried out through a technical analysis of the conditions for the retrogression in the realization of rights, or their limitations. This approach excludes a more structural consideration of the dynamics of wealth concentration that underpin austerity.

Austerity measures are often imposed by creditors with the leverage to request particular strategies for satisfying debt at all costs. While economic influences stemming from international human rights law cause unease, international impositions of economic strategy are a normality. International law has long been a vehicle for the imposition of economic restructuring, at times adopting the language of human rights in the push for “adjustment with a human face.”<sup>9</sup> International financial institutions play a central part in defining the economic ideology followed in times of crisis. While the moral responsibility of respecting human rights may be inferred from the severe consequences of these bodies’ actions in the international sphere, precise legal obligations are harder to establish.<sup>10</sup> The responsibility for human rights falls solely on the state, which in turn often argues that the imposition of austerity measures by creditors makes its actions unavoidable.

Against this background, I examine the potential of the principle of equality and non-discrimination (or equality norm) in restricting austerity measures. While this principle is mostly interpreted as being limited to a prohibition of discrimination, scholars have called for its revitalization, particularly in an economically distributive sense.<sup>11</sup> Emerging interpretations develop a distinction between a broader notion of equality as a principle that informs the application of the legal system in its entirety and the more specific, grounds-based prohibition of discrimination.<sup>12</sup>

Beyond nondiscrimination and informing the application of particular socioeconomic rights such as the right to health, I argue that equality may take on a distributive function in combating policies of wealth concentration such as austerity.

In the first section of this paper, I introduce human rights law's responses to austerity measures. By analyzing human rights law standards on retrogressive measures, I identify limitations that allow for the legal justification of austerity. In the second section, I unpack the reduction of the equality norm to a prohibition of discrimination in human rights law. I assess emerging interpretations of the equality norm that go beyond identity-based nondiscrimination and highlight its distributive potential. Finally, I consider the application of a revitalized interpretation of equality to austerity measures and identify the need for further, more concrete considerations of equality as a fundamental norm of human rights law.

### Austerity and human rights law

The detrimental effects of austerity have been consistently demonstrated.<sup>13</sup> Under discussion are not their beneficial or detrimental nature, but rather their inevitability as the way to handle economic crises. Proponents of austerity claim that moments of crisis call for difficult choices to be made in prioritizing spending, justifying the reduction of living standards as a necessary evil.<sup>14</sup> Relevant to this examination is how human rights law may scrutinize this inevitability. Although policy makers use such crises to justify austerity measures, it is precisely during a crisis that human rights law must provide a safeguard against the deterioration of living standards. Beyond providing minimum standards, however, human rights do not seem to regulate distributive policies. While distribution may be required to safeguard and realize rights, the economic strategy to be adopted is left to the

discretion of states. And so the United Nations Committee on Economic, Social and Cultural Rights makes it clear that

*in terms of political and economic systems the [International Covenant on Economic, Social and Cultural Rights] is neutral and its principles cannot accurately be described as being predicated exclusively upon the need for, or the desirability of a socialist or a capitalist system, or a mixed, centrally planned, or laissez-faire economy, or upon any other particular approach.*<sup>15</sup>

Consequently, the adoption of wealth-concentrating austerity as a policy choice aimed at predicted economic gain per se does not seem to contradict human rights obligations. Only if the result of these measures is found to conflict with these obligations may a violation be identified. Analysis of compatibility must therefore be done on a case-by-case basis.

### *Justifying austerity*

Article 2 of the International Covenant on Economic, Social and Cultural Rights (ICESCR) establishes the obligation of states to “take steps ... to the maximum of [their] available resources, with a view to achieving progressively the full realization of the rights recognized in the [ICESCR].”<sup>16</sup> Requiring the *progressive* (as opposed to *immediate*) realization of rights is “a necessary flexibility device, reflecting the realities of the real world and the difficulties faced by any country in ensuring full realization of economic, social and cultural rights.”<sup>17</sup> Opening the space for justifying retrogression is an acceptance that economic circumstances may be beyond states' control.<sup>18</sup> The Committee on Economic, Social and Cultural Rights, while neutral to economic strategy, has stated that in employing retrogressive measures, states have “the burden of proving that they have been introduced after the most careful consideration of all alternatives and that they are

duly justified by reference to the totality of the rights provided for in the [ICESCR] in the context of the full use of the State party's maximum available resources."<sup>19</sup> Thus, not only is the stalling or halting of rights realization justifiable, but so is their retrogression.

One safeguard against non-realization and retrogression is found in the committee's "minimum core" doctrine, which determines that "a minimum core obligation to ensure the satisfaction of, at the very least, minimum essential levels of each of the rights is incumbent upon every State party."<sup>20</sup> However, the committee has been inconsistent in affirming the absolute or relative nature of minimum core obligations. In the context of the right to health, the committee at one point stressed that "a State party cannot, under any circumstances whatsoever, justify its noncompliance with the core obligations . . . , which are non-derogable."<sup>21</sup> It eventually returned, however, to the original position that the failure to fulfill minimum core obligations can be justified as long as it is demonstrated "that every effort has been made to use all resources that are at its disposition in an effort to satisfy, as a matter of priority, those minimum obligations."<sup>22</sup> For some, the provision for such justifications makes it possible for states to justify retrogressions that would otherwise be considered impermissible and unjustifiable.<sup>23</sup>

In the particular context of austerity measures, a letter by the chairman of the Committee on Economic, Social and Cultural Rights adds that, in justifying their adoption, states must demonstrate that the measures are temporary, necessary and proportionate, nondiscriminatory, and respectful of minimum core obligations.<sup>24</sup> An in-depth engagement with each of these conditions is not the purpose of this text.<sup>25</sup> It suffices to observe that the establishment of conditions for the analysis of compatibility is an *a priori* acceptance that wealth-concentrating austerity measures may be compatible with human rights standards. Even

if the nonfulfillment of minimum core obligations places a burden on the state to prove compatibility, the space is nevertheless allowed for justification under particular conditions.<sup>26</sup> This approach allows for an "as long as" formula in the examination of austerity: as long as standards are kept, wealth-concentrating austerity shall be permitted. As austerity is not per se incompatible with human rights standards, the determination of compatibility is left to a technical assessment under human rights law.<sup>27</sup> A crucial part of this assessment is that the state carries the burden of demonstrating compatibility.

Similarly, and in the context of the Greek austerity measures, the European Committee of Social Rights has noted that

*even taking into account the particular context in Greece created by the economic crisis and the fact that the Government was required to take urgent decisions, the Committee furthermore considers that the Government has not conducted the minimum level of research and analysis into the effects of such far-reaching measures that is necessary to assess in a meaningful manner their full impact on vulnerable groups in society.*<sup>28</sup>

While the European Committee of Social Rights does not offer particular alternatives, the ideological inevitability of austerity ends up challenged through neutral procedural language: "as a result, the Committee considers that it has not been discovered whether other measures could have been put in place, which may have limited the cumulative effects of the contested restrictions upon pensioners."<sup>29</sup> The committee equally avoids any interference in socioeconomic policy choices, relying on a more technical examination. Through this approach, however, the element of "legitimate public interest" in the measures remains unquestioned:

*while the invoked legislative measures could in principle be regarded as pursuing a legitimate public interest, the Committee is unable to consider that there are sufficient elements in the material before*

*it to justify restrictions to the Charter rights at stake as being proportionate and thus in conformity with what is permitted by Article 31 of the Charter.<sup>30</sup>*

Considering the measures to be in principle a legitimate public interest accepts at face value the ideological presuppositions underlying austerity. Through this approach, not only does human rights law fail to scrutinize the belief regarding the “trickle-down” benefits of wealth concentration and socioeconomic inequality, but also, by accepting *a priori* the legitimacy of the measures, it allows for the validation of an ideological assumption of compatibility between wealth accumulation and the postponement of human rights realization on the one hand, and human rights standards on the other. Meanwhile, the presupposition of such compatibility between a trickle-down approach and human rights law has been questioned.<sup>31</sup> Critics suggest that under a human rights-based approach to economic recovery, human rights would inform the election of policies in times of crisis, producing an economic strategy that works for rather than against human rights realization.

### *The human rights-based approach*

Austerity measures are not without alternative. The economic assumptions that underlie austerity have long been questioned within and outside the field of economics.<sup>32</sup> While grounded in the neoliberal assumption that temporary inequalities are beneficial for the economy, their economic inefficiency has been repeatedly demonstrated.<sup>33</sup> Alternative perspectives point to the socioeconomic value of safeguarding human rights standards in times of crisis.<sup>34</sup> But beyond economic efficiency, upholding human rights standards is not optional, given that states remain under obligations to progressively realize rights to their maximum available resources. Rights-based approaches take a further step, however, by rejecting assumptions that the postponement of rights realization or retrogressions may be necessary for economic recovery. Rather,

they take the realization of rights as the starting point for any strategy of economic recovery.<sup>35</sup> As clarified by Magdalena Sepúlveda Carmona, “From a human rights perspective, recovery must start with the most vulnerable and disadvantaged, who are rights holders rather than burdensome or passive recipients of charity.”<sup>36</sup>

The question arises as to the validity of leaving unquestioned the trickle-down position by reference to the neutrality of human rights law. As explained by Margot Salomon, scrutiny must seek to clarify to what extent the face-value acceptance of trickle-down economics is compatible with human rights law standards:

*On a human rights account, the argument that the poor will ultimately benefit, that is that they benefit “over time”, is difficult to defend. Human rights are not to be postponed for pronounced greater objectives, for example, an increase in national or global wealth or for benefits anticipated at some indeterminate time in the future. From the perspective of human rights theory, the argument made for sacrificing distributional equity in favour of rapid accumulation is rejected.<sup>37</sup>*

The argument that wealth-concentrating austerity may (if deemed justified) be compatible with human rights law cannot be sustained. Dangerously, it relies on a technocratic assessment that does not scrutinize an ideological perspective of economic recovery that promotes the postponement of human rights obligations.

