

# Health and Human Rights

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## EDITORIAL

# Free Speech, the Right to Health, and Genocide

JOSEPH J. AMON

### Introduction

The right to health is not usually realized through the benevolence of governments as much as the demands of populations. A critical part of those demands is manifest through the exercise of free speech: presenting evidence and demanding accountability.

In Zimbabwe in 2006, with my colleague Tiseke Kasambala, I interviewed more than 100 people living with HIV and more than 30 individuals from local and international nongovernmental organizations. We also interviewed local health experts, doctors and medical officials from private clinics and mission hospitals, government-appointed provincial and district AIDS coordinators, and representatives from the National AIDS Council.<sup>1</sup>

At the time, Zimbabwe had a growing HIV epidemic and few people receiving antiretroviral medicines. To quell dissent, the Mugabe government restricted freedom of speech and assembly. As dictators do, President Mugabe chose a dramatic moment to clamp down: on World AIDS Day.

HIV activists had organized demonstrations in the capital, Harare, to focus attention on the need for greater budget transparency and accountability. Although the demonstrators had a permit to march—the result of a judicial ruling allowing the protests—the police arrested five HIV activists under the Public Order and Security Act and charged them with incitement. Commenting on the arrests, one activist told us, “Because of the arrests, it will be difficult to get people to attend future marches or protests to advocate for their rights.”

Exactly the point of the government and police attacks.

Clashes between free speech and the right to health were also seen during the COVID-19 pandemic. In 2021, Human Rights Watch found that 83 countries had used the pandemic to justify violating the exercise of free speech and peaceful assembly.<sup>2</sup> One case the organization highlighted was that of Zhang Zhan, a 37-year-old journalist, who was sentenced to four years in prison by a Shanghai court for “picking quarrels

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and provoking trouble” by traveling to Wuhan and reporting on the coronavirus outbreak. In Ecuador, security forces beat and injured protesters demanding guidance for handling the bodies of people suspected of having died from COVID-19.<sup>3</sup>

More recently, at US colleges and universities, protests have erupted over Israel’s attacks on Gaza in response to Hamas’s terrorist attack on Israel. While these protests are not about the right to health in the United States, they are very much about human rights and health.

## Protecting free speech, addressing hate speech

As I noted in these pages in my last editorial, “threats to the right to health—and the full realization of all rights—are acute whenever countries face or create conflict.”<sup>4</sup> Accompanying conflict comes restrictions on free speech and, often, attacks on health workers who are perceived as partisan. Targeting health workers can be a way of silencing individuals who are witnesses to both vast destruction and individual persecution, including torture.

Of course, health workers are only one common target. Students, professors, and journalists are also frequently targeted—again, with the goal of shutting down speech and protest. However, academic freedom, free speech, and the freedom of the press are key tools that enshrine the right to question and criticize government policies and actions, whether it is based on fundamental principles or scientific evidence.

Universities in the United States, and globally, have often recognized, and even encouraged, students to engage in the right to speech, designating debating corners on campus or putting up with sit-ins, teach-ins, and marches that (minimally) disrupt campus operations.

Despite this history, and despite a long history of the US Supreme Court defending academic freedom, universities in the United States have recently been put under enormous pressure to restrict speech and protest, especially when it is directed against Israeli policies and military attacks on Palestine.<sup>5</sup> At Harvard, for example, the Trump administration

threatened to withhold US\$9 billion in research funding unless the University accepted external “audits” of academic programs, students, faculty, staff, and leadership for “viewpoint diversity,” as well as changes to the University’s admissions process, governance structure, and hiring practices.<sup>6</sup>

The demands also included reform of Harvard’s Divinity School, Graduate School of Education, School of Public Health, Medical School, Religion and Public Life Program, FXB Center for Health and Human Rights, Center for Middle Eastern Studies, Carr Center for Human Rights Policy, Department of Near Eastern Languages and Civilizations, and International Human Rights Clinic, all of which were alleged to “fuel antisemitic harassment or reflect ideological capture.”<sup>7</sup>

Harvard’s president responded to the demands by saying that “the University will not surrender its independence or relinquish its constitutional rights.”<sup>8</sup> In turn, the Trump administration froze US\$2.2 billion in funding and threatened to withhold the University’s tax exempt status and to block Harvard from enrolling international students.<sup>9</sup>

Of course, Harvard is not the only university that has been targeted—the Trump administration sees nearly all universities as adversaries. Vice President JD Vance, in a 2021 speech, laid out the case for attacking universities, referring to them as “hostile institutions.”<sup>10</sup> He closed his speech, to much applause, by quoting former President Nixon that “the professors are the enemy.”

This is not the first time universities have been criticized. At the founding of Johns Hopkins University, where I now sit, Thomas Henry Huxley’s inaugural speech was criticized for not opening with a prayer or closing with a benediction.<sup>11</sup> Supreme Court Justice Felix Frankfurter referenced this speech in *Sweezy v. New Hampshire*, a case central to contemporary issues of academic freedom and free speech, saying that “a university ceases to be true to its own nature if it becomes the tool of church or state or any sectional interest.”<sup>12</sup> In his plurality opinion for the court, Chief Justice Earl Warren said that “to impose any strait jacket upon the intellectual leaders in our colleges and universities would imperil the future of our nation.”<sup>13</sup>

Nonetheless, the Trump administration's attack on universities is ongoing. It is both financial and political, and it should not be considered a coincidence that human rights programs are overrepresented in the list above: calling out and standing up for human rights can put a target on your back.

Universities undoubtedly have an obligation to protect students from physical assault, harassment, and discrimination. They also have clear obligations not to interfere with academic freedom and speech. The suggestion, though, that *any criticism* of Israel is antisemitism can put these obligations at odds with each other. For example, in early 2024, a complaint was filed with the US Department of Education by the editor-in-chief of the online media platform Campus Reform, a source that describes itself as a “conservative watchdog in the nation’s higher education system.”<sup>14</sup> Johns Hopkins was only one of at least two dozen universities that the editor-in-chief filed complaints against.<sup>15</sup> The complaint “referred to a news article describing a letter” signed by Johns Hopkins faculty, allegedly “expressing solidarity with the people of Gaza and demanding an immediate ceasefire.”<sup>16</sup> In his complaint, the editor-in-chief said that “this praise is indicative of an environment that is hostile and unsafe for Jewish students.” There is no indication, however, that he spoke directly with any Johns Hopkins students.<sup>17</sup>

Other complaints filed directly with the university more clearly point to acts of antisemitism and harassment, although not always discernably linked to individuals associated with the University (such as anonymous social media posts and vandalism). The Department of Education’s investigation found that in every case, university staff offered to meet with the individual filing a complaint and to provide information on university policy and supportive resources.

Complaints were also filed by students reporting harassment related to Arab and Palestinian people and cultural practices. For example, a student reported that his supervisor told him not to wear his keffiyeh (traditional Palestinian head scarf) to work because “it symbolized terrorism,

hate and bad people.”<sup>18</sup> Students also filed a complaint against a professor who called Palestinians “barbaric animals” and “blood thirsty morally depraved animals.”<sup>19</sup>

## Antisemitism within US medical schools, health care institutions—and public health journals?

Increasing rates of antisemitism have also been alleged in medical schools, health care settings, and public health journals. Unlike the individual complaints above, these claims—made by scholars—allege systematic bias. But how good is the evidence?

In one study, two researchers examined videos of commencement ceremonies at 25 US medical schools for evidence of antisemitism, which the authors defined as wearing keffiyehs (defined by the authors as symbols associated with political violence and support of terrorism), Palestinian flags, and “banners, buttons, and signs” calling for divestment or proclaiming “occupation is a health crisis” or “stop bombing hospitals.”<sup>20</sup> They found that 2.5% of graduates wore “offensive stoles” or keffiyehs and 1.7% carried banners or signs, wore buttons, or protested “verbally.” Of course, wearing a keffiyeh or including a Palestinian flag on a graduation stole is not antisemitism, just as wearing a Chicago Bulls hat is not evidence of being a gang member.<sup>21</sup> While the researchers state that they recorded the number of students wearing stoles with flags of any country, they do not report this data.

Other published articles similarly stretch definitions of antisemitism and use questionable methods to investigate alleged experiences of antisemitism. For example, a December 2024 article published in the *Journal of Religion and Health* alleged increasing antisemitism, including in health-related academic journals.<sup>22</sup> The evidence came primarily from social media posts and the results of a survey distributed through four Jewish medical associations.

Unfortunately, the article has serious flaws in its methods and analysis. For example, the authors state that they conducted systematic reviews



of journal articles published between 2000 and 2023 by searching for the terms “antisemitism,” “antisemitic,” and “Holocaust” within titles and abstracts. The authors found a tenfold increase in publications. It is unclear whether this is a positive or negative outcome.

The authors also examined nearly 900,000 X posts from 220,405 self-identified health care professionals published between January 1, 2020, and April 1, 2024. The authors state that individual accounts were identified using a proprietary algorithm and that posts were selected based on “a proprietary query built of keywords and phrases related to the topic of antisemitism while carefully excluding any tagged conversations which were deemed irrelevant to the topic.” In their presentation of the results, the authors report that “conversations” about antisemitism increased fivefold.

They conclude that these findings “might reflect increased antisemitism within the health-care community.” However, the combination of proprietary algorithms and lack of specific information on the number of “conversations” (and not just the scale of increase) makes their analysis of social media unclear and not subject to review and confirmation. The authors’ suggestion that a greater increase in social media posts including the term “Gaza” compared to “Holocaust” suggests increased antisemitism is puzzling, and the use of terms such as “WHO” (for World Health Organization) and “mafia” as part of their search strategy is inexplicable.

The most specific evidence the authors present for their claim of “escalating antisemitism within the United States healthcare community” is drawn from an online survey completed by 170 “Jewish-identifying healthcare students and professionals.” The authors acknowledge that this is not a representative sample.

Although the survey did not ask respondents to identify specific medical or scientific publications that they felt were antisemitic, the authors state that respondents did so in the free-text section of the survey, which asked for “comments or experiences.” The authors then mischaracterize each of the articles identified.

For example, they claim that a number of articles say that Israeli and/or Jewish health professionals practice organ harvesting, withhold medical care from Palestinian Arabs, and deliberately target Palestinian health care workers and/or ambulances. They also cite a short oral testimony by Salam (a pseudonym) published in 2024 in *The Lancet* as “using Nazi imagery.”

None of these claims is true. None of the articles mention organ harvesting.

Some of the articles discuss Israeli government policies that limit access to health care, and some mention the Israeli military targeting health care workers or ambulances, but there is no mention of Israeli or Jewish health professionals doing so.

The claim that a letter published in *The Lancet*, entitled “There Is No Way to Leave Gaza,” uses Nazi imagery is also false. Salam’s letter is a firsthand account of life in Gaza and describes a precarious daily existence alongside personal experience of loss. The letter begins:

*On Oct 8, the second day of the ongoing aggression in the Gaza Strip, my father was supposed to have his chemotherapy diffuser pump removed at a local hospital in Gaza. Yet, due to the escalating danger, I had to remove it myself as I followed his doctor’s instructions over the phone.*

It ends with:

*Two of my friends lost their homes and have sought refuge in a hospital. That hospital has been threatened with bombardment, but they have nowhere else to go. Despite all this, I am one of the lucky few with a roof overhead and a bathroom shared with only 20 other people.<sup>23</sup>*

## Politicizing scientific publications and politicized peer review

Ordinarily, peer review provides a process for addressing methodological flaws, the mischaracterization of cited works, and the soundness of research findings and conclusions.

However, peer reviewers are not always objective. Shortly after the second article mentioned above was published in December 2024, I submit-



ted a response to the journal that pointed out the obvious errors in the article. Several rounds of reviews of my response followed. Some were helpful, and some were outraged by my critique.

One reviewer insisted that Salam's use of the term "concentration camp" to describe Gaza was in fact Nazi imagery and that, besides, Salam, in their 750-word account, should have condemned the October 7 attack by Hamas before recounting their personal experience. It made me wonder what a better term might be to describe mass detention, inhumane living conditions, dehumanization, violence and psychological torture, and complete isolation from accountability. It also made me wonder whether a victim of the US bombing of Hiroshima would be asked to first criticize the Japanese attack on Pearl Harbor. Another reviewer suggested that my response to the article was based on neither methodology nor fact but was an "emotional reaction."

As the editor-in-chief of *Health and Human Rights*, I see nearly all peer reviewers' comments for our journal articles. It educates me, but it is also my role to ensure that the reviews are accurate and fair and that our peer reviewers have diverse expertise.

It worries me, though, that scientific journals are coming under attack alongside universities. The Trump administration has forced the withdrawal of scientific manuscripts co-written by government employees; and journal authors, worried about backlash and defunding, have asked to submit papers with pseudonyms. This is not how science should work.

According to a recent article in the health news service STAT, the Trump administration has also begun targeting specific scientific journals. A letter sent by the interim US attorney for the District of Columbia to the editor-in-chief of *CHEST* (published by the American College of Chest Physicians) stated that "it has been brought to my attention that more and more journals and publications like *CHEST* Journal are conceding that they are partisans in various scientific debates."<sup>24</sup> Language in the letter alluded to fraud regulation and postal codes, suggesting possible prosecution. The *New England Journal of Medicine* and the jour-

nal *Obstetrics and Gynecology* have also received letters.

These attacks should come as no surprise. Robert F. Kennedy Jr., before being approved as secretary of the Department of Health and Human Services, said that in his first week in office, he would

*call in all of the scientific journals and ... say to them ... you've been lying to the public, you are representing yourself as a neutral and reliable source of health information, and you have done tremendous damage ... you are publishing fake science ... and I am going to litigate against you under the racketeering laws, under the general tort laws; I am going to find a way to sue you.*<sup>25</sup>

The Trump administration has also targeted members of National Institutes of Health science review boards, firing 43 experts—nearly 90% of whom were women, Black, or Hispanic. None was given a reason for their early dismissal from five-year terms.<sup>26</sup>

## Targeting DEI and weaponizing viewpoint diversity

The weaponization of viewpoint diversity is similar to past efforts to demand "equal time" for creationism, but goes much further, using the power of the state to silence some views and shift money to ideological fellow travelers. It is consistent with the Trump administration's attitude of impunity—ignoring the courts, firing military lawyers and whistleblowers, threatening media outlets, and extorting protection money (e.g., pro bono legal work for partisan causes). But viewpoint diversity does not actually mean that the Trump administration will allow diverse viewpoints: Trump has disappeared lawful residents to overseas prisons, banned transgender individuals from military service, and imposed restrictions on the genders they can use on US passports—efforts to punish and silence.