In this context, questions as to the role of equality in combating wealth concentration and extreme inequality have sparked debates on the limits and unexplored potential of human rights law in achieving global justice.<sup>38</sup>

### Equality restricted

Socioeconomic distribution has generally been sidelined in the development of human rights. Recently, some scholars have highlighted the

insufficiency of what is often termed the “minimums approach” in human rights law.<sup>39</sup> For them, human rights have focused widely on providing only the bare minimum, or the basic needs for a life in dignity, a notion coherent “with the liberal-egalitarian and social-democratic idea of sufficiency within a welfare state.”<sup>40</sup> For Samuel Moyn, “in the age of human rights, the pertinence of fairness beyond sufficiency has been forgotten.”<sup>41</sup> While inequality logically describes a relationship between more than one person, the focus has been limited to one of its components—namely, the poor and deprived individual. Nothing within human rights law concerns, it seems, the other side of the relationship, the privileged few. Consequently, “one could imagine one man owning everything—an absolute overlord—and he would not violate the current scheme of human rights, so long as everyone had their basic rights fulfilled. Even perfectly realized human rights are compatible with radical inequality.”<sup>42</sup> This compatibility is, however, conceptual. While legally possible within Moyn’s description of human rights law, the factual compatibility between the realization of human rights and socioeconomic inequality is at best questionable.

After all, the impacts of socioeconomic inequality on the realization of human rights have been demonstrated.<sup>43</sup> For example, in the context of the right to health, the correlation between socioeconomic disadvantage and a lower life expectancy and higher rates of diseases may raise central issues under the right to health.<sup>44</sup> Inequality-inducing austerity measures put in place by Spanish authorities had a severe impact on the universality, accessibility, affordability, and quality of health care, pointing to potential violations of the right to health under the ICESCR.<sup>45</sup> Impacts on health are observed not only in directly related issues such as compromised access to quality nourishment or rising mental health problems but also in relation to other socioeconomic rights.<sup>46</sup> Given that the right to health is a “fundamental human right indispensable for the

exercise of other human rights,” austerity measures on health have widespread damaging effects.<sup>47</sup> The disparate impacts of austerity on access to health care raise serious concerns under the right to health, particularly when read through an equality lens.<sup>48</sup> In this context, interpreting equality distributively may shift our perspective from one of insufficiency to one of maldistribution.<sup>49</sup>

### *Revitalizing the equality norm*

Shortcomings in the approach of bodies such as the Committee on Economic, Social and Cultural Rights and the European Committee of Social Rights to socioeconomic inequality have prompted renewed investigation into the limitations and potential of the equality framework.<sup>50</sup> Former United Nations Special Rapporteur on extreme poverty and human rights Philip Alston and scholars have proposed the “revitalization of the equality norm” in recognition of the direct connection between socioeconomic inequality and the realization of human rights.<sup>51</sup> The challenge lies particularly in identifying the normative consequences that may be inferred from such a connection. While the present understanding of equality allows for an indirect assessment of socioeconomic inequality, a renewed interpretation aims at identifying the presence of a normative command of distribution stemming from a positive notion of equality. An assessment of the aspects of a “renewed” principle of equality and nondiscrimination could shed some light on how austerity could be coherently dealt with under human rights law.

The principle of equality and nondiscrimination is a central principle of human rights law and a crosscutting norm that guides the application of this legal system in its entirety.<sup>52</sup>

Initially, the human rights provisions of equality and nondiscrimination safeguarded what may be defined as formal equality or the provision of equal treatment. Critiques highlighted the “emptiness” of this legal formulation of equality, which appeared

only to repeat a command for the realization of particular rights and to offer no additional normative content of its own.<sup>53</sup> These critiques prompted responses in the effort to substantiate the equality norm, made evident in the evolution of the concept of substantive equality.<sup>54</sup> In this developed reading, the substance of equality requires an enhanced analysis of the realization of rights in relation to subjects' factual circumstances of inequalities. In the context of austerity, for instance, an analysis of formal equality could not identify the disparate effects of raising consumption taxation (such as VAT) equally across the population.<sup>55</sup> Substantive equality, however, looks at the concrete outcomes of a determinate act rather than focusing solely on treatment.<sup>56</sup>

An approach extending beyond equal treatment has already been present in courts' and treaty bodies' evaluations of equality.<sup>57</sup> In its varying formulations, substantive equality has increasingly informed legal assessments of equality.<sup>58</sup> Socioeconomic considerations are not so easily brought within the scope of law, however. The separation of powers prevents judicial interference in executive or legislative competences.<sup>59</sup> Additionally, in the case of international human rights law, resistance to interference in such socioeconomic matters is stronger, given the field's supranational (and consequently external) nature. Within the legal consideration of socioeconomic distribution, therefore, one stumbles upon the difficult exercise of defining how far human rights mechanisms can go in defining the obligations under human rights law.

In the face of such impediments in addressing matters of distribution, socioeconomic inequality has been addressed mostly indirectly, such as through the inclusion of "poverty" or "socioeconomic disadvantage" within lists of prohibited grounds of discrimination.<sup>60</sup> As highlighted by Sakiko Fukuda-Parr, a direct assessment of economic inequality as an issue of distribution is deliberately kept from the agenda of human rights,

in alignment with particular political interests.<sup>61</sup> Consequently, there is a dissonance between the assessment of distribution within a society and the analysis of differential treatment on the basis of socioeconomic disadvantage.

In going beyond nondiscrimination, authors have proposed a disentanglement of equality as a broader, positive notion from the more negative prohibition of discrimination.<sup>62</sup> Put simply, while nondiscrimination tackles issues of recognition and identity-related matters of disadvantage under particular grounds, equality corresponds to a command of effecting equality, including through distribution. To be sure, such a clear-cut distinction cannot be made without sacrificing attention to the complex relation between distribution and recognition.<sup>63</sup> Not only does nondiscrimination place positive obligations on states regarding disadvantage and inclusion, but it also contains a distributive element of its own. Interpreting equality as a positive version of nondiscrimination can equally result in its further reduction to positive obligations under the prohibition of discrimination.

Calls for the revitalization of the equality norm seem to take a different path, therefore, going beyond the common formulation of particular provisions of equality and nondiscrimination. As an argument of systematic coherence, it stretches beyond one provision, concerning equality as an underlying principle, calling for a clarification of its normative consequences as such. This exercise seems to follow a notion of legal principle as a general norm (as opposed to one particular rule) inferable from a legal system in its entirety, and which informs the interpretation of all of this system's particular provisions.<sup>64</sup>

Importantly, a turn to interpretation brings a political debate on the limits of human rights law in tackling economic policy questions such as austerity within the domain of legal theory. The neutrality of human rights law is set aside as a mere alternative interpretation that is in fact insufficient

for creating coherence as to the fulfillment of the system's normative propositions. A focus is therefore placed on the realization of the system in its entirety and thus on the language of human rights law and the interdependence and indivisibility of rights. The references to "everyone" in particular provisions are not meaningless.<sup>65</sup> It is an explicit reference to the fundamental nature of equality, as the unequal realization of rights renders them ineffective. An interpretation of a norm that does not command the creation of the conditions of possibility for its own realization could not logically be accepted. If an interpretation allows for a behavior that makes such a right non-realizable, it can only be incorrect and illogical. Or, as passionately put by Hans Kelsen, "an obligation whose content does not include its own realization—what a self-contradiction!—is actually without content; it is no obligation at all."<sup>66</sup>

### *Interpreting socioeconomic rights*

Socioeconomic rights are inevitably distributive, requiring considerations of resource allocation for their realization. In the context of the right to health, the Committee on Economic, Social and Cultural Rights has affirmed that states are under a core obligation "to ensure equitable distribution of all health facilities, goods and services" and that a "failure to take measures to reduce [their] inequitable distribution" is a violation of the obligation to fulfill the right to health.<sup>67</sup> Furthermore, "the suspension of legislation or the adoption of laws or policies that interfere with the enjoyment of any of the components of the right to health" is a violation of the obligation to protect the right to health.<sup>68</sup> The committee also stresses that equality and nondiscrimination address integral components of the right to health.<sup>69</sup> In sum, "the existing gross inequality in the health status of the people, particularly between developed and developing countries, as well as within countries, is politically, socially and economically unacceptable and is,

therefore, of common concern to all countries."<sup>70</sup> Wealth-concentrating austerity that cripples the realization of the right to health is therefore in gross dissonance with states' obligations under socioeconomic rights.