Much of these efforts have been conducted through executive orders targeting "DEI" (diversity, equity, and inclusion) and leaving no clear sense of which words, phrases, or ideas will result in a de-

nial of funding or some other punishment.<sup>27</sup> Part of the Trump administration's attack on speech, and truth, is the closing down of the Voice of America, which was founded with the mission to counter Nazi propaganda with accurate and unbiased news.

Another example of attacks on speech is the deportation proceedings against international students, with little due process. Columbia University student Mahmoud Khalil, who was a negotiator for Columbia students during talks with university officials, has been disappeared to a prison in Louisiana. Rumeysa Ozturk, a 30-year-old Turkish student, was picked up off the street for writing an op-ed in a student newspaper, despite the fact that the State Department found no evidence that she engaged in antisemitic activities or made public statements supporting Hamas.<sup>28</sup> Yunseo Chung, a lawful US resident who moved to the United States as a child, was deported after being arrested at a sit-in at Barnard College. Rasha Alawieh, a kidney transplant specialist from Lebanon, was deported even though a federal judge ordered that she not be removed until a hearing could be held. Momodou Taal, a doctoral student at Cornell University, had his visa revoked after he participated in campus demonstrations. Taal self-deported, saying that "I have lost faith I could walk the streets without being abducted." Mohsen Mahdawi, a Palestinian and a Buddhist, was detained even though he sought to build dialogue with Jewish students and spoke at churches, synagogues, and colleges, "extolling empathy as the key to a resolution" in the Middle East.<sup>29</sup> As of mid-April 2025, almost 1,000 international students and scholars at universities across the country had lost their legal status, according to the Association of International Educators.<sup>30</sup>

## Violations of the right to health, war crimes, crimes against humanity, and genocide

There is a simple reason for the Trump administration to restrict speech and assembly and to crack down on universities and faculty. Silencing debate about Gaza—a conflict where violations of the right to health are occurring, where war crimes have been

committed, and where crimes against humanity and acts of genocide are ongoing—is prelude and practice for silencing debate at home.

### *Violations of the right to health*

As a scholar and as the editor-in-chief of this journal, I feel an obligation to speak out about Israel's violations of the right to health in Gaza, including decimating the health care system; limiting access to health services as a punitive measure; directly attacking patients, medical personnel, health facilities, and ambulances; and threatening or restricting access to the underlying determinants of health.<sup>31</sup>

**Decimating the health care system.** Attacks on health began immediately after Hamas's attack on Israel on October 7, 2023. By April 6, 2024, Israeli defense forces had destroyed 26 hospitals.<sup>32</sup> In September 2024, the World Health Organization (WHO) reported that "every single hospital in Gaza has been affected, and no hospital remains fully functioning," and that "the healthcare system is now close to collapse."<sup>33</sup> WHO also declared that "the systematic dismantling of healthcare must end."<sup>34</sup> This systematic destruction of Gaza's health care system was described by scholars Neve Gordon and Nicola Perugini as "medical lawfare," ultimately resulting in "medicide."<sup>35</sup>

**Limiting access to health services as a punitive measure.** On April 7, 2025, the heads of six UN agencies—the Office for the Coordination of Humanitarian Affairs, UNICEF, the United Nations Office for Project Services, the United Nations Relief and Works Agency for Palestine Refugees in the Near East, the World Food Programme, and WHO—issued a joint statement saying that "we are witnessing acts of war in Gaza that show an utter disregard for human life."<sup>36</sup> More than two million people were trapped at crossing points, with humanitarian supplies such as food, medicine, fuel, and shelter items unable to reach those in need.

Two weeks earlier, the head of WHO posted on social media that 50 health workers and 143 patients had been kept in one building at Al-Shifa Hospital with extremely limited food and water

and only one nonfunctional toilet. Patients were in critical condition and lacked access to basic medical supplies and medicines; two patients who were on life support died due to a lack of electricity.<sup>37</sup>

**Directly attacking patients, medical personnel, health facilities, and ambulances.** Between October 2023 and March 2025, 1,813 incidents of violence against or obstruction of access to health care in Gaza were reported.<sup>38</sup> Health facilities were damaged 353 times, at least 624 health workers were killed, and 351 health workers were arrested by Israeli forces. In some cases, staff were prevented from providing care to their patients; in other cases, Israeli forces unlawfully evacuated hospitals and interfered with the treatment of wounded and sick patients, including denying medical workers access to medicines and supplies.<sup>39</sup>

Over the course of five days in March 2025:

- The Turkish-Palestinian Friendship Hospital and an adjacent medical school were demolished by Israeli forces, who claimed that the hospital was being used by Hamas. The hospital was the only specialized cancer hospital in Gaza.<sup>40</sup> The Turkish Ministry of Foreign Affairs condemned the “deliberate” destruction as “part of Israel’s policy aimed at rendering Gaza uninhabitable and forcibly displacing the Palestinian people.”
- Fifteen Palestinian paramedics and rescue workers were killed by Israeli forces. An investigation revealed that the emergency responders were shot “one by one” and their bodies gathered and buried in a mass grave, along with their ambulance and a United Nations (UN) vehicle that had accompanied the medics. The Palestinian Red Crescent Society said that the Israel Defense Forces had impeded the collection of the bodies for several days.<sup>41</sup> The same day, two paramedics were killed after their ambulance was shot at by Israeli forces, and an Israeli military attack on Nasser Hospital, the largest hospital in southern Gaza, killed two people, injured several, and sparked a large fire.<sup>42</sup> The attack hit the surgical building of the hospital. Among those killed was a 16-year-old boy who had undergone surgery two days earlier.
- An office of the International Red Cross was shelled by an Israeli military tank despite being clearly marked.<sup>43</sup>
- The Israeli Defense Forces assaulted medics from the Palestinian Red Crescent Society as they tried to treat injured Palestinians and caused damage to at least one ambulance before confiscating its keys.<sup>44</sup>

These attacks represent, at a minimum, willful disregard for international humanitarian law and the lives of Palestinian health professionals.

**Threatening or restricting access to the underlying determinants of health.** Since October 2023, Israeli authorities have deliberately obstructed Palestinians’ access to food and water. The UN Special Rapporteur on the right to food, Michael Fakhri, stated in March 2024 that “Israel has mounted a starvation campaign against the Palestinian people in Gaza.”<sup>45</sup> In July, Fakhri said that Israel has used starvation with the intent to destroy, in whole or in part, the Palestinian people.<sup>46</sup>

Israeli forces have also attacked and destroyed water and sanitation infrastructure, including wastewater treatment plants. On January 24, 2024, the UN reported that 87% of water, sanitation, and hygiene facilities in Gaza Governorate were either destroyed or damaged.<sup>47</sup> Between October 2023 and July 2024, Palestinians in Gaza had access to an average of between 2 and 9 liters of water per day—well below the minimum emergency humanitarian standards of 15 liters per capita per day recommended by WHO.<sup>48</sup>

From October 2023 to August 2024, municipalities in northern Gaza and Gaza City reported the destruction of 97 water wells, 13 major sewage pumps, 57 generators used for wells, 204 waste collection vehicles, and 255,000 meters of water and sewage lines.<sup>49</sup>

This destruction goes far beyond restricting access to the determinants of health: it involves the leveling of entire neighborhoods and the destruc-

tion of farms, schools, universities, businesses, places of worship, cemeteries, cultural and archaeological sites, government buildings, water and sanitation facilities, hospitals, and clinics. This can only be seen as a campaign to erase and eradicate Palestinian physical and cultural existence in Gaza entirely.

### *Allegations of war crimes, crimes against humanity, and genocide*

Following Hamas's attack on Israel, statements from Israeli government officials echoed Nazi statements about Jews 80 years ago: "Human animals must be treated as such. There will be no electricity and no water, there will only be destruction. You wanted hell, you will get hell" (Major General Ghassan Alian).<sup>50</sup> "I have ordered a complete siege on the Gaza Strip. There will be no electricity, no food, no fuel, everything is closed. We are fighting human animals, and we act accordingly" (Israeli Defense Minister Yoav Gallant).<sup>51</sup> "Gaza will become a place where no human being can exist" (retired Major General Giora Eiland).<sup>52</sup> Trump has cheered on these calls and proposed that the United States "take over" and "own" the Gaza Strip and send Palestinians into exile in other countries.<sup>53</sup>

In November 2024, the International Criminal Court issued arrest warrants against Israeli Prime Minister Benjamin Netanyahu and Defense Minister Gallant, as well as Mohammed Diab Ibrahim al-Masri, commander-in-chief of Hamas's military wing.<sup>54</sup> The court's judges concluded that there were reasonable grounds to believe that all three men were responsible for war crimes and crimes against humanity. Specific charges against Netanyahu and Gallant included the starvation of civilians, intentionally directing attacks against civilians, murder, and persecution. Charges against al-Masri included murder and hostage-taking. Israel's blockade of Gaza and interference with humanitarian assistance can be considered collective punishment of the civilian population, also a war crime.<sup>55</sup>

In a series of rulings from 2024, the International Court of Justice ordered that Israel prevent genocide against Palestinians and "take immediate and effective measures to enable the provision of

urgently needed basic services and humanitarian assistance to address the adverse conditions of life faced by Palestinians in the Gaza Strip."<sup>56</sup>

Israel has denied seeking to commit genocide, stating that "it acted with the intention to defend itself, to terminate the threats against it and to rescue the hostages."<sup>57</sup> Israel's collective punishment and racist narratives about Palestinians, not to mention the more than 50,000 dead and wholesale destruction, belie the idea that Israel was merely acting in self-defense.<sup>58</sup>

Human rights organizations have alleged that Israel's deliberate attacks on access to water in Gaza and its restrictions on access to humanitarian assistance constitute the crime against humanity of extermination and acts of genocide.<sup>59</sup> In March 2024, Francesca Albanese, the UN's Special Rapporteur on the situation of human rights in the Palestinian territories, released a report concluding that "there are reasonable grounds to believe that the threshold indicating that Israel has committed genocide has been met."<sup>60</sup>

In April 2025, Albanese, alongside UN Special Rapporteurs on the right to health, the right to a healthy environment, the rights of internally displaced persons, the right to freedom of assembly and association, the rights of persons with disabilities, the right to education, and the right to adequate housing, among other UN officials, released a statement that Israel's actions in Gaza are leading to the "destruction of Palestinian life."<sup>61</sup>

## Conclusion

In 1948, in the aftermath of World War II, the Universal Declaration of Human Rights set out fundamental human rights. The preamble begins by saying that "recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world."<sup>62</sup> The declaration is sometimes critiqued as aspirational. It is important, though, to have aspirations.

Suzanne Nossel, former CEO of PEN America, recently wrote, "Rooting out antisemitism will ultimately depend not just on enforcing rules or



applying pressure. It will demand defending threatened principles of openness, respect for differences, compassion and solidarity. These are principles that undergird American society, and the place of Jews within it.”<sup>63</sup> The same is true globally, wherever there is hate, discrimination, and senseless attacks.

Twenty years after the Rwandan genocide, Stewart Patrick and Patrick McCormick published an article on the Council on Foreign Relations website about key lessons of the genocide.<sup>64</sup> But a more personal view was expressed by Freddy Mutanguha, a survivor of the Rwandan genocide who has spoken about the importance of testimony as a part of healing: “Testimony is important for many reasons. We need to speak to release our anger; to process our experience, and reduce the trauma; to honour the memory of our murdered loved ones and community; to secure a measure of justice, and to begin the long road to peace and reconciliation.”<sup>65</sup> These are lessons broader than just the Rwandan genocide: attacks on free speech are attacks on remembering—and healing.

In a recent interview, Nobel Prize-winning economist Joseph Stiglitz noted that “what makes for good societies, for good economies” is democracy. He continued:

*An essential part of democracies is free media and strong universities. Strong universities are important because they provide the critique, to evaluate what governments are doing, to ascertain when there's an encroachment on democracies, to criticize it when they are doing things that are against the interests of people, when there are conflicts of interest. That's why anti-democratic forces always begin the attack on the media and on universities.*<sup>66</sup>

There is no way forward without looking back, remembering, recentering the importance of human rights, and seeking understanding and peace across differences and divides.

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## PERSPECTIVE

# What's Old Is New Again in Addiction Treatment: The Expansion of Involuntary Commitment in the United States

JOHN C. MESSINGER AND LEO BELETSKY

## Introduction

The recent confirmation of Robert F. Kennedy Jr. as the secretary of the Department of Health and Human Services has raised numerous concerns regarding the future shape of the United States' medical and public health systems. Among his controversial opinions is support for involuntary commitment at abstinence- and faith-based “healing farms” for people struggling with addiction.<sup>1</sup> Some of Kennedy's beliefs stem from his own experience with addiction and recovery, which involved a variety of abstinence-based programs.<sup>2</sup> He is far from the first politician to advocate for forced addiction treatment, which is growing in popularity as a central feature of the overdose crisis response. Upward of 25 states added new—or expanded existing— involuntary commitment statutes between 2015 and 2018 alone, a trend that invokes the United States' grim history of institutionalization as a dominant approach to addiction and mental health problems.<sup>3</sup>

While state-level laws allowing for forced addiction treatment are becoming commonplace, their implementation has been limited in most jurisdictions. Lack of funding, human rights concerns, and logistical constraints have thus far rendered existing legal mechanisms largely dormant. For example, California became one of the most recent adopters of forced addiction treatment through the passage of Senate Bill 43, which expanded the criteria for psychiatric involuntary commitment to include substance use disorder in isolation as a qualifying diagnosis.<sup>4</sup> However, the use of this law is exceedingly rare because most patients fail to meet the criteria for involuntary commitment once they are no longer acutely intoxicated from substances, and those who do are unable to be placed because residential addiction treatment facilities do not have the infrastructural capacity to enact involuntary holds. One study from 2015 found that of the 33 states

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with laws permitting involuntary commitment for substance use disorder, fewer than half regularly adopted this approach.<sup>5</sup>

As it stands, the United States is sitting on a sleeping giant where nearly every state has the capability to forcibly treat people for substance use disorders provided that the political climate allows for the expansion of funding to establish treatment facilities designated for this use. While the severity of the ongoing overdose crisis warrants swift and definitive intervention, we must be wary of the use of involuntary commitment for substance use disorder given the dearth of evidence supporting its use either domestically or abroad. Furthermore, the research that does exist on this subject is often not generalizable because ethical concerns limit the ability to conduct randomized controlled trials. One international review from 2009 synthesizing 30 years of research on coerced addiction treatments found that studies were generally inconsistent and of low quality.<sup>6</sup> A more recent study from Sweden found that individuals released from compulsory addiction treatment had a threefold increased risk of dying immediately following their release.<sup>7</sup>

The state of the research in the United States is even more abysmal: as noted by a 2015 study, of the twenty states implementing involuntary commitment for substance use disorder, only seven were able to consistently report utilization data.<sup>8</sup> For years, compulsory treatment programs have functioned with little scrutiny—facilities providing care to those involuntarily committed for addiction release little information regarding the treatments they provide, and rarely (if ever) release data regarding patient outcomes.

### Massachusetts as a cautionary tale

To illustrate the risks of wide involuntary commitment deployment, we need to look no further than the Commonwealth of Massachusetts, which, along with Florida and North Carolina, is one of the country's highest utilizers of these laws. Each year, Massachusetts forces upward of 6,000 people into addiction treatment at great cost to its taxpayers.<sup>9</sup> This system is promulgated under a law referred to

as Section 35, which allows for the forceful detention and placement of individuals into dedicated involuntary addiction treatment facilities for up to 90 days at a time.<sup>10</sup> Despite Section 35's widespread deployment, and repeated efforts to increase transparency, the nature of its implementation and efficacy has remained shrouded in mystery.<sup>11</sup> Until now, the most comprehensive reports on outcomes of involuntary commitment for substance use disorders in Massachusetts have been limited to data from 2011–2015.<sup>12</sup>

Recently, however, the Massachusetts Department of Public Health (DPH) was forced to shed more light on this system. In late 2024, it released a statutorily mandated report comparing outcomes of voluntary versus involuntary addiction treatment.<sup>13</sup> In this study, those subjected to involuntary commitment were younger (more than 80% were under the age of 45) and more often white (82%) compared to those receiving voluntary treatment.<sup>14</sup> The vast majority of participants receiving any addiction treatment, voluntary or involuntary, were insured through Medicaid.<sup>15</sup> To compare outcomes between different forms of addiction treatment, the report looked specifically at individuals who had both received voluntary treatment and undergone involuntary commitment between 2015 and 2021, comparing numerous health-related outcomes at 30 and 90 days after each treatment episode. Most notably, the report found that after release from involuntary treatment, individuals had a 1.4-fold increased risk of non-fatal overdose and possibly an increased risk of death from any cause.<sup>16</sup>

While these findings may come as a surprise, they serve as further proof of the concerns that we and many others have raised for years and warrant a deeper dive to fully understand their significance.<sup>17</sup> What happens to people subjected to involuntary commitment for substance use disorders? How might this lead to an increased risk of overdose and death? Moving forward, what should the United States do to ensure that involuntary commitment for substance use disorders does not continue to harm those it seeks to help?

Although the exact details of involuntary commitment for substance use disorders will vary state

by state, it is worth examining the existing system in Massachusetts to better contextualize findings from this most recent DPH report. In Massachusetts, all involuntary commitment episodes start with a petition filed to a court requesting that an individual be forced into treatment for addiction. While many different people (e.g., health care providers, law enforcement officers, court officials, and so on) may submit these petitions, most are filed by an individual's family member. In many cases, courts will then grant a warrant that allows the police to locate and physically detain the individual in question for a hearing to determine whether they qualify for involuntary commitment.<sup>18</sup> It is important to note that an individual need not have been charged with or found guilty of a crime in order to be forcibly committed. Once sentenced to involuntary commitment, the individual is then sent to one of several treatment facilities across the state. Most facilities are run by the DPH or the Department of Mental Health, but the largest and most notorious is owned and operated by the Department of Corrections and staffed by prison guards.<sup>19</sup> Although involuntary commitment for substance use disorders is branded as "treatment," one can see how many parts of this process more closely approximate the process of incarceration than that of medical care.

Once at a treatment facility, the patient is monitored while they undergo withdrawal—for patients with opioid use disorder, this process is excruciating and may last days, with only minimal relief provided from adjunctive medications. The exact details of treatment beyond this point are murky. One study investigating the experiences of individuals released from forced addiction treatment in Massachusetts found that fewer than one in five participants were offered medications for substance use disorder or scheduled for community-based follow-up, raising concerns about the standard of care in involuntary commitment facilities.<sup>20</sup> The outcomes for these patients were perhaps even more worrisome—fewer than one in ten participants actually attended their scheduled follow-up, and more than one-third reported relapsing on the day of their release.<sup>21</sup> While relapse is an expected

part of the process for patients struggling with addiction, it becomes particularly dangerous for people whose tolerance for drugs has been reduced by being in an institutionalized setting. This is not simply a theoretical risk—this phenomenon has been studied extensively for people released from prisons, with studies showing a dramatically increased risk of overdose death, particularly in the first two weeks following release.<sup>22</sup> We believe it is this same underlying process that may be driving the increased rates of overdose detected in the most recent data from the Massachusetts DPH.

### Implications for the US response and beyond

With the shift in the federal administration, there is now a risk that dormant involuntary commitment mechanisms will become more actively deployed across the United States. Policy makers who support the expansion of involuntary commitment for substance use disorders as a solution to the ongoing overdose crisis must reconcile mounting evidence that this approach may increase the number of deaths among people who use drugs.

In Massachusetts and elsewhere, shutting the system down is not a realistic option in the short term—thousands of people receive treatment through involuntary commitment each year, and the practice remains politically popular. However, we must start the process of dramatically redistributing budgetary funds toward evidence-based voluntary treatment options and away from involuntary commitment. In 2023, the Massachusetts governor's budget allocated more than US\$22 million to the Massachusetts Alcohol and Substance Abuse Center, the involuntary treatment facility housed alongside a state prison, while providing less than US\$7 million to harm reduction services across the state.<sup>23</sup> This imbalance of resources has led to overreliance on involuntary commitment for substance use disorders as a first-line intervention.<sup>24</sup> For instance, there have been numerous anecdotes from those treating addiction in the community that people are volunteering themselves for involuntary commitment because they are otherwise

unable to access treatment. Additionally, the recent DPH report found that areas with access to more robust voluntary treatment services had proportionately lower rates of involuntary commitment for substance use disorders.<sup>25</sup> Nationally, we must ensure that states seeking to implement involuntary commitment for substance use disorders have first taken care to allot sufficient resources to voluntary treatment options.

In cases where involuntary commitment is still needed, we must aim to use the least restrictive measures possible and guarantee the provision of evidence-based treatments to mitigate the risk of overdose. Courts evaluating patients for involuntary commitment for substance use disorders should consider alternative, less restrictive measures such as mandated outpatient or intensive outpatient programs, depending on the severity of an individual's addiction. Those who do not meet the criteria for involuntary commitment should be directed to voluntary treatment options. We must also work to set treatment standards for involuntary commitment for substance use disorders, such as guaranteed provision of medications for substance use disorders for patients who are interested. The importance of these interventions cannot be understated—buprenorphine and methadone used in the treatment of opioid use disorder are the most effective treatments available for addiction, leading to a more than 50% reduction in all-cause mortality.<sup>26</sup> Additionally, facilities must guarantee community-based follow-up for all individuals being discharged from treatment. Finally, we must ensure that treatment is provided in health care settings by trained medical and psychiatric providers. Although a Massachusetts bill passed in 2017 required that facilities for women be operated by the DPH or the Department of Mental Health, state house and senate bills providing the same protection for men have not been passed despite several attempts.<sup>27</sup>

Given that drug overdose remains a leading cause of death for US residents under 45, we must do all that we can to protect the lives of those experiencing addiction.<sup>28</sup> Although involuntary commitment for substance use disorders has

been proposed as a desperate measure to prevent overdose, it has backfired. In Massachusetts, the magnitude of the system of involuntary commitment for substance use disorders will make change difficult. However, if we resort to this as the primary means of addressing the overdose crisis, we do so at the cost of the lives of those forced into treatment for addiction.

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## PERSPECTIVE

# Public Reporting on Solitary Confinement in Australian and New Zealand Prisons and Youth Detention Facilities

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## Introduction

Recent national inquiries in Australia and New Zealand describe historic failures in the treatment of people in government-run institutions, including the routine use of restrictive and traumatizing practices.<sup>1</sup> However, restrictive practices such as solitary confinement remain widespread in prisons and youth detention facilities, despite their known harms to physical and mental health and their potential to infringe human rights.<sup>2</sup> The use of solitary confinement on children, Indigenous People, and those living with a disability (for example, a learning disability or serious mental illness) is of particular concern and is likely to violate international human rights conventions.<sup>3</sup>

To avoid repeating past mistakes, it is imperative that restrictive practices in custodial settings be transparently reported and subject to public scrutiny.<sup>4</sup> Although solitary confinement is a health and hu-

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man rights issue of global importance, in this essay we take a regional perspective by examining the extent to which there is regular and transparent reporting on solitary confinement in Australian and New Zealand prisons and youth detention centers.

## Defining solitary confinement

Solitary confinement is used for many reasons in carceral settings, including to manage the risk of violence (either by or toward the person who is subjected to solitary confinement), to contain infectious disease outbreaks, and to manage severe behavioral disturbance. According to the United Nations (UN) Standard Minimum Rules for the Treatment of Prisons (the Mandela Rules), solitary confinement is the confinement of prisoners for 22 hours or more per day without meaningful human contact.<sup>5</sup> While any duration of solitary confinement may be harmful, prolonged solitary confinement lasting over 15 consecutive days is more likely to cause profound and irreversible physical and psychological harm.<sup>6</sup>

Worldwide, many different official reporting terms are used for restrictive practices that may or may not involve solitary confinement. In Australia and New Zealand, common terms include *segregation*, *separation*, *isolation*, *lockdown*, *confinement*, *secure care*, and *special care*.<sup>7</sup> *Seclusion* is used in mental health settings, where it has a more consistent definition and is routinely monitored and reported.<sup>8</sup>

In Australia, national correctional guidelines define “separation and segregation” as the “separate confinement of a prisoner ... for the protection and safety of others where there is no other reasonable way to manage the risk/s to safety, security, or good order and discipline of the correctional centre.”<sup>9</sup> This definition sometimes conflicts with other jurisdiction-specific guidelines. For example, in the New South Wales Youth Justice procedures, separation can also refer to keeping groups of young people—rather than individuals—apart.<sup>10</sup> In New Zealand, the Corrections Act of 2004 defines segregation as “the opportunity of a prisoner to associate with other prisoners [being] restricted or denied.”<sup>11</sup>

In youth detention settings, the term *isolation* is commonly used. For example, in the Victorian Youth Justice Act of 2024, isolation means “the placement of a child or young person in a locked room or other contained area—(a) separated from other children and young persons held in custody in the youth justice custodial centre; and (b) separated from the normal routine of the youth justice custodial centre.”<sup>12</sup> The act adds that isolation is not occurring if the young person is “participating in, or has the opportunity to participate in, the normal routine of the youth justice custodial centre but separate from other children and young persons.” In the Australian Capital Territory, isolation is defined as “the physical confinement of a child or young person on their own for a notable period of time, e.g. greater than 10 minutes.”<sup>13</sup> In some Australian jurisdictions—for example, Western Australia—the term *confinement* equates to segregation as a form of punishment.<sup>14</sup> Finally, *lockdown* has no official definition but is commonly used to refer to an institutional response whereby a group of people within an institution have their movements restricted, usually in response to an internal threat such as a violent incident or staff shortages.

These overlapping, ambiguous, and inconsistent definitions of practices that may or may not equate to solitary confinement make monitoring difficult.

## International human rights frameworks

Many UN instruments and bodies mention solitary confinement. These include international treaties such as the International Covenant on Civil and Political Rights and the Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, as well as reports by the UN Special Rapporteur on torture and the UN Subcommittee on Prevention of Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment. Perhaps the most widely cited UN source on solitary confinement is the Mandela Rules, which defines solitary confinement and asserts that it should occur “only in exceptional cases as a last resort, for as short a time as possible and subject to

independent review.”<sup>15</sup>

The Optional Protocol to the Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (OPCAT), adopted by the UN General Assembly in 2002, provides for the establishment of national preventive mechanisms to monitor places of deprivation of liberty, including restrictive practices such as solitary confinement.<sup>16</sup> New Zealand ratified OPCAT in 2007. Five independent agencies, including the Ombudsman, monitor and report on OPCAT compliance in New Zealand. In 2013, the UN Subcommittee on Prevention of Torture visited New Zealand and reported its findings, including on the use of solitary confinement and other restrictive practices.<sup>17</sup> Australia ratified OPCAT in 2017. Inspection mechanisms are coordinated by the Commonwealth Ombudsman and involve ombudsman’s offices for the commonwealth and each state and territory, in addition to several other bodies. However, national preventive mechanisms are not yet active in all Australian jurisdictions. Furthermore, in 2023 the UN Subcommittee on Prevention of Torture suspended (and later terminated) an inspection visit to Australia because of obstacles to carrying out its mandate.<sup>18</sup> The inspection team encountered “a discourteous, and in some cases hostile, reception,” incorrect information, and the inability to access certain places of detention in Queensland and New South Wales.<sup>19</sup> This indicates that Australia is not yet compliant with its OPCAT obligations.