The equal enjoyment of the right to health requires distributive considerations in the realization of this right and refers to more than just a prohibition of unjustified distinctions as safeguarded under nondiscrimination. This distributive interpretation is not limited to the right to health. Equally harshly affected by austerity, the right to social security provides a framework for a distributive interpretation. For Beth Goldblatt, "understanding the right as one of the vehicles to achieve distributive justice gives real effect to the principle of equality within human rights. Providing social security equally requires more than the eradication of status-based discrimination."<sup>71</sup>

Distributive equality can also be read into the right to fair wages, and a minimalistic interpretation of "fairness" as equating a right to a minimum wage has been criticized as failing to acknowledge the right's distributive essence.<sup>72</sup> This was exemplified in the context of the Greek austerity policies, in which the European Committee of Social Rights found the disadvantage suffered by some workers disproportionate when taking into consideration a broader assessment of wage distribution. It stated that "to be considered fair within the meaning of Article 4§1, the minimum or lowest net remuneration or wage paid in the labor market must not fall below 60% of the net average wage."<sup>73</sup> This comparative analysis was also present when reading article 4§1 in light of the nondiscrimination clause of the preamble of the European Social Charter, finding the reduction of wages of persons aged under 25 to be manifestly disproportionate.<sup>74</sup> Similar points have been raised under the right to social security as an inherently distributive provision.<sup>75</sup> It is clear that socioeconomic rights require resource allocation by definition, which, despite allowing for a

progressive (as opposed to immediate) realization, sets concrete obligations as to what must guide realization.<sup>76</sup> While states must progressively realize socioeconomic rights, observance of the principle of equality and nondiscrimination configures an immediate obligation “that requires not merely the proscription of arbitrary differentiation between groups but also the promotion of substantive equality in the enjoyment of rights”—in other words, equality of outcomes between protected groups.<sup>77</sup>

The equality norm, as commanding distribution in the creation of the conditions for the realization of socioeconomic rights, can only reject the presumption of a legitimate public interest in wealth-concentrating austerity. Courts’ and treaty bodies’ reviews cannot ignore distributive equality in determining the legitimacy of these measures, relying merely on an assessment of proportionality or reasonableness. Equality and nondiscrimination is not merely another factor to be balanced against other interests.<sup>78</sup> Only when the principle is reduced to a technical framework of identity-based equality is it possible to sideline distributive equality to the detriment of rights realization. The revitalization of the equality norm seeks, thus, to highlight that such limitation contributes only to a fundamental dissonance between the principles of human rights law and their actualization.

While this revitalized interpretation of the equality norm elucidates the limitations of current human rights law structures, it still requires conceptual development.<sup>79</sup> As exemplified by Gillian MacNaughton’s formulation of a right to social equality, these interpretative elaborations do a good job at demonstrating the presence in the current human rights framework of instruments with the potential for addressing socioeconomic inequalities.<sup>80</sup> In doing so, they act as immanent critiques, demonstrating inconsistencies from a point of view internal to the human rights law framework itself.<sup>81</sup> Highlighting the interdependence of human rights and the foundational nature of the equality

norm points to the right direction in addressing socioeconomic inequality, particularly because it demonstrates that minimalistic interpretations of equality are not a necessity. They do not, however, clarify much about the nature of equality as a norm of international law. Concrete investigations of issues such as austerity may provide an opportunity to imagine if and how the equality norm could be instrumentalized against wealth accumulation.

Naturally, an academic intervention can only suggest a certain reading of the equality norm, and the role of applying it to a concrete case remains with the courts and treaty bodies that are faced with instances of a legal assessment of socioeconomic inequality. If equality is to be revitalized, however, coherence demands that an interpretation which accepts wealth concentration at face value under the guise of neutrality be abandoned. As exemplified by the right to health, although retrogression may be accepted under particular conditions, the *principle* of equality and nondiscrimination cannot be ignored. Beyond an examination of the reasonableness of retrogressions or the proportionality of limitations to equality, austerity can be rejected for the ideology that underlies it. While such a shift in interpretation may raise questions regarding the limits of law in determining economic policies, this rejection does not break human rights law’s neutral approach regarding economic models. To the contrary, it rejects the co-optation of human rights by ideologies that concentrate wealth and exacerbate socioeconomic inequality.<sup>82</sup>

## Conclusion

Austerity measures are demonstrably detrimental to the realization of human rights. While the human rights law framework generally prohibits retrogressions in rights realization, it allows for exceptions based on an unclear and uncritical acceptance of trickle-down economics as a “legitimate public interest.” The principle of equality and nondiscrim-

ination, while increasingly interpreted to safeguard substantive equality, has been significantly limited in its application to socioeconomic matters. In the context of austerity, its interpretation is contained within a peripheral framework of safeguarding particular instances of identity-based equality. Socioeconomic equality, meanwhile, has been widely disregarded as part of the equality framework under human rights law. In this paper, I have elaborated on proposals for a renewed interpretation of the equality norm, considering its possible effects for analyzing austerity. Interpreted as a principle of human rights law, equality and nondiscrimination must inform all aspects of rights realization and not only be invoked within the balancing of interests. Within this reading, the validity of wealth concentration as a legitimate public interest cannot be presupposed. Distributive equality must thus inform the reconsideration of the assumed compatibility between austerity measures and human rights law, overcoming the exclusion of distributive assessments justified through the ideological neutrality of human rights.

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## PERSPECTIVE

# Climate Change and Economic Inequality: Are We Responding to Health Injustices?

THALIA VIVEROS-UEHARA

### Introduction

As climate change increases the prevalence of diseases, morbidity, and mortality, the half of the world's population that still lacks access to quality, affordable, and resilient health care finds it more difficult to prevent, treat, and rehabilitate from such impacts.<sup>1</sup> They, who bear the least responsibility for the greenhouse gas emissions currently warming the Earth's atmosphere—unlike the global richest 10% of the population—are the ones whose health is most compromised.<sup>2</sup> Are we addressing these climate change-related health injustices that economic inequality makes increasingly clear? In this essay, I contend that while current responses to the intricate interplay between climate change and health are well intentioned and crucial, they remain partial and, therefore, insufficient. This is because they focus primarily on reducing greenhouse gas emissions to prevent more frequent and intense climate events (climate change mitigation) while placing health system resilience through development and adaptation as a secondary priority (climate change adaptation).

Such oversight in climate change adaptation still leaves the most egregious health injustices unaddressed, right at our doorstep, as illustrated by the recent onslaught of climate hazards. Just this past October 25, category 5 Hurricane Otis struck the coast of the Mexican state of Guerrero, encountering a scenario devoid of a national adaptation plan.<sup>3</sup> At the national level in Mexico, the number of people without essential health services had risen by 23% between 2018 and 2022 due to budget cuts, while in Guerrero, more than 188,000 people lacked health care access already as of 2018.<sup>4</sup> The hurricane severely damaged over 120 hospitals in Acapulco alone, the state's capital city. This confluence of unfortunate factors—the weather event and the lack of a resilient health system—left 323,000 children in urgent need without adequate care.<sup>5</sup>

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Had Mexico invested in health infrastructure with a view toward adapting for climate change, the devastation wrought by Otis could have been less severe.

With this in mind, I provide an overview of some initiatives currently being undertaken by intergovernmental organizations, states, civil society, and research communities to respond to such health injustices. I conclude not in dismay but with a gesture toward hope in these actors' potential to leverage their agency, foster cross-sector solidarity, and draw on the human rights framework to chart a more transformative course toward a distributive, corrective, and procedural balance in favor of those at the bottom rung of the socioeconomic spectrum.

### Addressing health injustices through climate change mitigation and adaptation

Throughout history, humanity has faced numerous health and environmental challenges that are deeply entwined with economic inequality and associated patterns of social exclusion.<sup>6</sup> Commentators have noted that the wealth generation of the affluent has come at the expense of the environment and the climate system.<sup>7</sup> Better-off individuals in income and wealth, benefiting primarily from an extractive and greenhouse gas-emitting economic model, have access to the means and circumstances that lead to better health outcomes.<sup>8</sup> Meanwhile, the less affluent—especially historically marginalized groups such as children, women, and racial and ethnic minorities—bear the health repercussions of the environmental devastation and climate system alteration stemming from wealth generation.<sup>9</sup> These health injustices are compounded by these populations' limited resources and the discrimination they face, resulting in markedly worse health outcomes.<sup>10</sup>

In facing such health injustices, history has also shown us that the agency and cross-sector solidarity of change agents, harnessing the potential of

the human rights framework, can greatly facilitate the distributive, corrective, and procedural scales of justice in favor of the less affluent.<sup>11</sup> These transformative efforts involve ensuring the availability of accessible, acceptable, quality, and resilient health care services for everyone (corrective justice), within the flow of resources toward populations that lack them (distributive justice), and fostering the participation of affected individuals and groups in decision-making (procedural justice).<sup>12</sup>

At the heart of the health injustices spurred by the climate crisis lies a highly differentiated gradient of vulnerabilities among populations.<sup>13</sup> As illustrated by the seminal work of the late epidemiologist Anthony McMichael, these asymmetries are determined primarily by two factors: exposure to climate-related hazards (extreme or slow-onset climate events) and the social infrastructure in place to withstand the effects of such events (sensitivity of each group).<sup>14</sup> Both factors entail several determinants that are conducive to the enjoyment of the right to health. On the one hand, the environmental determinants crucially include a safe climate—a component of a healthy environment.<sup>15</sup> On the other hand, the social determinants encompass health infrastructure that is essential for populations to prevent, treat, and recover from climate-related diseases, primarily through health care facilities.<sup>16</sup>

Therefore, a transformative response to the health injustices exacerbated by climate change—the topic of a special section on health rights and the urgency of the climate crisis published in this journal two years ago—involves at least two aspects related to both environmental and social determinants.<sup>17</sup> First is mitigation, which entails reducing the greenhouse gas emissions that are warming our atmosphere and leading to an increased frequency and intensity of climatic events. Second, as the United Nations High Commissioner for Human Rights underscores, is the need to build resilient health care systems as a form of both adaptation and development.<sup>18</sup> This latter is particularly imper-

ative for the half of the world's population currently lacking access to such services, a deficiency acutely impacting historically marginalized populations—such as women and racial and ethnic minorities experiencing widespread discrimination.<sup>19</sup>

Which of such aspects (mitigation and adaptation and development), then, are incorporated in the responses to the intricate interplay between climate change and health by change agents such as intergovernmental institutions, courts, civil society, and research communities?

### Intergovernmental organizations

The international climate change regime, under the United Nations Framework Convention on Climate Change, has enacted several instruments with the dual aims of (1) mitigation, to prevent our planet from warming beyond 2°C—ideally, even beyond 1.5°C above preindustrial levels—and (2) adaptation, to increase the ability to adapt to the adverse impacts of climate change. However, it was only in 2010 at the 16th session of the Conference of the Parties (COP) that countries were urged to formulate national adaptation plans inclusive of health considerations.<sup>20</sup> Moreover, it was not until the 2015 Paris Agreement that the regime recognized the importance of human rights, including the right to health.<sup>21</sup> As of 2021, only 49 countries reported having a health national adaptation plan, whereas of the more than 190 submitted nationally determined contributions (NDCs), 63% set health adaptation priorities.<sup>22</sup> While there has been no comprehensive assessment on how well national adaptation plans or NDCs align with the human rights framework, preliminary observations on the former suggest a prevailing lack of consideration by countries to prioritize bridging existing gaps in access to affordable, quality, and resilient health care services for marginalized populations currently without it.<sup>23</sup>

The World Health Organization has been

pivotal in addressing the current gap within the Framework Convention on Climate Change relating to adaptation and development in health. Since 2008, it has released a series of initiatives and publications to assist countries in planning toward these goals.<sup>24</sup> At COP26 in 2021, the World Health Organization fostered political momentum to formalize the Alliance for Transformative Action on Climate and Health, aiming to construct climate-resilient and sustainable health systems.<sup>25</sup>

Increasingly, intergovernmental organizations are beginning to prioritize adaptation and development within the climate change-health nexus, akin to their efforts with mitigation. In October 2023, the COP27 presidency launched the health pillar of the Sharm El Sheikh Adaptation Agenda.<sup>26</sup> A key area of this pillar's work is to build the resilience of health systems and health care facilities, ensuring quality health care amidst a changing climate.<sup>27</sup> Moreover, for the first time in international climate negotiations, a Health Day will be observed at the upcoming COP28 in Dubai this December 2023, with discussions set to focus on climate-resilient health systems and health adaptation as central themes.<sup>28</sup>

### Courts

At the country level, the human rights framework can be particularly influential in countries with monist constitutions that recognize the right to health and have open clauses regarding international human rights law, yet where health care systems have recently been weakened at the expense of the most vulnerable.<sup>29</sup> The recent surge in climate change litigation in Latin American countries seems to offer a prospect in this regard. However, in this region, while half of such lawsuits rely on the right to health to influence judicial decision-making, the remedies provided thus far are seldom distributive or corrective.<sup>30</sup> They typically mandate reductions in greenhouse gas emissions (mitigation) but do

not go so far as to require the provision of resilient health care services (adaptation and development) to the vulnerable communities bringing these claims—communities that confront both the risks of climate change or climate change-inducing industrial activities and the historical neglect of this key social determinant of health.<sup>31</sup>

### Civil society and the health sector

Health Care Without Harm, Alianza Médica contra el Cambio Climático (Medical Alliance against Climate Change), the 2018 call of the International Council of Nurses, and the Global Climate and Health Alliance (GCHA) represent a still small but growing number of civil society initiatives aiming to address climate change and health concerns simultaneously. The first two focus primarily on strengthening the mitigation potential of the health care sector by advocating for a reduction in its environmental footprint.<sup>32</sup> Similarly, while the International Council of Nurses acknowledges the importance of the quality and availability of health care in reducing existing health vulnerabilities, its recommendations emphasize environmental impact reductions instead of the health care deficiencies exacerbated by economic inequality.<sup>33</sup>

Meanwhile, GCHA's overarching vision centers on health as a driver for climate change mitigation, based on the well-acknowledged fact that reducing greenhouse gas emissions can yield "health co-benefits" globally.<sup>34</sup> The GCHA incorporates this critical vision into its evaluation of countries' NDCs, focusing on actions within the health sector.<sup>35</sup> It evaluates whether countries have completed a vulnerability and adaptation assessment or initiated resilience and preparedness planning, paying particular attention to health care.<sup>36</sup> Initiatives like this could substantially benefit from incorporating a human rights lens—for example, by broadening the assessment criteria not

only to ensure compliance with planning but also to illuminate crucial aspects of the substance of the plans along the distributive, corrective, and procedural dimensions of justice. This includes a focus on availability, accessibility, acceptability, quality, and resilience, especially through the participation of socially excluded populations.<sup>37</sup>

### Research communities

In September 2021, just a few months before COP26 took place in Glasgow, 260 journals, predominantly in the medical field, simultaneously published an editorial.<sup>38</sup> They called for wealthy nations, which have contributed disproportionately to the environmental crisis, to give more to support low- and middle-income countries in building "cleaner, healthier, and more resilient societies."<sup>39</sup> While this call placed equity at the center of the global response and highlighted the need to support the redesign of health systems, its focal point was the need to keep the global temperature rise below 1.5°C—that is, mitigation—to protect public health.<sup>40</sup>

The research community has also begun exploring the potential of strategic litigation in the realm of public health and climate change. In October 2021, the European Public Health Association co-hosted a dialogue emphasizing the crucial role of health care professionals in gathering and documenting evidence in medical files, which can subsequently be utilized in climate litigation to urgently challenge CO<sub>2</sub> emitters.<sup>41</sup>

Both highly visible scholarly initiatives focus solely on climate change mitigation. However, balancing these efforts toward climate change adaptation, more recent endeavors are increasingly emphasizing the importance of building resilient health systems. For instance, the Wellcome Trust's Climate Impacts Awards funding scheme, launched just this year, supports interdisciplinary research aimed at addressing the needs of populations most

at risk from the health impacts of climate change.<sup>42</sup> Additionally, in August 2023, the Centre on Law and Social Transformation at the University of Bergen, in collaboration with the Bergen Centre for Ethics and Priority Setting in Health, fostered a global academic exchange on ways to ensure fairness and effectiveness in health systems in the context of inequalities and climate change.<sup>43</sup>

## Conclusion

While the synopsis of initiatives provided by this essay is by no means comprehensive, I have tried to set forth an initial barometer on such responses. Current initiatives' focus on climate mitigation, while crucial, is insufficient on its own. The urgent provision of accessible, acceptable, quality, and resilient health care to the 3.5 billion people in the world who need strengthened prevention, treatment, and cure is rarely advocated for, yet they are the most at risk of health impacts from climate change. If the climate change-health agenda advocates *solely* for emissions reduction or the improved carbon footprint of *existing* infrastructure, it will predominantly benefit the income groups that already have access to adequate quality health care and are thus able to better withstand the health impacts of climate change.

The recent momentum of health in climate change adaptation, as seen through initiatives such as the Sharm El Sheikh Adaptation Agenda and COP28 Health Day, becomes even more promising when paired with the transformative potential of cross-sector solidarity and the human rights framework, as history has demonstrated. Addressing the health injustices stemming from the intertwined crises of climate change and economic inequality is an “all hands on deck” endeavor, aiming to redistribute resources, compensate those affected, and empower the voiceless. Indeed, intergovernmental organizations, states, civil society, and research communities all play a vital role in this effort, with

their agency, collaboration, and use of the human rights framework being profoundly instrumental.

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## PERSPECTIVE

# Pharmaceutical Patents and Economic Inequality

THOMAS POGGE

A human right is realized when all persons have secure access to its object, to what this right is a right to. States and particularly governments have a responsibility to make this happen—principally by not taking measures that prevent such secure access. Governments currently award and enforce 20-year product patents on pharmaceuticals in accordance with the TRIPS Agreement they included in the 1995 founding treaty of the World Trade Organization.<sup>1</sup> Patent enforcement involves preventing generic manufacturers from offering patented medicines at competitive prices. So protected from competition, patented medicines are often sold with exorbitant monopoly markups that effectively deprive many poor patients of access to them.

It is true that governments, in their 2001 Doha Declaration, explicitly declared that their “Agreement can and should be interpreted and implemented in a manner supportive of [World Trade Organization] members’ right to protect public health and, in particular, to promote access to medicines for all.”<sup>2</sup> But these words did not result in universal access to important new medicines—far from it.