The UN Declaration on the Rights of Indigenous Peoples is also relevant to this issue, considering the overrepresentation of Aboriginal and Torres Strait Islander People and Māori in prisons and youth detention facilities in Australia and New Zealand, many of whom are also living with a disability.<sup>20</sup> The disproportionate exposure of Indigenous People to solitary confinement perpetuates the intergenerational trauma and human rights abuses of centuries of colonization. People with a disability, including serious mental illness, are also likely to experience solitary confinement when they are imprisoned.<sup>21</sup> This is in contravention of the UN Convention on the Rights of Persons

with Disabilities and the Mandela Rules, the latter of which states that “the imposition of solitary confinement should be prohibited in the case of prisoners with mental or physical disabilities when their conditions would be exacerbated by such measures.”<sup>22</sup>

## Reporting on solitary confinement in custodial facilities in Australia and New Zealand

We aimed to identify reporting mechanisms that provide regular data on solitary confinement (or its equivalent terms) in prisons and youth detention facilities, similar to the publicly available data on seclusion in psychiatric facilities.<sup>23</sup> To do this, we searched the websites of prison and youth justice monitoring authorities in Australian and New Zealand jurisdictions and then directly contacted those authorities to ensure that we had not missed any major sources of information.

We identified relevant reports from all jurisdictions in Australia and New Zealand (Table 1). However, the information that these reports provided on solitary confinement was variable and often ambiguous. Even when the reports provided quantitative data on restrictive practices, in most cases it was difficult to know whether these practices amounted to solitary confinement. Most reports gave limited detail on the incidence, duration, and reasons for solitary confinement, and the demographic profile of the people exposed to it. Several reports commented on the difficulty the investigation team had experienced when accessing data on restrictive practices. For example, an investigation of the Darwin Correctional Centre by the Northern Territory Ombudsman found inconsistent reporting of the time spent out of cells for people subject to separate confinement.<sup>24</sup>

Several reports commented on the impact of staff shortages on restrictive practices. For example, a report by the New Zealand Ombudsman covering an eight-day period in early 2020 found that most prisoners in two units at a maximum-security prison spent 22–23 hours per day in their cell and were therefore subject to solitary confinement.<sup>25</sup> This

practice was influenced by staff shortages.<sup>26</sup> Similar issues related to staff shortages were noted in reports from Western Australia and Queensland.<sup>27</sup>

We found jurisdiction-wide quantitative data

on restrictive practices from several jurisdictions, including Victoria, New South Wales, Tasmania, Western Australia, and New Zealand.<sup>28</sup> Interpretation of the data required some understanding of the

TABLE 1. Reports discussing separation, segregation, and isolation in Australian and New Zealand prisons and youth detention facilities

Jurisdiction	Reporting authority	Report(s)	URL
Australia	Australian Human Rights Commission	Follow Up Procedures to Australia's Sixth Periodic Review: Submission to the Committee Against Torture (2023)	<a href="https://humanrights.gov.au/">https://humanrights.gov.au/</a>
Australian Capital Territory	ACT Inspector of Correctional Services	Reviews of the Alexander Maconochie Centre (2022) and the Bimberi Justice Centre (2023)	<a href="https://www.ics.act.gov.au/">https://www.ics.act.gov.au/</a>
New South Wales	NSW Inspector of Custodial Services	Reports on inspections of prisons and youth justice centers Use of Force, Separation, and Confinement in NSW Juvenile Justice Centres (2018)	<a href="https://inspectorcustodial.nsw.gov.au/">https://inspectorcustodial.nsw.gov.au/</a>
	NSW Ombudsman	Annual reports	<a href="https://www.ombo.nsw.gov.au/reports/annual-report">https://www.ombo.nsw.gov.au/reports/annual-report</a>
Northern Territory	Northern Territory Office of the Children's Commissioner	Monitoring reports on Don Dale Youth Detention Centre (2021) and Alice Springs Youth Detention Centre (2021)	<a href="https://occ.nt.gov.au/">https://occ.nt.gov.au/</a>
	Ombudsman Northern Territory	Separate Confinement: A Thematic Investigation into Practices in Darwin Correctional Centre (2024)	<a href="https://ombudsman.nt.gov.au/">https://ombudsman.nt.gov.au/</a>
Queensland	Queensland Ombudsman	Inspection reports on Cleveland Youth Detention Centre (2024) and Brisbane Youth Detention Centre (2019)	<a href="https://www.ombudsman.qld.gov.au/publications/detention-inspection-reports/">https://www.ombudsman.qld.gov.au/publications/detention-inspection-reports/</a>
South Australia	Justice Action	Report on the South Australian Prison System (2023)	<a href="http://justiceaction.org.au/wp-content/uploads/2023/03/Report-South-Australian-Prison-System.docx.pdf">http://justiceaction.org.au/wp-content/uploads/2023/03/Report-South-Australian-Prison-System.docx.pdf</a>
	Ombudsman South Australia	Investigation into the Treatment of Young People in the Adelaide Youth Training Centre (2019)	<a href="https://www.ombudsman.sa.gov.au/">https://www.ombudsman.sa.gov.au/</a>
	Office of the Guardian for Children and Young People	Training Centre Visitor reports	<a href="https://gcyp.sa.gov.au">https://gcyp.sa.gov.au</a>
Tasmania	Office of the Custodial Inspector Tasmania	Reports on custody inspections and inhumane treatment in dry cells (2024)	<a href="https://www.custodialinspector.tas.gov.au/">https://www.custodialinspector.tas.gov.au/</a>
Victoria	State Government of Victoria	Youth Justice quarterly reporting	<a href="https://www.justice.vic.gov.au/">https://www.justice.vic.gov.au/</a>
	Minister for Corrections	Final Report of the Cultural Review of the Adult Custodial Corrections System (2022)	<a href="https://www.vic.gov.au/">https://www.vic.gov.au/</a>
	Parliament of Victoria	Inquiry into Victoria's Criminal Justice System (2022)	<a href="https://www.parliament.vic.gov.au/get-involved/inquiries/">https://www.parliament.vic.gov.au/get-involved/inquiries/</a>
	Victorian Ombudsman	A Thematic Investigation of Practices Related to Solitary Confinement of Children and Young People (2019)	<a href="https://assets.ombudsman.vic.gov.au/">https://assets.ombudsman.vic.gov.au/</a>
	Yoorrook Justice Commission	Yoorrook Report into Victoria's Child Protection and Criminal Justice Systems (2023)	<a href="https://yoorrookforjustice.org.au/">https://yoorrookforjustice.org.au/</a>
Western Australia	Western Australia Office of the Inspector of Custodial Services	Reports on prisons and youth detention centers Reports on the use of confinement and management regimes and the management of prisoners requiring protection	<a href="https://www.oics.wa.gov.au/publications">https://www.oics.wa.gov.au/publications</a>



definitions used in each of those jurisdictions, but in many cases, this at least provided a benchmark to show how those practices were tracking over time and, in some cases, between facilities.

The Australian Productivity Commission publicly reports national benchmark data on the average time spent out of cells by people in prison, although it does not yet have a comparable indicator for children in youth detention.<sup>29</sup> Data on time out of prison cells are also reported by some individual jurisdictions, such as Tasmania.<sup>30</sup> In New Zealand, benchmark data on time spent out of cells are tracked internally by the Department of Corrections, and nationwide data on segregation and separation have been published by the Department of Corrections Office of the Inspectorate.<sup>31</sup> Data on time out of cells are valuable but uninformative with regard to solitary confinement. Nonetheless, the existence of these data suggests that it may be possible to collect and report data on instances where the time out of cells is less than two hours per day, or where there was no meaningful human contact during that time (rule 44 of the Mandela Rules).

## Children in solitary confinement

Although any person may be harmed by solitary confinement, children are at particular risk because of their developmental immaturity and lesser capacity to advocate for their own rights. The UN Rules for the Protection of Juveniles Deprived of Their Liberty, adopted by the UN General Assembly in 1990, state that “closed or solitary confinement or any other punishment that may compromise the physical or mental health of the juvenile concerned” is “strictly prohibited.”<sup>32</sup> Despite recent inquiries and the well-acknowledged harms of subjecting (typically vulnerable and traumatized) children to solitary confinement, the Australian Human Rights Commission remains “seriously concerned” about the use of solitary confinement in Australian youth detention facilities.<sup>33</sup> Similar comments have been made in New Zealand, and the comments are echoed in many of the inspection reports listed in Table 1.

As shown in Table 1, we found statewide data on restrictive practices in youth justice facilities from New South Wales and Victoria. Victoria provides regular quarterly reporting on the number

TABLE 1. *continued*

Jurisdiction	Reporting authority	Report(s)	URL
New Zealand	New Zealand Children and Young People's Commission	Reports on youth detention facilities	<a href="https://www.manamokopuna.org.nz/publications/reports/">https://www.manamokopuna.org.nz/publications/reports/</a>
	New Zealand Human Rights Commission	Segregation, Restraint, and Pepper Spray Use in Women's Prisons in New Zealand (2021) Thinking Outside the Box? A Review of Seclusion and Restraint Practices in New Zealand (2017) Time for a Paradigm Shift: A Follow Up Review of Seclusion and Restraint Practices in New Zealand (2020)	<a href="https://tikatangata.org.nz/our-work/thinking-outside-the-box">https://tikatangata.org.nz/our-work/thinking-outside-the-box</a> <a href="https://www.solitaryconfinement.org/solitary-confinement-in-new-zealand">https://www.solitaryconfinement.org/solitary-confinement-in-new-zealand</a>
	New Zealand Office of the Inspectorate	Reports on inspections of New Zealand prisons Separation and Isolation Thematic Report (2023)	<a href="https://inspectorate.corrections.govt.nz/">https://inspectorate.corrections.govt.nz/</a>
	New Zealand Ombudsman	Reports on unannounced inspections of New Zealand prisons	<a href="https://www.ombudsman.parliament.nz/">https://www.ombudsman.parliament.nz/</a>
	Abuse in Care Inquiry	Uses and Abuses of Solitary Confinement of Children in State-Run Institutions in Aotearoa New Zealand (2022)	<a href="https://www.abuseincare.org.nz/">https://www.abuseincare.org.nz/</a>
	Waitangi Tribunal	Māori with Lived Experience of Disability: Part I (2019)	<a href="https://forms.justice.govt.nz/search/Documents/WT/wt_DOC_150437272/Wai%202575,%20B022.pdf">https://forms.justice.govt.nz/search/Documents/WT/wt_DOC_150437272/Wai%202575,%20B022.pdf</a>

of isolation episodes for children in youth justice facilities. These figures are broken down into behavioral-based isolation and isolations based on concerns for the security of the center. They provide no detail about the age, sex, or ethnicity of the children exposed to isolation, or the duration of episodes. For most other jurisdictions, reporting appears to be less consistent, and it relies on ad hoc inspections of individual carceral facilities. Most of these inspection reports provide little quantitative data, with several reports commenting that this was because the data were not accurately recorded by the justice authority. The impact of staff shortages was mentioned in several reports. For example, a 2024 report on a Queensland youth justice facility housing mostly Aboriginal young people found that staff shortages contributed to high levels of separation.<sup>34</sup>

In New Zealand, the use of solitary confinement in institutions that house young people has come under scrutiny as a result of the recent Royal Commission of Inquiry into Abuse in Care. An independent report for the commission, published in 2022, explores the history of solitary confinement practices in these settings, which include youth justice facilities. The report concludes that the use of solitary confinement is widespread, often punitive, and inconsistent with human right principles.<sup>35</sup> While some of the more “extreme practices” of past decades no longer occur, the report notes that “the use of ‘secure’ rooms and units for children persists and continues to be a source of grave concern.”<sup>36</sup>

## Research and policy implications

Australia and New Zealand are high-income countries with high scores on indices of public trust and democracy.<sup>37</sup> And yet, recent major inquiries in both countries show that there have been decades of widespread human rights abuses involving people in state care, including children.<sup>38</sup> Numerous recent inspections of places of detention in Australia and New Zealand have shown that at least some of the abusive practices referred to in the inquiries are still happening in prisons and youth detention centers.

As signatories to OPCAT, Australia and New Zealand have adopted mechanisms for monitoring places of detention. However, there are still major gaps in routine reporting, in part because of ambiguous definitions and a lack of transparency involving restrictive practices that may or may not amount to solitary confinement. Regardless of definitions, the amount of time that people in Australian prisons spend out of cells is already routinely reported by the Productivity Commission; and in New Zealand, these data are routinely collected and reported internally by the Department of Corrections. This suggests that mandatory public reporting of all episodes in which a person spends less than two hours per day outside their cell would not be difficult, at least for adult custodial settings. We argue that to prevent further human rights violations such as those identified in recent inquiries, this reporting should be routine and mandatory for both prisons and youth detention facilities.

Mandatory reporting will require clear, universally agreed-upon definitions for key terms such as segregation, separation, confinement, and isolation. There must be fewer terms used to describe the same thing. Routine reporting on restrictive practices should include information about the person affected, including sex, age, ethnicity, and the presence of any physical, mental, or cognitive disability. It should also record the main reason for the restrictive intervention and its duration.

Research is needed to help develop better alternatives to solitary confinement. While this is not straightforward, there is already a large body of literature from the mental health sector on how to reduce restrictive practices.<sup>39</sup> Many of these practices could be adapted for use in custodial settings. The recent eradication of tie-down beds in New Zealand prisons shows that research-led changes in restrictive practices can be achieved on a national scale.<sup>40</sup> If Australia and New Zealand wish to avoid repeating the wrongs of the past, both countries must commit to protecting the rights of their most disadvantaged people, including those who are incarcerated.

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# Discrimination in Health Care: A Scoping Review of the Ontario Experience

GEORGE DRAZENOVICH

## Abstract

This scoping review examines systemic and direct health care discrimination in Ontario, Canada, from 2021 to 2024, analyzing claims, contexts, affected groups, interventions, and research gaps. It reviews 23 Human Rights Tribunal of Ontario cases, 11 articles, and 5 gray literature reports. Findings highlight prevalent discrimination claims, including denial of service, denial of entitlement, service removal, and reprisal, which disproportionately affect Indigenous Peoples, racialized groups, and individuals with disabilities. Studies emphasized policy and educational interventions, advocating culturally informed practices and rural resource equity. Following the spirit and intent of human rights law, which is preventative and remedial and not punitive, the review recommends several policy reforms, increased representation of marginalized groups, and mediation to address claims. It urges codifying health care as a constitutional right to ensure an inclusive system meeting Ontario's diverse needs.