In 2013, an important hepatitis C drug, sofosbuvir, was introduced by Gilead Sciences in the United States at a price roughly 3,000 times its variable cost of production—US\$84,000 per course of treatment—and at lower but similarly unaffordable prices in poorer countries.<sup>3</sup> Five years after its introduction, only about 7% of the 71 million persons living with hepatitis C had been treated.<sup>4</sup> The others continued to suffer—and to spread the disease. Many who catch hepatitis C nowadays would not have done so if the new drug had reached a larger percentage of the relevant patient population. Insofar as patients suffer or die because willing and able generic manufacturers are prevented by law from selling them the medicines they need for their grave diseases, the governments that adopt and enforce these laws are arguably violating the patients’ human rights.<sup>5</sup>

It is true that Egypt could and did reject Gilead’s patent application, finding that sofosbuvir lacks novelty and inventiveness. It is true that Malaysia could and did issue a compulsory license permitting generic production of sofosbuvir for domestic consumption. It is true that the world’s “least developed

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countries” are not required to grant patents on new pharmaceuticals and, lacking domestic manufacturing capacity as they do, may ask a capable state to issue a compulsory license for export to them—though the required process is so cumbersome that it has been used only once in the last 20 years, when Canada licensed its firm Apotex to deliver three batches of anti-HIV/AIDS combination therapies to Rwanda.<sup>6</sup>

While the so-called TRIPS flexibilities *could* be used to substantially improve access by poor people to new medicines, they are not in fact so used. One key reason for this is that weaker states are reluctant to risk sanctions imposed upon them by powerful pharmaceutical firms and their even more powerful governments. For example, the Office of the US Trade Representative issues *Special 301 Reports* that place states on a Priority Watch List if they are deemed insufficiently supportive of US firms’ legitimate business interests, prominently including their intellectual property rights.<sup>7</sup>

It should also be mentioned that some pharmaceutical firms have licensed important new pharmaceuticals for generic production in some poorer countries. Gilead has done this with sofosbuvir. But understandably, these voluntary licenses do not include “the majority of middle-income countries, where most of the hepatitis C burden lies. For example, Argentina, Brazil, China, Georgia, Iran, Mexico, Peru, Turkey, and Ukraine are all excluded from Gilead’s voluntary license.”<sup>8</sup>

That poor people overwhelmingly lack access to new medicines is a foreseeable effect of our globalized innovation regime, which makes innovators reliant on monopoly markups and therefore highly motivated to prevent low-priced sales of their proprietary pharmaceuticals. Originators plausibly fear that such sales would undermine their income from selling their product to the rich and well insured at hundreds, even thousands, of times the cost of production. And they have no chance to earn meaningful profits from sales to

the poor, seeing that 42% of the human population—well over three billion people—are so poor that they cannot even afford a healthy diet valued at the purchasing-power equivalent of US\$3.66 per person per day on average.<sup>9</sup>

In the case of infectious diseases, patents provide an additional incentive to price medicines out of the reach of less affluent patients, as doing so keeps the target disease alive, thereby ensuring future demand. If sofosbuvir were universally accessible, the incidence of hepatitis C, and hence demand for its cure, would dwindle fast. Thus, a patent-holding firm profits even from those who cannot afford its product, as they infect others who can. That pharmaceutical firms have this incentive is not a criticism of them. It is an indictment of the innovation regime our governments are upholding in our names. This regime is not merely unjust by excluding the poor but also counterproductive by undermining population-level strategies to contain, suppress, and eradicate infectious diseases.

It is worth noting that patent incentives would work poorly in the pharmaceutical sector even if extreme poverty were eradicated. In ordinary markets, as people become more affluent, more of what they need is supplied by competing producers and sellers at prices near the variable cost of production—diets improve. With an important patented medicine, by contrast, the single seller finds it profitable to raise the price in response to rising ability to pay, ensuring continued exclusion of the less affluent. Here the proportion of patients that it is optimal to exclude depends on the shape of the demand curve. If a minority is much richer than the rest, this demand curve can be highly convex and the profit-maximizing price may then exclude a large majority of the patient population, as happened with sofosbuvir. The patentee rationally sacrifices sales to most potential buyers because lowering its sales price would entail an earnings loss from reduced markup exceeding the earnings gain from increased sales volume. Given large financial

inequalities, both globally and in most countries, patented medicines routinely exclude most of the patients who need them. These inequalities would continue to aggravate the human rights impact of pharmaceutical patents even if all incomes worldwide were to double or quadruple. Even in an affluent population, patents on an important product that has no close substitute will exclude the hindmost—in sharp opposition to the “Leave No One Behind” motto of the Sustainable Development Goals. As pharmaceutical patents deepen the impact of financial inequality by cutting many patients off from the medicines they need, so greater financial inequality—reflected in a more convex demand curve—broadens exclusion from patented medicines.

### Replacing patents with impact rewards

Universal access to new medicines could be achieved through a global buyers’ alliance—including national health systems and insurers—which would tell each originator how much it can charge various kinds of buyers for its product. Such an alliance could effectively dictate prices, as the originator’s sole alternative would be to take a loss on its entire R&D investment. But such a monopsony would greatly reduce pharmaceutical R&D: investors would not spend billions on developing important new medicines if their return were wholly at that alliance’s discretion. Is there a feasible regime that would ensure the profitability of pharmaceutical R&D without the massive human rights denials entailed by monopoly patents?

Years ago, Aidan Hollis and I proposed that a coalition of willing countries should institute a Health Impact Fund as an optional scheme of impact rewards, to be paid through preannounced large annual disbursements divided among important new medicines according to health gains achieved with them in the preceding year.<sup>10</sup> Each invention would partake in 10 such distributions

and then go generic in its 11th year. The number of new pharmaceuticals entering the scheme each year would depend on the size of the annual disbursements. With, say, 12 pharmaceuticals entering the scheme each year, replacing a similar number exiting at the end of their reward period, the scheme would consistently support about 120 important new medicines with each disbursement. In such a scheme, important new medicines would be instantly available at competitive or even lower prices. Yet pharmaceutical R&D would still be reliably incentivized—and more broadly than at present: by valuing the health and survival of all human beings equally, the scheme would finally create strong incentives to develop remedies against the heretofore neglected diseases concentrated among the poor, such as tuberculosis, malaria, hepatitis, HIV/AIDS, pneumonia, meningitis, diarrhea, and many tropical diseases.

Though such an impact reward scheme might eventually be financed from its own endowment, it would require substantial state funding in its early years. But it would also generate large cost savings for taxpayers through much lower drug prices and much better health around the world. If pharmaceutical firms were paid for achieved reductions in disease incidence, they would be highly motivated to include even the poorest people in a population-level strategy of fighting diseases to extinction. Thus, Gilead Sciences would have found it profitable to invest in diagnostic efforts to identify hepatitis C patients around the world and to ensure they have access to a full course of treatment with proper instructions and adherence support to forestall the emergence of drug resistance.

Because it would largely avoid the wasteful expenditures now typical of the pharmaceutical sector—costs for patenting and associated litigation, economic deadweight losses, and costs arising from corrupt marketing practices and counterfeiting—an impact reward scheme would not require increased fund flows into the pharmaceutical

sector. But it would greatly raise the share of such funding devoted to R&D and effective delivery and—partly thereby—greatly improve this sector’s efficiency and human rights record.

The described impact reward scheme improves in five main ways upon innovation prizes and other pull mechanisms, such as advance market commitments.<sup>11</sup> It constitutes a structural reform, establishing stable and predictable long-term innovation incentives. It lets innovators, who know their own capacities best, decide which innovations to pursue across the whole range of disease areas. It avoids having to specify a precise “finish line,” which is difficult to get right in advance, and instead rewards each registered innovation according to the benefits produced with its deployments. It avoids having to specify a reward-for-benefit rate, which instead evolves endogenously through market forces. It gives innovators strong incentives also to promote (through information, training, technical assistance, discounts, and so on) the fast, wide, effective diffusion of their registered innovations.

Two ways in which an impact reward scheme would help realize human rights are distinctly egalitarian. By ensuring that important new medicines are immediately available at competitive prices and that their effective delivery is well rewarded, it would ensure that even impoverished and remote populations have access to such treatments. And by rewarding health gains regardless of patient finances, it would greatly intensify investments in combating the heretofore neglected diseases of poverty.

In addition, an impact reward scheme would massively reduce the overall disease burden by incentivizing pharmaceutical firms to fight diseases at the population level, aiming for their containment and extinction. Finally, it would also avoid the destructive effects of exorbitant monopoly markups, such as massive efforts at regulatory capture toward preserving and extending the flow of monopoly rents (exemplified by efforts to stall US

Food and Drug Administration action on Vioxx), widespread misprescribing induced by kickbacks to health care professionals, and intense efforts to sell unsuitable drugs to vulnerable populations (as evidenced in the US opioid crisis which—fueled by high markups that would disappear if profits were proportioned to health gains achieved—is now killing some 100,000 people annually).<sup>12</sup>

### Understanding economic inequality

It is noteworthy that the two egalitarian advantages of impact rewards are invisible in conventional economists’ understanding of economic inequality. According to this understanding, any measure of economic inequality must be based on information solely about the distribution of income and wealth—including non-money items such as real estate, home-grown foodstuffs, and public services, all valued at local prices. A general change in prices or product availabilities does not affect economic inequality; such data are excluded from the informational base of inequality measures. Thus, if an important medicine goes off-patent, becoming much cheaper, inequality remains unchanged because purchasing power is deemed irrelevant to measuring economic inequality based on income or wealth.

Though the conventional economists’ view seems self-evident, it can be challenged with this highly simplified example involving two persons and two commodities. The rich person has \$1,000 a month and spends \$200 on necessities and \$800 on discretionaries. The poor person has \$100 a month and spends \$80 on necessities and \$20 on discretionaries. Now necessities become 25% more expensive and discretionaries 20% cheaper. The rich person can consume as before, spending \$50 more on necessities and \$160 less on discretionaries, for new monthly savings of \$110. The poor person must adjust—for example, by spending \$92 on necessities and \$8 on discretionaries (reducing

consumption by 8% and 50%, respectively). It seems that the rich person has become economically better off because she can consume the same amount of both necessities and discretions and actually saves \$110 under the new price scheme, while the poor person has become worse off because she must consume fewer necessities and fewer discretions. This would imply that economic inequality between them has widened.

Conventional economists refute this conclusion by insisting that income inequality has remained unchanged at 10-to-1: what matters is not what people happen to buy but what they *can* buy, their option space. For any basket of necessities and discretions the rich person can buy, the poor person can buy a corresponding basket one-tenth its size. The price changes leave this fact unchanged.

This reasoning ignores, however, that some consumption patterns are feasible for the rich but infeasible—indeed fatal—for the poor person. The latter must maintain a certain minimum consumption of necessities to ensure survival, the most basic imperative of *homo oeconomicus*. What seems paradoxical to conventional economist doctrine is then true nonetheless: a drop in the price of necessities reduces not merely poverty (by increasing the purchasing power of money) but also economic inequality.

While I have presented the argument in diachronic terms, it can be restated in synchronic terms to show how prices can be relevant to comparing economic inequality across two populations or indeed two possible futures of the same population. If our governments had established impact rewards rather than monopoly markups as rewards for important pharmaceutical innovations, global and national economic inequality would be substantially lower even if the distribution of (monetized) income and wealth were exactly what it is now. To be sure, that better choice would in fact have resulted in more egalitarian distributions of

income and wealth, as well as a much smaller global disease burden with consequent higher income and wealth across the board.

### Self-reinforcing economic inequality

How then did we end up with such a toxic regime for rewarding important pharmaceutical innovations, one that persistently harms and kills millions of people around the world?

Before TRIPS, poorer states generally imposed only weak patent protections. India was the “pharmacy of the world” because its ingenious generic manufacturers could typically, by finding a different way of making a newly patented drug, invent around its Indian seven-year process patent and then supply it legally to patients in India and in other developing countries with similarly permissive patent laws. By adopting a globally uniform regime of strong 20-year product patents, governments ended this life-saving opportunity, enabling pharmaceutical innovators to collect substantial monopoly rents from affluent patients in the Global South with the foreseeable side effect of excluding much larger numbers of patients from patented medicines altogether.

The TRIPS revolution thus highlights the following two further links of patents to economic inequality. In the pharmaceutical sector especially, innovations require substantial investments. Rich people and organizations therefore have a large advantage in reaching important innovations first. Strong patents enable them to charge road tolls from others. TRIPS globalizes these road tolls, creating substantial financial flows from poorer to richer countries and thereby entrenching and exacerbating international inequality.

Why then did developing countries sign up to TRIPS? World Trade Organization membership offered them “most favored” access to the much larger markets of the richer countries. The affluent states used the greatly superior bargaining power

derived from their much greater wealth to extract a concession, TRIPS, that would help them stay ahead. The highly inegalitarian TRIPS Agreement bears the imprint of, and perpetuates, an extreme international disparity of economic power that was unjustly accumulated through a period of extreme violence, with enslavement, genocide, and colonialism.

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# The Legal Determinants of Scarcity: Expanding Human Rights Advocacy for Affordability of Health Technologies

LUCIANO BOTTINI FILHO

## Abstract

Recognizing law as a determinant of scarcity in health care is vital. This paper underscores the need for a comprehensive approach to manage scarcity beyond intellectual property, using targeted regulations to promote affordability and counter market distortions. I argue that relying on law solely to ensure democratic deliberations for resource allocation overlooks market failures and economic inequalities that contribute to scarcity. I examine different “legal determinants of scarcity” that can be used, on the basis of the right to health, to improve or positively influence the availability and affordability of health technologies through complementary policies such as direct price control, competitive procurement, competition laws, and public-private partnerships. I conclude by asserting that health care affordability must be a central positive human rights obligation in economic and health policies and that states must strive to diversify their approaches to eliminate persistent economic barriers.

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## Introduction

In global health, the burden of scarce resources has been a dominant discourse to justify differential treatment among patients with different health care needs.<sup>1</sup> In the name of scarcity, policy makers have to prioritize, and they prefer interventions that attain thresholds of cost-effectiveness and value considerations. Consider, for instance, patients in need of dialysis: due to the prohibitive costs of dialysis, health economists recommend that most health systems deprioritize this group of patients, generally forcing lower-income countries not to invest in this therapy; meanwhile, such rationing for dialysis is less frequent in wealthier states.<sup>2</sup>

The notion of scarcity has driven selective exclusions in the allocation of health care, but this is a reality that may be remedied by political choices.<sup>3</sup> Under the International Covenant on Economic, Social and Cultural Rights (ICESCR), states are obliged to use the best of their capabilities to maximize resources and pursue policies that promote the affordability of health care.<sup>4</sup> That includes not only existing budgets and financial resources but any other available measure, including legislation, to enable the progressive realization of rights.<sup>5</sup> This positive obligation is effective even in the context of extreme scarcity, such as public health emergencies, where states need to adapt policies to use all their capacity, including the authority to regulate private actors to respect, protect, and fulfill the right to health.<sup>6</sup> In addition, efforts to fulfill the right to health must be designed in accordance with human rights standards, such as affordability (or economic accessibility, a subcomponent of the long-accepted right to health framework of availability, accessibility, acceptability, and quality).<sup>7</sup>

However, human rights scholars (notably within this very journal) have framed the right to health as a right to a fair deliberation about the resources that exist in a given moment, and not primarily as a way to redress unfair market conditions that are the very reason that health systems

are forced into painful resource dilemmas.<sup>8</sup> To shift from scarcity determinism, this paper articulates the notion of “legal determinants of scarcity” in health care and how such determinants should be harmonized with a socioeconomic rights framework that places affordability (or lower costs) at the center of health care policymaking in access to health technologies (e.g., vaccines, medicines, medical devices, and other health products). By “legal determinants of scarcity,” I mean laws that influence, whether positively or negatively, a policy for resource availability (e.g., taxation) or that serve as a precondition for a policy that can minimize scarcity (e.g., a competitive procurement system that is not prescribed by law).<sup>9</sup> This concept could be applied to other economic factors in health care scarcity that are manageable through regulation (e.g., availability of the workforce, organ donations, or access to telemedicine), but this paper will examine only health technologies, where intellectual property (IP) normally remains at the center of human rights debates.

For general economic and social rights practitioners, the goal of resource mobilization and affordability may sound more intuitive, but in the global health and human rights community specifically, this stance is not common. Lawrence Gostin et al. have argued that legal determinants of health involve laws focusing primarily on public health outcomes and not exactly on the generation of more resources, so reframing them with an economic and social rights framework is useful for departing from the scarcity mindset and enhancing advocacy efforts.<sup>10</sup> Gostin et al.’s concept of legal determinants of health consists of any legal instrument that can be used against the “underlying social and economic causes of injury and disease,” but the economic reasons for low levels of access to health care and health technologies that undermine population health, including market failures and poor price control, do not have a dominant place in their agenda.<sup>11</sup> Although the Lancet Commission’s main

report on the legal determinants of health does briefly mention public-private partnerships (PPPs) and IP issues, the reference is made within the context of law and governance and not primarily in order to dismiss unnecessary rationing.<sup>12</sup> In general, scholars have not fully addressed the options available for improving affordability other than promoting exceptions or “flexibilities” to patents, even though affordability is mentioned as one objective of the legal determinants.<sup>13</sup>

With a rhetoric that unconditionally accepts scarcity rather than challenging it, the World Health Organization report *Institutionalizing Health Technology Assessments: A How to Guide* seems to be incompatible with the progressive realization of economic and social rights. The guide provides recommendations in which rights are regarded as troubling advocacy tools that may derail priority setting and in which public laws should instead be used mainly for ensuring compliance with rationing decisions.<sup>14</sup> Under this skeptical view of the transformative power of human rights, the right to health is not “universal” and should be limited to just “a reasonable set of public services.”<sup>15</sup> Nothing in the report examines how law can also be a determinant of affordability and resource mobilization during priority setting. Similarly, the World Health Organization report on value-based health care falls short of presenting affordability as a main pillar of access to health care and focuses more on the quality, cost-effectiveness, and equitable distribution of a set of patient-oriented health benefits packages.<sup>16</sup>

To counter this narrative, we must reframe law as a determinant of health by embracing an economic and social rights approach against the mantra of scarcity in global health. Thus far, the closest advocacy around legal determinants of scarcity has been tied to the IP regime, where there is an established record of human rights mobilization. Yet patents are not the only reason that health care is unaffordable. Realizing the right to health

must include other policies beyond exceptions to patents, despite the challenges inherent in building rights claims around complex economic processes of market regulation. To this end, this paper explores some key complementary policies that have been underemployed as part of states’ obligation to maximize resources established by article 2 of the ICESCR, identifying a range of legal determinants of scarcity (beyond IP laws) that influence the price of health technologies. These complementary policies, which are listed in the 2020 *WHO Guideline on Country Pharmaceutical Price Policies*, are direct price control, price negotiation and contractual mechanisms, competition laws, and PPPs.<sup>17</sup>

Below, I begin by exploring the need to broaden the scope of the legal determinants of scarcity in areas other than IP. I then illustrate the application of legal determinants of scarcity, demonstrating their capacity to be accepted as a human rights concern in areas such as price control, procurement, competition laws, and PPPs.

## The disproportionate attention to IP advocacy

Traditionally, to address concerns of affordability and maximum resources, human rights scholars have advocated for the reform of domestic and international IP laws.<sup>18</sup> This section will demonstrate that policy makers and patients should explore other routes such as those listed in the World Health Organization’s pharmaceutical policy guidance, including price control and procurements laws.<sup>19</sup> This section argues that legal determinants of scarcity are indirect or circumstantial to health affordability. Therefore, they are not a guarantee of affordability of health care; instead, they have to be carefully customized among many options to minimize potential downsides.