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*There are many good recommendations from the jury, but they are meaningless if they are not acted on and nothing changes. Nothing can undo what has happened, but the status quo is unacceptable. It is our responsibility to honour Ruthann by ensuring that these recommendations are implemented and make transformative changes in the delivery of health services for our communities so that these tragedies don't continue to happen.*

—Grand Chief Alvin Fiddler on the Coroner's Inquest into Ruthann Quequish<sup>1</sup>

Ruthann Quequish lived in Kingfisher Lake First Nation, a community in Northwestern Ontario, Canada; at 31 years of age, she died of diabetes-related complications after making several visits to the community's nursing station.<sup>2</sup> The Office of the Chief Coroner conducted a discretionary inquest to investigate the circumstances surrounding Ruthann's death. According to Kate Forget, inquest counsel with the Indigenous Justice Division of Ontario's Ministry of the Attorney General and member of Matachewan First Nation, discretionary inquests are held as a public service to identify systemic issues and arrive at recommendations for, in this context, how the health system can be improved so that more equitable health care can be provided.<sup>3</sup> The inquest provided several constructive recommendations for concrete actions and reforms that various health care groups named in the jury's findings could implement.<sup>4</sup> Adding to these findings, Grand Chief Alvin Fiddler stated, "Ultimately, it was neglect, racism, and chronic underfunding that killed Ruthann. There is a critical lack of health care services across [Nishnawbe Aski Nation] territory that continues to claim the lives of our members."<sup>5</sup> Neglect, racism, and chronic underfunding are systemic issues that perpetuate health care discrimination in Ontario. Canadian courts have consistently defined discrimination as differential treatment—intentional or unintentional—that disadvantages individuals or groups based on protected grounds.<sup>6</sup> Protected grounds refer to "age, ancestry, colour, race, citizenship, ethnic origin, place of origin, creed, disability, family status, marital status (including single status), gender identity, gender expression, receipt of public

assistance (in housing only), record of offences (in employment only), sex (including pregnancy and breastfeeding), sexual orientation."<sup>7</sup>

Differential treatment in health care experienced by Indigenous Peoples and other racialized and marginalized groups, globally and in Canada, can constitute a violation of international human rights. This includes article 12(2)(d) of the International Covenant on Economic, Social and Cultural Rights, which mandates the progressive realization of health rights.<sup>8</sup> In addition, it may compromise article 25(1) of the Universal Declaration of Human Rights, a guiding principle for human rights.<sup>9</sup> In Canada, such disparities may violate sections 7 and 15 of the Canadian Charter of Rights and Freedoms, which protect the security of the person and equality.<sup>10</sup> The Supreme Court of Canada, in *Chaoulli v. Quebec (Attorney General)*, interpreted section 7 to include timely access to health care, stating that "access to a waiting list is not access to health-care."<sup>11</sup> At the same time, discrimination based on protected grounds directly implicates section 15. Courts assess violations by examining whether the state has taken reasonable and progressive steps to address differential treatment and disparities.

This review aims to analyze health care discrimination in Ontario and support the province in implementing effective solutions in line with human rights obligations regarding health care. Canadian legal scholars suggest that the equality rights framework of the Canadian Charter of Rights and Freedoms should address systemic disadvantages, including barriers to health care access, as a matter of constitutional protection.<sup>12</sup> Groups such as the Wellesley Institute recommend codifying the right to health care in domestic law, including constitutional protections, to align with Canada's international obligations.<sup>13</sup>

Building on previous scoping reviews by Sarah Hamed et al. and Sibille Merz et al. on health care discrimination in other jurisdictions but focusing on the Ontario experience, this review aims to (1) determine the context of discrimination claims (e.g., denial of entitlement, denial of service, removal of service, reprisal); (2) summarize what kind of discrimination claims (direct or systemic)



are being made; (3) identify which groups are most represented in discrimination claims and studies; (4) describe what is currently being done or what recommendations are being made to address the issue; and (5) identify further remedies, including rights-based ones, to better prevent discrimination from arising.<sup>14</sup>

## Rationale

While Canadians value the public health care system, they, along with 92% of physicians, agree that it requires significant reform, according to a survey commissioned by the Canadian Medical Association.<sup>15</sup> When asked for focus areas for reform, survey respondents identified timely access, equity, and sufficient supplies and support for health care professionals. Additionally, discrimination in Canadian health care is linked to adverse health outcomes, such as unmet care needs among Indigenous and other racialized groups, including Black and South Asian populations, underscoring the urgency of reform.<sup>16</sup> Discrimination has tangible health consequences. For instance, Jude Mary Cénat found that 32.55% of Black participants experienced significant discrimination, linked to lower COVID-19 vaccination rates and higher anxiety.<sup>17</sup> Similarly, Wanda Phillips-Beck et al. reported a 5.2 odds ratio of unmet health care needs for Indigenous People facing racism, deterring care-seeking.<sup>18</sup> To better grasp the scope of discrimination in the Canadian health care system, it is essential to situate the review within Ontario's context. This is due to the unique features of Canada's health care system.

## Canadian health care context

As Danielle Martin et al. explain in *The Lancet*, the Canadian health care system “is less a truly national system than a decentralized collection of provincial and territorial insurance plans covering a narrow basket of services, which are free at the point of care. Administration and service delivery are highly decentralized, although coverage is portable across the country.”<sup>19</sup> The Canada Health Act pro-

vides the framework for how the public health care system in Canada is funded and operationalized, including which jurisdiction (federal, provincial, or territorial) has responsibility for which areas.<sup>20</sup>

Thus, when reviewing the scope of discrimination in the health care system, it is important to study provincial jurisdictions specifically, as provincial governments bear the brunt of responsibility for delivering services to the people of any given province. Canadian provinces maintain a great deal of authority and responsibility regarding health services. However, national ethics and the Canada Health Act still bind provinces together regarding the maintenance of a publicly funded and accessible health care system.

Consequently, in Canada, health care is considered a public service, protected and guided by federal law but delivered by provinces. The Ontario Human Rights Code protects vulnerable people according to what is referred to in the code as protected grounds and in what is referred to as protected areas, including health care.<sup>21</sup> Human rights legislation aims to prevent discrimination from occurring in the first place and, where it is found to have occurred, provide remedies that can, to the extent possible, bring the person back to wholeness and restore any rights that may have been violated.<sup>22</sup>

This review approaches discrimination in health care according to the spirit and intent of human rights law, which is preventative and remedial, not punitive. Therefore, the primary interest of this scoping review is to discover common themes regarding instances of direct or systemic discrimination in Ontario; find out what actions health care services are currently taking to prevent discrimination; and summarize the literature's recommendations for how the health care system can build a more inclusive and responsive approach to the needs of diverse groups.

## Materials and methods

This scoping review analyzed claims and reports of health care discrimination by reviewing empirical qualitative, quantitative, and mixed-method stud-

ies on discrimination in Ontario and findings from the Human Rights Tribunal of Ontario (HRTTO).

The review sought to determine what kind of discrimination claims are being made, to which protected group people belong (referred to in human rights law as the protected ground), and what orders or recommendations are being made to address the issue(s) (referred to in human rights law as remedies). The review was based on the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) extension for scoping reviews, which supports transparency and objectivity.<sup>23</sup>

### *Search strategy*

**Time frame.** To better manage volume and content and to cover, at least in part, the pre- and post-pandemic period during which specific claims were made regarding COVID-19 restrictions or mandates, I applied a time frame of three years (2021–2024). COVID-19-related cases emerged organically from the data due to public health interventions. Additionally, this time frame tracks with that of the published scoping review of Hamed et al. and Merz et al., making comparisons and synergies between these more relevant.<sup>24</sup>

**Databases.** I used several databases. CanLII (a public database of Canadian legislation and court rulings) was utilized to identify HRTTO cases.<sup>25</sup> ProQuest and PubMed were used to identify peer-reviewed studies. A search using Microsoft's AI Copilot was used to access reports from prominent bodies responsible for delivering reports of discrimination and improving the health care system. These bodies include the Canadian Medical Association, the Ontario Medical Association, the Patient Ombudsman of Ontario, and the Ontario Human Rights Commission.

**Search terms.** For the literature review, I used the search terms “discrimination,” “healthcare,” “Ontario,” “equity,” and “rights” to capture health care discussions within a human rights framework, based on discussions with academic supervisors and consultation with previous reviews, notably

Merz et al. and Hamed et al. For the HRTTO cases, I used the search terms “discrimination,” “health,” “care,” “rights,” “access,” and “decision”; I excluded “equity” because it is not a standard legal term in tribunal jurisdiction. I did not use “COVID” as a search term because the focus was on discrimination broadly, not pandemic-specific issues, although these issues, among others, arose during this period. A brief subsection in the discussion further contextualizes COVID-19's relevance to the review.

**Inclusion and exclusion criteria.** I included only those subjects pertaining to discrimination in health care in the province of Ontario between 2021 and 2024. Excluded articles include those with no nexus with the issue of discrimination in health care, as described above. HRTTO records that were process-oriented and administrative, such as a decision on publication bans without reference to the substance of the case, were excluded. Finally, peer-reviewed articles were excluded if the study had no nexus with a health care setting, system, or service.

**Data extraction.** I extracted all records, reports, and judicial findings from the aforementioned databases and websites.

The CanLII database yielded 78 results. After conducting a review of all of these cases, I excluded 55 of these because they did not meet the above-mentioned inclusion and exclusion criteria. This left me with a total of 23 HRTTO cases.

The ProQuest search yielded 33 studies. After screening the records' content and reports for adherence to the inclusion and exclusion criteria, I selected 11 studies. As with the CanLII search, some of the articles lacked a nexus with an identified health care setting, although they focused on the experience of racialized and other protected groups. The PubMed search yielded three studies, but I excluded all of them because they did not meet the inclusion and exclusion criteria.

For the gray literature search, the Ontario Human Rights Commission website yielded one report that fell within the search criteria; the Ontario

Medical Association yielded one; the Ontario Patient Ombudsman yielded one; and the Canadian Medical Association yielded two.

In total, 119 records were identified, with 39 retained: 23 HRT0 cases, 11 studies, and 5 reports. Figure 1 provides a PRISMA flow diagram for the scoping review process.

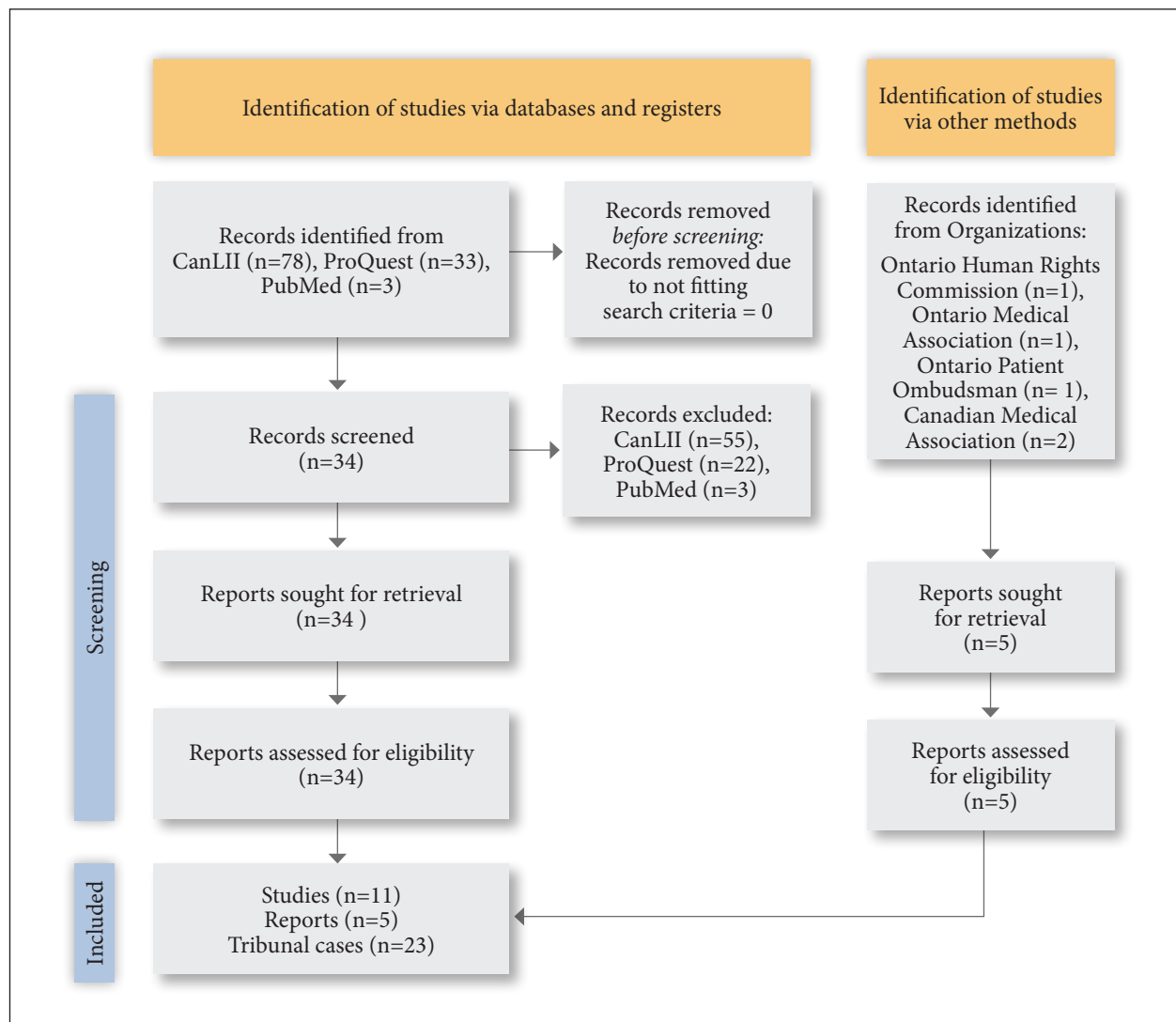
## Results

This section presents findings from the HRT0 cases, empirical studies, and gray literature, organized into subsections for clarity.