To begin, the dissatisfaction with IP laws among human rights practitioners has been evident since the 2000s, with General Comment 14

and the United Nations Sub-Commission on the Promotion and Protection of Human Rights' subsequent resolution on intellectual property rights and human rights, followed by a continuous cycle of other similar texts issued at the United Nations level reiterating the need to flexibilize IP laws in the face of health needs.<sup>20</sup> A similar discussion followed with respect to article 15(1)(b) of the ICESCR (access to science), which, it can be argued, prevails over patent holders' rights to property.<sup>21</sup>

Accordingly, the overdominance of IP as a barrier to realizing the right to health is equally salient in international political dialogues on drug affordability. During the United Nations Secretary-General's High-Level Panel on Access to Medicines, most of the external submissions revolved around IP policies. Exceptions were some allusions to competition laws, negotiation power, and local product development.<sup>22</sup> France complained about the IP focus of the consultation procedure, affirming that "by reducing the scope ... the panel significantly limits its methods and conveys a limited interpretation of issues affecting access to medicines."<sup>23</sup> The Secretary-General's final report also places a strong emphasis on IP, as if all costly drugs were the result of the failures in IP regimes. Alternative policies are seen only in terms of permissible measures to supplement the patent system (for instance, raising competition issues as a subfield of the regulation of non-patented drugs).<sup>24</sup>

Few at the United Nations level have linked other policies to laws that promote affordability more holistically. In a major exception to the IP focus, former Special Rapporteur on the right to health Anand Grover produced, in 2013, one of the most comprehensive reviews of the alternative policies open to states to ensure the affordability of medicines, mentioning direct interventions in the market such as price control and competition laws.<sup>25</sup> However, the report falls short of indicating that there is an immediate obligation to reform leg-

islation or regulatory frameworks on other forms of price control, as human rights practice has required for IP laws. Disappointingly, human rights discourse remains narrowly focused on IP. For instance, in the aftermath of the COVID-19 pandemic, calls from human rights bodies have been focused mainly on relaxing IP rules to promote access to new vaccines and drugs.<sup>26</sup>

This dogmatic vision does not recognize that, in many cases, supporting legal tools should be introduced. Empirically, IP flexibilities—exceptions to IP provisions for public health reasons, such as compulsory licenses of patented pharmaceuticals or parallel imports of generic versions—may not bear fruit.<sup>27</sup> In the case of compulsory licenses, such a measure has succeeded in only a few cases, predominantly for HIV treatments (and without comparing what could be achieved by a combination of other policies).<sup>28</sup> To make matters worse, compulsory licenses may result in negative impacts on affordability, despite frequent support from academics.<sup>29</sup> Ideally, just signaling the possibility of a compulsory license can persuade a producer to cut prices, particularly where countries already benefit from local industrial power or have access to external generic makers.<sup>30</sup> In practice, research has shown that the potential discounts are not as great as when there is a combination of other policies (as experienced by countries with the highest savings, particularly when producing locally is more expensive than procurement abroad).<sup>31</sup>

These hurdles are even more challenging for developing countries, where human rights advocacy has persistently warned against IP laws. For the poorest countries, economic models often predict that instruments such as compulsory licenses will not be successful. Pharmaceutical companies and exporting states can exercise political pressure for IP implementation or, in the case of suppliers, blackmail a country with market withdrawal or exclusion from new research.<sup>32</sup> Examples of proposed

compulsory licenses that in fact generate price reductions are generally from countries that are able to threaten the patent holders with local production or another supplier.<sup>33</sup> Countries without access to products manufactured in the Global South may be left with the only alternative of the Doha Declaration to import from high-income producing countries (with Rwanda being reportedly the only case of that so far).<sup>34</sup>

### Frontiers of law to challenge scarcity as a barrier to realizing the right to health

Access policies for health technologies imply some legal basis and do not operate outside the scope of law, administrative authorizations and competencies to control excessive prices.<sup>35</sup> Some of these legal determinants of scarcity arise in the price environment and not at the research and development (R&D) and patents level, where human rights scholarship is traditionally focused.<sup>36</sup> For instance, the unaffordability of patented and non-patented products requires intervention in the pricing environment (the moment at which technology producers set their prices or profits).<sup>37</sup> Some of these regulations are “semantic flexibilities,” measures allowed in the IP regime under domestic laws or not specifically prohibited by the Agreement on Trade-Related Aspects of Intellectual Property Rights (e.g., price controls or a doctrine prohibiting excessive prices).<sup>38</sup>

This section reviews some of those complementary frameworks found in the *WHO Guideline on Country Pharmaceutical Price Policies*, such as direct price control, price negotiation and contractual mechanisms, competition laws, and PPPs.<sup>39</sup> These represent neglected areas that have rarely been addressed as a right to health concern. The conceivable right to health advocacy may vary for each policy at hand: some advocacy efforts could focus on judicial interpretation (e.g., competition

laws), while others might be more conducive to extrajudicial campaigns, legislative action, and political influence to establish an adequate regulatory environment for promoting access to health technologies (e.g., PPPs).

#### *Direct price control*

An intuitive tool that can be incorporated by human rights advocacy is to call for laws and regulations that directly control pharmaceutical prices. This intervention consists of regulatory techniques generally used for pharmaceutical markets, but price controls can be used for any aspect of health care, including health insurance. Even in the United States, which embraces a predominantly free-market model, there are laws to protect the uninsured from overcharges in hospitals.<sup>40</sup> Many countries have introduced price regulation through different legal formulae and institutions: some have national agencies mandated with dictating the prices of patented drugs (e.g., Brazil and Canada), and others also have arrangements at the regional level (e.g., Canada, with a coordinated generic price control).<sup>41</sup> For pharmaceutical products, the two most common forms of price control are price markups (or price caps) and reference pricing, which imposes values of reimbursement for different categories of drugs to stimulate lower spending for health services or to induce the industry to mark down its products.<sup>42</sup>

Given the nature of international obligations (which ordinarily adopt a state-centered approach), it would be subject to debate how much human rights could be effectively employed to enforce direct price control on private for-profit pharmaceutical companies (though, as mentioned before, states must deploy their regulatory power to maximize resources). However, there are possible legal pathways through local jurisprudence and constitutional developments that could serve as a lesson and inspiration for future activism. In contrast

to international law, some jurisdictions impose horizontal obligations on private actors, providing a legal opportunity to invoke the right to health against excessive prices.<sup>43</sup>

One record of a more progressive usage of the right to health in private contractual relations to enforce price control is a line of jurisprudence built by the Brazilian Supreme Constitutional Court. In awarding an interim injunction to suspend the increase of up to 40% for private health insurance under new regulations of the national health insurance agency, Justice Carmen Lúcia stated in 2018 that “healthcare is not a commodity,” “life is not a business,” and “dignity is not profit.”<sup>44</sup> Similarly, Justice Marco Aurélio intervened in 2018 against excessive price readjustments for elderly users of private health insurance as a practice incompatible with the right to health under the domestic constitutional system. He noted that private contracts are governed by the right to health, and thus the state may exercise its regulatory power to pursue public interests: “Health promotion, even in the private sphere, is not linked to profit assumptions ... The health insurance lucrative market cannot flaunt the importance of this social service, recognized in Article 197 (right to health).”<sup>45</sup>

The effectiveness of price control policies in promoting health technologies may depend on their careful management. For instance, in 2016, the Colombian Constitutional Court rejected a constitutional complaint against a national statute that empowered the government to regulate the prices of health care products, deeming such regulations consistent with the right to health.<sup>46</sup> Nevertheless, Colombia’s experience with price regulation has yielded mixed results. While pharmaceutical costs have decreased by 43%, there has been a doubling of government public health expenditures through more purchases.<sup>47</sup> The success of price regulation may hinge on factors such as thoughtful drug administration but can equally depend on more resources to meet an extraordinarily pent-up de-

mand of previously neglected patients. The positive impact can vary depending on the specific drug, as seen in the case of over-the-counter contraceptives in Colombia, where price regulation has led to improved access.<sup>48</sup>

### *Negotiation and procurement*

While laws may impose direct control over prices, they can also create conditions whereby governments can negotiate for discounts on retail prices of a health technology. Contractual relations have rarely received attention as a human rights concern, with the notable exception of cases involving health care corruption.<sup>49</sup> However, other regulatory factors may also affect the use of resources through price negotiation, transparency, and rules of procurement.<sup>50</sup>

First, there is great scope for advancing the negotiating powers of governments in health care, as not all countries have a policy of price negotiation.<sup>51</sup> The United States had been lagging in this regard until 2022, when it partially removed legal restrictions that had prevented the federal government from negotiating pharmaceutical prices in one of its public coverage programs.<sup>52</sup> In other countries, such as France, government regulations allow greater negotiation powers than in the United States, particularly if new medications do not provide significant additional benefits.<sup>53</sup> Similarly, developing countries have sustained access to medicines by continuous negotiation, as demonstrated by Brazil’s HIV program (though this policy may be less effective in countries lacking institutional capacity or bargaining power).<sup>54</sup>

In August 2022, the Inflation Reduction Act was signed into law in the United States, introducing limited powers to secure price deals for selected prescribing medicines.<sup>55</sup> These reforms target users of the federal program Medicare, who are people aged 65 and over. In addition to capping out-of-pocket expenses and holding pharmaceutical companies accountable for price hikes exceeding

the inflation rate, the legislation is anticipated to yield substantial government savings. Potential negotiations could result in savings between US\$16.0 billion and \$28.3 billion, depending on the selection criteria, as approximately 60 new drugs may be eligible for the program by 2029.<sup>56</sup> This new law has been criticized by corporations, which argue that it breaches the right to property, suggesting that health advocates should also engage human rights in price negotiations.<sup>57</sup>

Another determinant of the negotiation environment is price transparency. This requirement can be imposed by laws in many forms: for example, by prior notification of a planned increase or a report about new drugs approved in a market.<sup>58</sup> Transparency is also related to access to information on how the price is fixed in other markets. Where prices in other countries are public, states can benchmark between markets.<sup>59</sup>

Moreover, it is not only the possibility of negotiating that stimulates affordability; correlated procurement laws can also ensure lower costs.<sup>60</sup> Comparative analyses of procurement policies in different countries suggest that a combination of factors—such as centralized purchasing, transparency of pricing in markets, corruption control, strong auctioning models, price benchmarking, or preference for generic products—results in better deals.<sup>61</sup> Conversely, a badly designed procurement process can result in gains in one tender being annulled by losses in another contract for similar drugs, as experienced in Belgium.<sup>62</sup>

In such negotiations, certain clauses are directly linked with affordability. Conditional contracts for new technologies are denominated management entry agreements (MEAs), setting out the expected delivery, budget, or clinical outcomes in order to clarify uncertainties and guarantee lower costs. Clauses in MEAs are variable and may offer different avenues to balance access to technology with reduced costs, while sharing the risks between the government and manufacturers for

specific goals: for example, budget control; safety monitoring, clinical efficacy, and cost-effectiveness; or usage and distribution of a technology.<sup>63</sup>

MEAs remain a strategy mostly undertaken in developed countries.<sup>64</sup> Part of this is due to the fact that MEAs tend to favor emerging technologies for expensive treatments or new advancements by orphan drugs, cancer, and other applications with low cost-effectiveness. Another explanation is that developing countries do not hold the same level of preparedness to negotiate and bargain the terms of the contract—unless encouraged by an acute crisis, such as in the world battle to ensure early HIV treatments. Few countries have adopted this model systematically, but Italy has exhibited significant savings in health care in doing so (€192 million in 2022).<sup>65</sup> As developing economies, Colombia and Brazil have also considered adopting these contracts, particularly because of the enforceability of the right to health, which may determine the mandatory supply of new technologies before all evidence of performance has been produced.<sup>66</sup> While additional research with empirical data is being undertaken, MEAs may offer a way to demand price discounts until the suggested public health savings are confirmed.

### *Competition laws*

Designed to regulate market abuse and price distortion, competition laws may sometimes be applied against the pharmaceutical industry in a way that facilitates access to new technologies. However, countries may be unable or reluctant to enforce a more competitive market due to circumstances such as methodological barriers to determining excessive prices and a lack of transparency and access to data relating to the items that make up the costs of health care products.<sup>67</sup>

In developing countries, competition laws in general have only recently taken effect, and, despite some good progress, many countries still have little practice in the field and face difficulties in investi-

gating, identifying, and prosecuting misconduct.<sup>68</sup> Even though there are some successful cases, they may still be articulated without human rights language, and many countries may not directly address price profiteering in the pharmaceutical market.

The challenges of prosecuting companies for price gouging are experienced by developed countries as well. In the European market, historically, European Union law has not been well suited to challenge unaffordability as a sign of unfair pricing and has been timid in considering substantive human rights in competition laws.<sup>69</sup> In European Union case law, definitions of value and fairness have been rather muddled in examining excessive pricing (this concept also being ambiguous), and competition authorities have made little difference.<sup>70</sup> In the past few years, there has been a notable resurgence of interest in using the competition framework to combat market distortions resulting from excessive pricing. The first such investigation was initiated in 2017, focusing on Aspen.<sup>71</sup> The European Commission ultimately reached an agreement with the manufacturer in 2021. Under this agreement, Aspen committed to legally binding price reductions averaging 73% for six off-patent cancer drugs.<sup>72</sup>

Another example of increased attention to competition as a tool to address excessive prices comes from South Africa. The country had an early precedent of resorting to competition laws strategically during the early 2000s, in a critical time of the HIV pandemic, bringing a pioneering challenge against a patent holder. In 2003, an agreement was reached with GSK (formerly GlaxoSmithKline) and Boehringer Ingelheim to withdraw prosecution for excessive prices of antiretrovirals before a competition tribunal.<sup>73</sup> Under the settlement, the companies authorized generic licenses and restricted their royalties to 5% of the net sales. Two decades later, the South African Competition Commission finally turned against another patent holder for

excessive pricing by investigating Roche, producer of the oncological drug Herceptin.<sup>74</sup> The case is still pending but demonstrates the more active stance of the South African authorities to inspect the market after passing an amendment to the domestic competition legislation in 2018 enhancing investigations into excessive pricing.<sup>75</sup> With these reforms, the burden of proof rests with the accused company to demonstrate reasonable pricing, if it is found to be in a dominant market position.<sup>76</sup>

In such cases, even though competition laws could be associated with human rights violations, a human rights framework is yet to be established more comprehensively in the literature and further espoused by advocacy. Kwanghyuk Yoo has recently advocated a connection between the right to health and competition laws, considering the context of the pharmaceutical market of the United States and alluding to issues of market abuse by intermediaries and collusion between brand owners by purchasing the right to delay the production of generic suppliers.<sup>77</sup> However, such views are centered on business and human rights guidelines to regulate business actors and thus lack enforceability since they are not binding legal obligations.<sup>78</sup>

### *Public-private partnerships*

PPPs address one type of scarcity—a lack of scientific projects, local technology development, and private investment—that could eventually lead to lower prices of new health technologies if coproduced or managed by public and private entities. The success of PPPs may require specific supporting laws that authorize and govern the delegation of public services or that provide more safeguards for the parties involved.<sup>79</sup> Projects in countries without specific legislation on PPPs may not perform as well as others with adequate legal provisions.<sup>80</sup> Currently, specific PPP laws appear to encourage more investment in countries where other procurement laws and institutional capacity do not offer certainty and flexibility to attract private financing.<sup>81</sup>

One field where PPPs have shown great potential is that of biosimilars. This type of treatment is a product very similar to another biological technology (substances produced naturally by organisms, such as animals and humans). The technology used to make these compounds is far too complex to be employed in some countries (particularly because of safety issues or lack of clinical data).<sup>82</sup> To find a way through this, PPPs can promote cooperation to build domestic capacity around technologies that will reduce the cost of producing biosimilars.

In Brazil, PPPs have paved the way for an exceptional trail of local innovation, acknowledged by the World Health Organization Council on the Economics of Health for All as a prominent model showcasing the reconfiguration of the economic landscape in support of public health interests as a common good.<sup>83</sup> Many of the technologies made available were previously pariahs in the massive right to health litigation against the state, as they would not be cost-effective or affordable for the government. While Brazilian PPPs were not overtly motivated by litigation, they do exhibit a certain connection to the prevalent number of lawsuits, as they represent a policy that has enhanced state capacity in sectors subject to substantial judicial scrutiny, thereby hinting at a developmental agenda. Such an increase in state capacity has been argued as a desirable effect of court interventions.<sup>84</sup>

Yet guidance on how to steer the right to health toward access to health technologies may still overlook the impact of PPPs. In relation to long-term kidney therapies, Diya Uberoi and Lisa Forman's analysis, for instance, underscores the potential of the right to health in facilitating patient access through legal actions and rights-based advocacy but fails to adequately acknowledge the role of PPPs in this context.<sup>85</sup> These contracts, though, may offer alternative means where direct litigation has failed (see the famous case of *Soobramoney*, in which a South African court upheld refusing a treatment for a renal patient).<sup>86</sup> In North Ethiopia,

before a pilot with a PPP was launched in 2013, local hospitals could not offer kidney treatments, including hemodialysis.<sup>87</sup> While this policy alone cannot fully dissipate cost pressures, since then, the PPP legal framework in Ethiopia has been further developed as a strategy of the Ministry of Health, and new agreements have expanded access to kidney treatments in other hospitals.<sup>88</sup>

## Conclusion

The central contention in this paper has been that, under the right to health, states have the obligation to apply legislation that optimizes market conditions, such as price formation, so as to privilege affordability. In many jurisdictions, alternative policies that could enhance affordability are denominated just as “legal barriers” or lack of “legal input” or necessary regulation, while they should be considered a failure of the right to health implementation by not adopting necessary laws.<sup>89</sup> Policy makers and human rights experts share a common tendency to look at affordability narrowly as a matter of IP laws, which has limited the range of rights-based approaches to legislate against scarcity. As a result, in comparison to removing IP barriers, such additional legal tools, from price control to competition laws, remain marginal in human rights mobilization.

These correlated policies (under the umbrella term of legal determinants of scarcity), however, cannot provide a “one size fits all” response to specific questions related to local development and market behavior. It is important to establish in each case—with targeted research in collaboration with health economists and pharmaceutical policy analysts—what the specific measures are that are most likely to create the right mix of regulation for each health care service or good. This will also contribute to the state being able to satisfy the reasonableness test by showing the meaningful steps it has taken toward the implementation of the right to

health through improving the legal environment.

Appreciating the existence of legal determinants of scarcity and broadening the human rights agenda is pivotal to integrating substantive policies with fair deliberations for priority setting. As Livio Garattini and Anna Padula note, “prices can hardly (if ever) be really right in a ‘market failure’ context.”<sup>90</sup> Consequently, procedural approaches to the right to health focused on priority setting will not fully engender the realization of the right to health unless the underlying causes of scarcity are duly confronted.

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