### *Human Rights Tribunal of Ontario cases*

Table 1 summarizes the 23 HRT0 cases by claim context, type of discrimination claim, protected grounds, and outcomes. Claims centered on the denial of entitlement (5), denial of service (13), removal of service (4), and reprisal (3), with 9 claims of direct discrimination and 14 claims of systemic discrimination. Disability (18) was the most cited ground, followed by sex (4), age (4), and others. Outcomes showed 9 cases founded, with others dismissed due to no finding of discrimination (6), timeliness (4), mootness (1), or jurisdiction (3). Jurisdictional limits often arose where clinical

FIGURE 1. PRISMA flow diagram



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decisions were outside the HRT0's scope.

An example of denial of entitlement is *A.H. v. Ontario (Children, Community and Social Services)*.<sup>26</sup> In that case, the applicant, A.H., claimed that policy limitations set by the Ontario Autism Program limited A.H.'s access to the level and range of programming recommended by their treating professionals. Thus, in this instance, the respondent was the government organization responsible for providing those entitlements. A.H. claimed that the provincial government agency interpreted the policy in a way that discriminated against them, denying A.H. this program entitlement.

An example of denial of service is *Beckford v. Ontario (Solicitor General)*.<sup>27</sup> In that case, Beckford claimed that the staff in the custodial facility to which he was sentenced placed him in a segregation unit, fully aware of his medical conditions and that such an act would exacerbate them. In so doing, Beckford claimed, the custodial facility denied him service.

An example of the removal of service is *Pankoff Estate v. The Corporation of the City of St. Thomas*.<sup>28</sup> The Pankoff Estate claimed that the long-term care facility discharged their family member after she was transported to the hospital due to issues associated with dementia. That experience was categorized as a removal of service.

As an example of reprisal, in *Fife v. Sienna Senior Living Inc.*, the applicant claimed that they were "reprised against by limits in visiting time when their mother was in palliative care and by the lack of quality care provided by the respondent facility and its staff" due to complaints the applicant

made about their mother's care.<sup>29</sup> In human rights law, a service or person cannot take punitive action against someone or their family because they raise a discrimination claim. In *Fife*, the adjudicator wrote:

*As the Tribunal set out in Noble v. York University ..., in an allegation of reprisal, the following elements must be established: a. An action taken against, or threat made to the applicant; b. The alleged action or threat is related to the applicant having claimed or attempted to enforce a right under the [Ontario Human Rights Code]; and c. An intention on the part of the respondent to retaliate for the claim or attempt to enforce the right.*<sup>30</sup>

After reviewing all 23 cases, I classified each one according to the type of discrimination being alleged: direct or systemic. This distinction was based on whether the discriminatory issue was a policy (categorized as systemic) or action that someone took (categorized as direct). As discussed further below, most cases cannot easily be classed as systemic or direct because they intersect. Interpretation and application of a policy drives a behavior, and vice versa. Nonetheless, these distinctions are useful when considering remedies. For systemic-oriented issues, policy or procedure changes can be made, while for direct cases, training can be provided to prevent similar situations from arising again or to provide compensation to the applicant to remedy injury to them as a result of the violation of their rights. For example, in *Powell v. Ontario (Solicitor General)*, the adjudicator found that discrimination occurred when the police failed to accommodate

TABLE 1. Human Rights Tribunal of Ontario cases (n=23)

Context of claims*	Type of discrimination	Protect ground(s)**	Outcome
Denial of entitlement (5) Denial of service (13) Removal of service (4) Reprisal (3)	Direct (9) Systemic (14)	Disability (18) Sex (4) Age (4) Gender expression (2) Sexual orientation (1) Family status (3) Ancestry (2) Race (3) Creed (4)	Dismissed – no discrimination found (6) Dismissed – due to timeliness (4) Dismissed – due to mootness (1) Dismissed – outside jurisdiction (3) Founded (9)

\* Some cases centered on more than one issue.

\*\* Applicants often listed more than one protected ground.

Powell's disability when she was in custody.<sup>31</sup> As a remedy, in addition to the respondent paying the applicant C\$2,000 in compensation for injury to dignity, feelings, and self-respect, the tribunal stated that the facility needed to "retain an external consultant, with human rights experience, to conduct a review of its policies, procedures, and protocols which relate to the screening of individuals when entering into custody, to ensure that they comply with the Code and in particular the recognition and treatment of persons with diabetes in their custody."<sup>32</sup> In this way, the systemic change in procedure may change the direct practice moving forward. Systemic reforms can therefore have a direct effect.

The claim of protected ground is self-explanatory. People can and do list several protected grounds that they believe are factors in their discrimination (e.g., disability, age, race). The adjudicator goes through these grounds to find evidence to support the claim. One of the limitations of the traditional system of an adjudicator selecting just one ground and conducting analysis on that ground is that it ignores the reality that multiple grounds of discrimination intersect. People often belong to several protected grounds simultaneously, and it is not easy to discern which specific ground was a factor in discrimination. This reality is reflected in many of the cases reviewed.

Finally, I looked at the outcome of each case. In particular, I analyzed the basis for dismissal in the 14 cases that were dismissed, as this is important for understanding the limitations in making claims before the HRTO and finding or creating alternative pathways for resolution. Frequently, adjudicators cite jurisdictional issues for why they need to dismiss a case. For example, in *Parratt v. Lakeridge Health*, the applicant alleged that they were discriminated against in the health facility due to a mental health disability when the facility used restraints on them and made other clinical decisions in the context of providing emergency medical care.<sup>33</sup> The adjudicator found that it was outside of the HRTO's jurisdiction because clinical decisions, even if later found to be incorrect, are outside the scope of the court's adjudication.

In arriving at their decision, the adjudicator—as many adjudicators did in the reviewed cases—drew on *Moshi v. Ontario (Ministry of Community Safety and Correctional Services)*. In *Moshi*, the HRTO found that

*The Tribunal has no jurisdiction to review a physician's clinical decisions based on whether or not they were medically appropriate: Kline v. Ontario (Community Safety and Correctional Services) ...; Canada Health Act v. London Health Sciences Centre ... An applicant cannot establish that a physician, for example, discriminated against him or her merely by showing that the doctor made a clinical decision based on the applicant's disability, which clinical decision turned out to be disadvantageous for the applicant. Doctors may make sound clinical decisions that end up compromising their patient's health, for some reason. They can also make mistakes that have adverse medical consequences for their patients. However, neither of these situations constitutes discriminatory treatment under the [Ontario Human Rights Code] ... To establish that a physician, for example, has discriminated against someone "because of" disability, an applicant would have to establish that there was some arbitrariness in the manner the physician treated him because of his disability. As the Supreme Court emphasized in McGill University Health Centre (Montreal General Hospital) v. Syndicat des employés de l'Hôpital général de Montréal ... the essence of discrimination is in the arbitrariness of its negative impact.<sup>34</sup>*

The period of this scoping review covered the COVID-19 pandemic, when masking and vaccines were prescribed by law. Interestingly, the protected grounds of cases that challenged vaccine mandates were frequently cited as creed and largely dismissed as outside of HRTO jurisdiction. For example, in *Oulds v. Bluewater Health*, in response to the mandatory vaccine requirement, the applicant stated to the respondent, a hospital requiring mandatory vaccinations:

*I am fully vaccinated with all the childhood vaccine requirements and my adult boosters are up to date. I am not against medical advancements. I would require more information before taking any treatment that has not been thoroughly identified or tested. I have a conscience given to me by my*



*Creator. That God conscience I access through prayer and meditation. This forms part of my connection to my Creator. Upon accessing that conscience, I am simply told by my Creator “no” in regard to this mandatory vaccination.<sup>35</sup>*

The respondent refused to accommodate on those grounds, stating, “Given that you have received previous vaccinations, these personal beliefs do not preclude you from being vaccinated. Moreover, even if the Hospital is wrong in its assessment of your creed beliefs, the Hospital is unable to accommodate your request to be exempt from the application of the policy.”<sup>36</sup>

The adjudicator noted that courts have struggled with the ground of creed, stating:

*The [Ontario Human Rights Code] itself does not define creed ... In an effort to assist with an understanding of what creed refers to, the Ontario Human Rights Commission enacted a policy recommending that the following characteristics are relevant when determining if a belief system is a creed under the Code. A creed: Is sincerely, freely and deeply held; Is integrally linked to a person's identity, self-definition and fulfilment; Is a particular and comprehensive, overarching system of belief that governs one's conduct and practices; Addresses ultimate questions of human existence, including ideas about life, purpose, death, and the existence or non-existence of a Creator and/or a higher or different order of existence; Has some nexus or connection to an organization or community that professes a shared system of belief ... I agree with and adopt the policy of the Commission. I note that a different adjudicator at this Tribunal has very recently upheld this definition of creed in Yeomans v. Superette.<sup>37</sup>*

The adjudicator dismissed the application, writing that while they accepted that the applicant's belief was sincerely and deeply held and that it may even be linked to their self-identity and self-definition, there was no additional basis upon which they could determine that it meets the other criteria to be considered a creed:

*If the submissions had included some examples about other life-guiding beliefs arrived at through dialogue with the Creator, or about other “alterations” to the*

*body that they similarly reject on the same grounds, then perhaps there could be connection to a particular and comprehensive, overarching system of belief ... What is left seems focused on a singular belief around the lack of efficacy of the COVID-19 vaccine and some perception that the vaccine could alter DNA, and the need for autonomy to make this specific vaccine choice. In the circumstances of this case, I find that the applicant has not demonstrated that “bodily autonomy”, including the personal choice not to vaccinate, even if the applicant has a sincerely held belief that it was dictated by a Creator, comes within the meaning of creed under the Code.<sup>38</sup>*

Consequently, the application was dismissed as being outside of the jurisdiction of the HRTO. The role of the HRTO is not to evaluate public health interventions but to assess for discrimination and, where it is found, apply remedies. In this case, the HRTO did not find that the ground of creed was satisfied—and that consideration, not the vaccine mandates, was the issue before it.

### *Empirical studies*

Table 2 summarizes the 11 articles found on ProQuest by study context, focus (direct or systemic), population, and recommendations. Contexts were public health policy (6) and education (5), with 3 systemic and 8 direct focuses. Vulnerable populations included Indigenous populations (3), racialized groups (3), and others. Recommendations ranged from strengthening rural health units to incorporating Indigenous cultural safety education. For instance, Ana Paula Belon et al. noted rurality as a vulnerability, suggesting equitable resource allocation.<sup>39</sup> Javiera-Violeta Durán Kairies et al. found that land-based education improved professionals' equity awareness for Indigenous care.<sup>40</sup>

After a review of the literature, I identified two main contexts of the studies: public health policy and education. Regarding policy, Belon et al. focus their review on inequities across public health units in Ontario.<sup>41</sup> As they write, “Public health units (PHUs), the regional public health bodies, are now required to address health equity through four requirements: (a) Assessing and Reporting; (b) Modifying and Orienting Public Health Interven-

tions; (c) Engaging in Multi-sectoral Collaboration; and (d) Health Equity Analysis, Policy Development, and Advancing Healthy Public Policies.” They were interested in how these reporting frameworks, one domain involving health equity analysis, were being implemented. The focus of their work, therefore, was systemic.

Interestingly, they identified rural communities as a vulnerable population and recommended that resources be directed equitably to support rural public health groups in their efforts to analyze health equity in their jurisdictions. Rurality is not a protected ground that people can claim under the Ontario Human Rights Code, but it is an issue discussed in the literature on human rights. Amanda Lyons writes:

*Rurality intersects with other identities, power dynamics, and structural inequalities—including those related to gender, race, disability, and age—to create unique patterns of human rights deprivations, violations, and challenges in rural spaces. Therefore, accurately assessing human rights and duties in rural spaces requires attention to the dynamics of rurality in a particular context, the unique nature of diverse rural identities and livelihoods, the systemic forces operating in and on*

*those spaces, and the intersections with other forms of structural discrimination and inequality.*<sup>42</sup>

The context of education refers to studies done to address discrimination in health care settings through educational interventions. As an example, Durán Kairies et al. describe how cardiovascular disease disproportionately affects Indigenous Peoples in Ontario.<sup>43</sup> Their research team was interested in determining the effect of a land-based educational intervention for professionals at a cardiac care center and university in a large urban city. The focus of their work was therefore categorized as direct. Durán Kairies et al. write that among the results they found was that participants, “by identifying and reflecting on their own power, positionality and privilege throughout the course, learned how to apply the knowledge they learned to create or further social change in the interest of equity and justice for Indigenous Peoples.”<sup>44</sup>

### Gray literature and reports

FivereportsfromtheCanadianMedicalAssociation, Ontario Human Rights Commission, and others highlighted commitments to address discrimination. The Canadian Medical Association apologized

TABLE 2. Articles found through ProQuest (n=11)

Context of study	Direct or systemic focus	Vulnerable population(s)*	Recommendations
Public health policy (6) Education (5)	Systemic (3) Direct (8)	Urban (2) Urban-rural (1) Rural (1) Racialized groups (3) Indigenous (3) South Asian (1) Disability (1) Gender (1) Gender expression (1)	Strengthen rural health units Engage and collaborate with vulnerable, racialized groups in design of health systems Support Indigenous ways of knowing and being with medical professionals Ensure that best practice policies reflect the diversity of communities Improve equity in health communications Incorporate Indigenous cultural safety education to foster an anti-racist work culture, as well as improved health Build awareness around the invisibility of mental health challenges Address challenges that perpetuate health inequalities so that people from remote communities have the dignity to die with their people, families, and culturally relevant supports Educate on unconscious bias and subtle norms that perpetuate gender bias Engage racialized people in the design of policies and quality improvement to address experiences of discrimination and racism at service centers Educate physicians on the range of trans issues

\*More than one vulnerable population may have been the focus of the studies

for failing Indigenous health equity, outlining three commitments: advancing Indigenous health, supporting reconciliation, and promoting internal change. The Ontario Human Rights Commission announced a policy to tackle Indigenous-specific discrimination, with Chief Commissioner Patricia DeGuire calling it “intolerable.”<sup>45</sup>

In 2024, the Canadian Medical Association apologized to Indigenous Peoples for failing to adequately use its privileged position as one of the leading national voices of health care physicians to advance equitable access to health care for Indigenous Peoples.<sup>46</sup> As part of its statement, the association, in collaboration with its Indigenous partners, outlined three major national commitments moving forward: (1) advance Indigenous health; (2) support physicians’ journey to truth and reconciliation; and (3) promote reconciliation for association employees and leadership. In 2023, the association published an article on equity and diversity in medicine, highlighting how gender discrimination affects women and impacts patient care, along with how health care leaders can promote change through policy reform.<sup>47</sup>

In April 2024, the Ontario Human Rights Commission announced that it is working on a policy to address discrimination against Indigenous Peoples in the health care system. In the statement, Chief Commissioner Patricia DeGuire said, “Indigenous-specific discrimination is pervasive throughout our health care system. This is intolerable. The Commission calls for immediate and practical change. The engagements and the survey are the start of the Commission’s work to develop vital human rights guidance to help prevent and address this discrimination.”<sup>48</sup>

In 2023, Sophie Nicholls Jones wrote an article for the Ontario Medical Association noting that while progress has been made, much work needs to be done to address systemic racism in Canada. In that article, Mojola Omole, a board member of the Black Physicians’ Association of Ontario, in reflecting on her experience in medical school, said, “We didn’t really talk openly about systemic racism. We didn’t talk about what microaggressions are.”<sup>49</sup> To remedy this experience, the article suggests

increasing black representation in medical schools and reviewing the curriculum to examine implicit and explicit bias and how faculty and the student body contribute to its perpetuation.

## Discussion

### *Tribunal review: Strengths, limitations, options for mediation, and intersecting grounds*

This review analyzes human rights tribunal cases, unlike many scoping reviews. Western democracies designate tribunals and courts to adjudicate human rights claims, particularly in health care discrimination. HRT cases often result in remedies such as compensation and policy revisions, but, as noted in many of the cases reviewed, face jurisdictional limits, particularly concerning clinical decisions, because they require arbitrariness to be deemed discriminatory. HRT adjudicators, while experts in human rights law, are not medical experts and frequently defer to clinicians when assessing the appropriateness of clinical interventions for a given patient, unless there is clear *prima facie* evidence that a decision was arbitrary. With its procedural and legal burden of proof, the formal tribunal process is not well-positioned to address the unconscious bias prevalent in many health care settings.

Jasmine Marcelin et al. discuss how unconscious bias affects patient-clinician interactions within health care settings.<sup>50</sup> Dipesh Gopal et al. highlight that bias can influence clinical decision-making, contributing to diagnostic errors and cognitive biases that impact patient safety.<sup>51</sup> Although the formal tribunal process is not well suited to finding unconscious bias as part of its adjudication decisions, tribunals can still encourage alternative forms of resolution and disposition. Mediation is an effective means to address these experiences because it is a different kind of procedure than the adversarial method characterizing the formal tribunal process.<sup>52</sup>

Mediation resolves nearly 60% of HRT cases before they reach the formal adjudication stage.<sup>53</sup> The HRT promotes mediation, announcing in October 2024 that it is “preparing to

launch a mandatory mediation process whereby all applications will proceed to a mediation, after confirming jurisdiction. Mediations have proven to be very successful in resolving applications at the HRTO and are aligned with the HRTO's mandate, which encourages resolution through alternative dispute resolution methods rather than traditional adversarial approaches.<sup>54</sup> Given these directions, health care providers might consider investing in mediation training and processes to resolve discrimination claims early to arrive at faster remedies and drive policy changes.

Another issue identified in the review of HRTO cases was that applicants frequently selected multiple grounds of discrimination regarding their personal characteristics. In the HRTO cases reviewed, many applicants claimed multiple grounds of discrimination in a single case, and most often, the adjudicator analyzed each ground separately, as this is a standard adjudication procedural process. However, as noted by the Ontario Human Rights Commission, the Supreme Court of Canada has recognized the problem with this approach:

*Writing for the minority in the Mossop case, Madam Justice L'Heureux-Dubé remarked, "it is increasingly recognized that categories of discrimination may overlap, and that individuals may suffer historical exclusion on the basis of both race and gender, age and physical handicap or some other combination ... categorizing such discrimination as primarily racially oriented, or primarily gender-oriented, misconceives the reality of discrimination as it is experienced by individuals. Discrimination may be experienced on many grounds, and where this is the case, it is not meaningful to assert that it is one or the other. It may be more realistic to recognize that both forms of discrimination may be present and intersect."<sup>55</sup>*

Most applicants, as found in the analysis of the HRTO cases, claimed multiple grounds. This review suggests that the experience of intersecting grounds of discrimination and the impact of such intersections should be an essential focus for the judiciary and health and social scientists. The reality of intersecting identities when assessing and interpreting discrimination is an important area

for further research because, as noted by Justice L'Heureux-Dubé, it reflects lived experience. Models and interventions addressing people presenting with intersecting grounds is a promising area of further inquiry and development.

### *COVID-19 and discrimination claims*

COVID-19 public health interventions raised significant public controversy and became highly politicized during this scoping review's time frame. Consequently, it is important in the interest of a more fulsome review to briefly discuss some of the literature surrounding the pandemic in relation to discrimination in health care. Vaccine hesitancy was stronger among minority and lower socioeconomic groups in Canada.<sup>56</sup> Groups such as the Canadian Civil Liberties Association called attention to the human rights concerns and civil liberty implications of COVID-19 public health interventions.<sup>57</sup> Kevin Bardosh notes that too many human rights organizations were silent during this period, a moralizing narrative tended to accompany interventions, and there was very little tolerance for debate or dissent, hallmarks of liberal democracies.<sup>58</sup> Irrespective of where one lands on the public health policy response to COVID-19, there is broad consensus among leading Canadian physicians, health organizations, and advocates that a national inquiry into Canada's COVID-19 response is required to address a range of issues related to the impact of the public health interventions, including differential impacts for minority groups and important civil liberties implications.<sup>59</sup>

### *Rurality as a protected area*

Lyons's identification of rurality and the systemic forces operating in rural spaces, combined with the intersections with other forms of structural discrimination and inequality, is a unique perspective and deserves further and more sustained analysis in Ontario. Statistics Canada provides the foundational framework for rural definitions in health data.<sup>60</sup> Many of Ontario's health organizations adopt these definitions.<sup>61</sup> The health care gap in Ontario between urban and rural/small population



centers is marked by disparities in provider access, service availability, travel burdens, wait times, health outcomes, infrastructure, and workforce retention.

Rural and small population centers face systemic challenges, including fragmented mental health services and reliance on urban centers for specialized care. Injury rates, particularly from motor vehicle collisions, increase with rurality due to longer driving distances and hazardous work environments (e.g., agriculture).<sup>62</sup> Rural physicians are forming associations and groups to address the unique needs of people in rural settings. Ruth Wilson et al., for example, note that

*policy decisions are often guided by urban health care models without understanding the potential negative effects in rural communities. Rural communities need rural-based solutions and to develop regional capacity to innovate, experiment, and discover what works. An opportunity exists to narrow health disparities by providing care closer to home. Rural communities need an effective health care system with a stable workforce.*<sup>63</sup>

The literature, including Wilson et al., identifies several strategies aimed at developing evidence-based rural health care planning that accounts for unique community needs.<sup>64</sup> The Canadian Medical Association recommends strengthening workforce retention through the implementation of immigration policies to attract health care workers to rural areas, paired with supports such as competitive salaries and community integration.<sup>65</sup> The Canadian Mental Health Association calls for improved funding models to account for rural disparities, adequate resources for mental health and specialized care, and better data to optimize resource distribution.<sup>66</sup>

## Conclusion

The purpose of this scoping review was to discover common themes regarding instances of direct or systemic health care discrimination in Ontario; find out what is currently being done to prevent discrimination; and summarize the literature's recommendations for how the health care system can

build a more inclusive and responsive approach to the needs of diverse groups. Implicit in this scoping review was the presumption that most Canadians view health care as a fundamental entitlement. As noted by the Standing Senate Committee on Social Affairs, Science and Technology:

*the existence of public opinion polls that reveal that Canadians, encouraged by politicians and the media, believe they have a constitutional right to receive health care even though no such right is explicitly contained in the Charter. Nor does any other Canadian law specifically confer that right, although government programs exist to provide publicly funded health services.*<sup>67</sup>

Scoping reviews like this one provide people invested in this issue the necessary data to move forward with meaningful reforms that preserve the value of Canada's publicly funded and accessible health care system, which is rightly a source of pride for Canadians.<sup>68</sup>

The next steps for those invested in building a functional, inclusive public health care system in Ontario are to build on the findings of this review to address the discrimination currently present in the province's health care system and to support meaningful and measurable remedies, including advancing proposals to enshrine the right to health as a positive, constitutional right. A rights-based approach to health care can provide leverage for groups to advocate for equitable resources to support the realization of a right to health and offer remedies for those who lack timely access to health care and who face marginalization from the health care system. Much is being done already, and these promising directions require ongoing support, sustained attention, and commitment from all stakeholders and citizens of the province. Other jurisdictions, similarly, ought to review their contexts and share those findings in public venues such as journals, conferences, and other settings so that all of us invested in health and human rights can co-construct improved systems that approximate more closely the aspirations of numerous human rights instruments that support and drive these efforts.



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# A Content Review of National Dementia Plans: Are Human Rights Considered?

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## Abstract

The World Health Organization has set a target for 75% of member states to have national dementia plans by 2025. These plans should align with human rights standards, such as the Convention on the Rights of Persons with Disabilities. The aim of this study was to complete a review of global national dementia plans and their human rights content according to the convention's principles. A categorization matrix of pre-identified human rights themes was produced prior to data collection and extensive inclusion criteria were adopted to ensure thorough assessment using deductive content analysis. Each dementia plan was

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reviewed by at least two independent assessors. Forty plans were included in the final analysis. We found that basic human rights were covered by the plans, with community inclusion acknowledged in 39 plans (97.5%). However, there was less coverage of non-coercive practices and the participation of people with dementia in the design and delivery of services or policies, with only 24 plans (60%) mentioning these aspects. This is the first global review of human rights content within national dementia plans. More must be done to ensure that all such plans align with human rights standards so that the human rights of persons with dementia are respected, protected, and promoted.

## Introduction

People with dementia often experience infringements of their human rights. For example, in many countries, such individuals have commonly been denied legal capacity due to the use of substitute decision-making processes and coercive practices in care services.<sup>1</sup> Coercive practices such as involuntary treatment, seclusion, and restraints can exclude people with dementia from the wider community and significantly worsen their well-being and quality of life.<sup>2</sup> Also, sometimes persons with dementia are provided with only limited and segregated activities, are denied choice, and have little to no access to community spaces.<sup>3</sup> Moreover, they have rarely been included in opportunities to participate in the design or delivery of services or policies that affect them.<sup>4</sup>

In 2017, the World Health Organization (WHO) adopted its Global Action Plan on the Public Health Response to Dementia 2017–2025, which aims to achieve “a world in which ... people with dementia and their carers live well and receive the care and support they need to fulfil their potential with dignity, respect, autonomy and equality.”<sup>5</sup> All 194 WHO member states adopted this plan at the World Health Assembly in 2017, signifying a commitment to make dementia a priority. The first action area of the plan calls for 75% of WHO member states to develop and implement national dementia policies, strategies, or plans by 2025.<sup>6</sup>

WHO’s Global Action Plan states that de-

mentia plans should be underpinned by human rights principles aligning with the Convention on the Rights of Persons with Disabilities (CRPD) and other rights standards.<sup>7</sup> The CRPD has been ratified by 186 countries, meaning that these governments have agreed to incorporate its principles into their policies and practices.<sup>8</sup> This is highly significant because there is growing concern over the human rights violations of people with dementia and there have been arguments that governments are not doing enough to protect those with dementia and their care partners.<sup>9</sup>

The priorities of dementia plans have ranged from specific care and treatment frameworks to the inclusion of and equality for people with dementia.<sup>10</sup> Previous reviews of dementia plans that have focused on human rights have not examined a broad range of plans; however, Alzheimer Europe identified in a 2023 report that the number of plans reporting legal mechanisms to protect legal capacity, such as advance care planning, has increased.<sup>11</sup> It also reported that the number of plans aligning with human rights standards has risen.<sup>12</sup> Hence, there is now a need for a global review of the human rights content of national dementia plans.

## Methods

### *Design*

We used deductive content analysis to conduct a comprehensive assessment of human rights content

in global dementia plans.<sup>13</sup> We chose this design due to its effectiveness in categorizing large amounts of qualitative data, allowing for a broad yet precise summarization of a particular phenomenon in both data collection and analysis.<sup>14</sup> Additionally, it is a flexible approach to collection and analysis that allows a significant number of key words relating to human rights in the national dementia plans to be identified.

### *Procedure*

**Search strategy.** We identified dementia plans through the Alzheimer Disease International (ADI) and Alzheimer Europe websites and WHO's MiNDbank database. MiNDbank is an online database that provides easy access to international resources, including national policies.<sup>15</sup> We also conducted scoping searches on Google and Google Scholar using the search strategy "country" + "dementia plan OR dementia strategy," with results limited to the first 10 pages. We conducted these searches between March and May 2023 and downloaded all plans into PDFs.

**Inclusion criteria.** To be included within our review, plans had to be:

- national dementia plans or strategies
- developed after the adoption of the CRPD<sup>16</sup>
- developed by the national government or ministry of health
- for a country that is a United Nations member state<sup>17</sup>
- publicly accessible
- written in English or amenable to translation
- the most recent version of the government plan (regardless of whether the implementation period was over)

**Translation.** We downloaded several plans not available in English. ADI recommended DocTranslator, a translation website, to help translate the plans into English.<sup>18</sup> For most plans, this website

worked well. For plans that could not be translated due to their underlying format, we copied paragraphs into Google Translate.

**Materials.** BH created a categorization matrix in the form of a template to enable a systematic content search relating to human rights. The template contained specific CRPD articles to ensure that the five human rights aspects we were particularly interested in were incorporated (see predetermined human rights themes). These included articles 5, 8, 9, 12, 14, 15, 16, 19, 25, 27, 28, and 29. We took inspiration from ADI and Dementia Alliance International's 2016 report.<sup>19</sup> We also included other words and terms synonymous with human rights, such as "autonomy," "empowerment," and "legal capacity," which allowed us to obtain a more complete picture of the human rights content. We also searched for specific mentions of the CRPD, the WHO global action plan, and the terms "human right(s)" or "right(s)." The template included space for the name and year of the plan, the name of the assessor, and a summary of the plan to be written. Additionally, BH created a glossary of the CRPD articles and rights synonyms. The template and glossary were created in Microsoft Word before the template was transferred to JISC Online Surveys V2 and shared with the team.

**Piloting.** To ensure the validity and reliability of the template, the assessors (BH, YM, JW, and SH) piloted three plans from different WHO regions. The four assessors individually searched for the human rights content using the search function (Ctrl+F) on the plans and inputted key words from the template. All assessors then read through the entire plans to contextualize the content found and ensure that no information was missed. The human rights content identified through our searches was extracted word for word, complete with the page number(s), and was submitted to the online survey template for BH to download and add to a shared OneDrive folder. BH then collated the submitted data and produced a feedback sheet before discussing this with principal investigator, MO. A team

meeting was held with the other three assessors to talk through any discrepancies. By piloting, we guaranteed the reliability of our methods regarding consistency in our analysis of plans. We also ensured high validity in our methods, using the CRPD principles and related synonyms to analyze the plans.

**Final procedure.** Once piloting was complete, the remaining plans were randomly and equally distributed among YM, JW, and SH before being randomly assigned to a second reviewer; this ensured that plans were independently assessed at least twice. After examination, the assessors met with one another to complete consensus work and discuss any discrepancies. BH read through every national dementia plan included for analysis. If no agreement could be made, BH and MO met to analyze and agree on the remaining issues. Afterward, the data were transferred to Excel spreadsheets, allowing the team to clearly identify any gaps in the content. BH and YM then combined the data and removed any duplications.

### *Analysis*

**Predetermined human rights themes.** We assembled the themes to match the rights groups from WHO's QualityRights initiative, a global initiative guided by CRPD principles that aims to improve the lives of people with mental health conditions and psychosocial disabilities, including dementia.<sup>20</sup> In its guidance for community mental health services, WHO states that the right to health for people with mental health conditions and psychosocial disabilities depends on a number of fundamental human rights principles: respect for legal capacity; non-coercive practices; participation; community inclusion; and recovery-oriented and person-centered care.<sup>21</sup> See Table 1 for definitions.

## Results

Our searches identified 58 plans worldwide. After screening (see Figure 1), we included 40 plans in our final analysis (this list is available upon request).

The eight plans we could not gain access to were those for Armenia, China, the Republic of Korea (version four), Russia, Singapore, Thailand, Uruguay (2023 version), and Vietnam. We could not translate the plan from Costa Rica due to the underlying format (the translation website would not recognize the PDF, nor could we copy and paste individual paragraphs into Google Translate). We excluded the plans of Bonaire, Curaçao, Gibraltar, Macao SAR, Puerto Rico, and Taiwan because they do not pertain to United Nations member states.<sup>22</sup> Although we were able to access the plans of Uruguay (from 2016) and the Republic of Korea (version three), we excluded them from our analysis because they are not the most recent plans.<sup>23</sup>

### *Summary of plans analyzed*

The plans analyzed were launched between 2010 and 2023, with Belgium (Wallonia) the oldest plan and Scotland's fourth version the most recent.<sup>24</sup> Plans where the implementation period had expired but no further plan had been launched (for example, Australia) were also included.<sup>25</sup> Twenty-seven plans were from the European WHO region (Austria, Belgium Flanders, Belgium Wallonia, Cyprus, Czechia, Denmark, England, Finland, France, Germany, Greece, Iceland, Ireland, Israel, Italy, Luxembourg, Malta, Netherlands, Northern Ireland, Norway, Portugal, Scotland, Slovenia, Spain, Sweden, Switzerland, and Wales), six from the Americas (Canada, Chile, Cuba, the Dominican Republic, Mexico, and the United States), three from the Eastern Mediterranean (Iran, Kuwait, and Qatar), three from Western Pacific (Australia, Japan, and New Zealand), and one from Southeast Asia (Indonesia). There were no plans from Africa. Despite the Belgium Flanders and Belgium Wallonia plans coming from one United Nations member state, we chose to include both of them due to their different governments.<sup>26</sup> Similarly, we included the plans from all four countries in the United Kingdom. Thirty-five plans were from high-income countries, four from upper-middle-income countries, and one from a lower-middle-income country.

Thirty-eight plans were dementia specific, and

two plans (Finland and Qatar) integrated dementia into other plans such as Qatar's National Health Strategy 2018–2022.<sup>27</sup> All plans provided a global and national context for their rationale, and all dementia-specific plans provided a summary of dementia as a condition, its etiology, and risk factors. Some plans also contextualized each of their action areas.

### *Human rights*

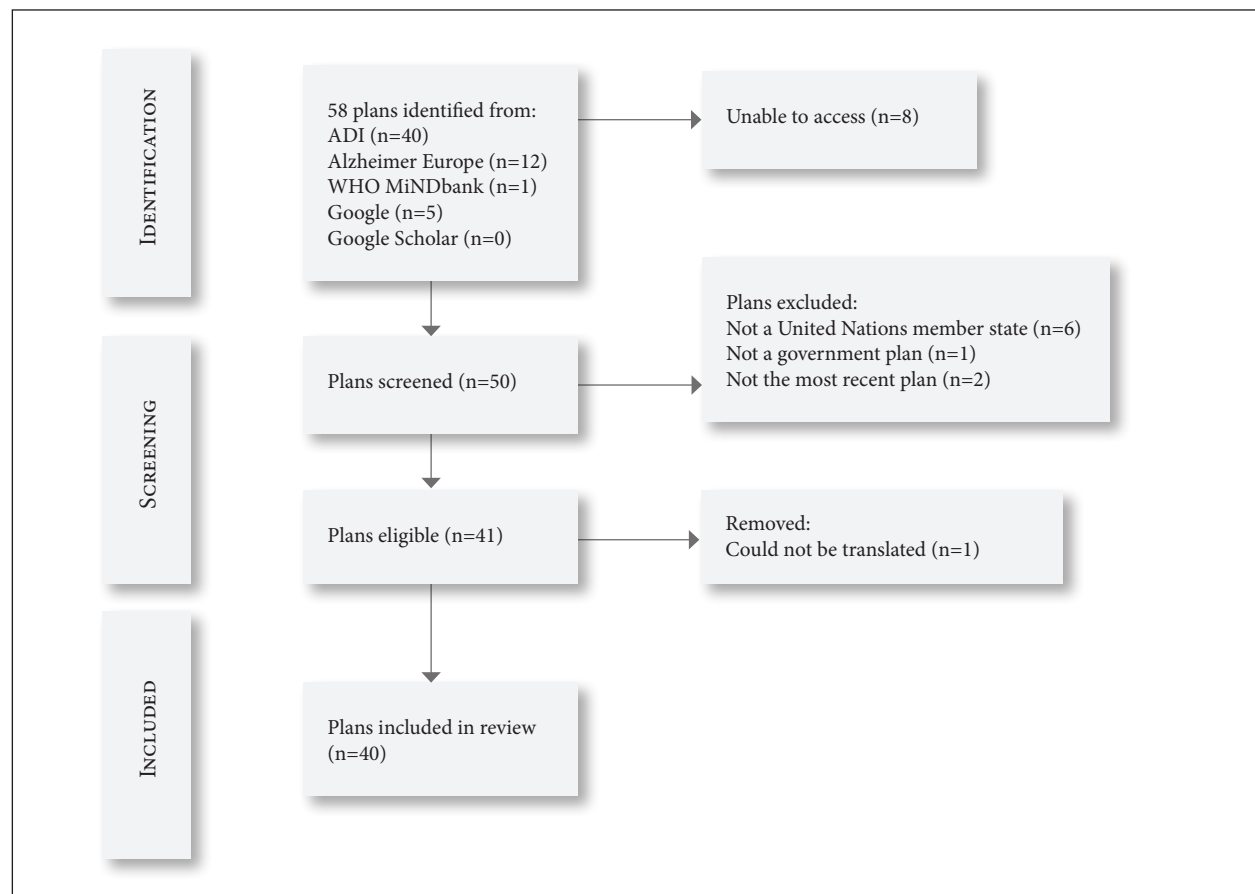
Of the plans analyzed, 11 (27.5%) mentioned the CRPD, whether in the main body of the plan or the references. In addition, 10 out of the 21 plans launched after 2017 mentioned WHO's global action plan. Table 1 shows the number of plans that mentioned anything in relation to the human rights themes, with examples of the explicit CRPD articles that relate to each theme.<sup>28</sup>

CRPD articles work together to ensure that

the human rights of persons with disabilities are respected, protected, and promoted, and hence each theme can be covered by several articles or principles. For example, the right to legal capacity—that is, the right to make decisions and have those decisions respected—could refer to decisions about things that affect a person's day-to-day life as well as decisions about things that affect the person's overall care, overlapping with the right to participation in the design and delivery of services and support options.

**Community inclusion.** People with dementia have the right to live and the right to make the same choices in life as others. They are entitled to choose where and with whom they live and to have the same access to community services as the general public.<sup>29</sup> Article 19 (living independently and being included in the community) of the CRPD, among

FIGURE 1. Screening of plans



others, encompasses this right.<sup>30</sup> We included the related term “dementia-friendly communities/societies” in our content searching. Thirty-nine (97.5%) of the plans examined mentioned community inclusion, primarily through the provision of dementia-friendly communities. Several of the references to community inclusion were recognitions that people with dementia should be included in the community and should be supported in this endeavor. To achieve this, many plans stated that dementia-friendly communities would be created in the wider community.

*People with dementia should be able to participate in social and community life. (Austria)<sup>31</sup>*

*Develop dementia friendly communities, where*

*all aspects of the community's built environment and approaches are dementia friendly, inclusive, promote respect and acceptance and enable participation. (Australia)<sup>32</sup>*

**Recovery-oriented and person-centered care.** Recovery-oriented care means enabling people with dementia to gain or regain control over their lives, have hope for the future, and live a life meaningful to them.<sup>33</sup> It relates to the conceptual framework of personal recovery, which encompasses five themes: connectedness, hope, identity, meaningfulness, and empowerment.<sup>34</sup> Person-centered care refers to using a collaborative approach with the person concerned and incorporating the person's opinions, voices, and personal histories into their care.<sup>35</sup> While both of these concepts clearly overlap,

TABLE 1. Number of plans mentioning each human rights theme

Rights grouping	Explicit CRPD principle(s)	Lay definition(s)	Number of plans (%)
Community inclusion	Article 19: Living independently and community inclusion	The right to remain free and independent and to receive the same opportunities and services as others in the place of their choosing, enabling people to live independently and participate in their communities.*	39 (97.5%)
Recovery-oriented and person-centered care	Article 26: Habilitation and rehabilitation Article 3: General principles such as respect for inherent dignity, individual autonomy (including the freedom to make one's own choices), and the independence of persons; respect for difference; and acceptance of persons with disabilities	Enabling people to identify what recovery means to them; helping them gain or regain control over their life, have hope for the future, and live a life meaningful to them.† Tailoring care to people's interests, abilities, and needs while taking account of their histories and personalities.‡	31 (77.5%)
Respect for legal capacity	Article 12: Equal recognition before the law	The right to make decisions for oneself and have those decisions respected by others.* The right to be recognized as a person before the law and have one's decisions legally respected.§	28 (70%)
Non-coercive practices	Article 16: Freedom from exploitation, violence, and abuse	The right to practices that do not involve the use of involuntary admission, involuntary treatment, seclusion, or physical, chemical, or mechanical restraint.*	24 (60%)
Participation	Article 29: Participation in political and public life	The right to participate in decisions about society as a whole, such as the design and delivery of care services and the development of policies and procedures, regardless of their expertise and experience.*	24 (60%)

Sources:

\* World Health Organization, *Guidance on Community Mental Health Services: Promoting Person-Centred and Rights-Based Approaches* (World Health Organization, 2021).

† M. Leamy, V. Bird, C. Le Boutillier, et al., “Conceptual Framework for Personal Recovery in Mental Health: Systematic Review and Narrative Synthesis,” *British Journal of Psychiatry* 199/6 (2011).

‡ S. Terada, E. Oshima, O. Yokota, et al., “Person-Centered Care and Quality of Life of Patients with Dementia in Long-Term Care Facilities,” *Psychiatry Research* 205/1-2 (2013).

§ Committee on the Rights of Persons with Disabilities, General Comment No. 1, UN Doc. CRPD/C/GC/1 (2014).



there are differences between the two. Although no specific article of the CRPD encompasses recovery-oriented and person-centered care, article 26 (habilitation and rehabilitation) arguably comes closest regarding recovery-oriented approaches.<sup>36</sup> Additionally, article 3 (general principles) aligns with person-centered principles (“respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons ... respect for difference and acceptance of persons with disabilities”).<sup>37</sup> Within this theme, we also searched for the following synonyms: “agency,” “dignity,” and “empowerment.” This theme was mentioned by 31 (77.5%) plans. Several countries provided explicit actions relating to recovery-oriented and person-centered approaches to dementia care.

*Support should be tailored to the individual person with dementia and their carers, not to managers of different services or health services. (Slovenia)<sup>38</sup>*

*Develop an efficient and coordinated system of care for people with dementia ... under a network approach (including long-term care), to provide person-centered and integrated care. (Dominican Republic)<sup>39</sup>*

**Respect for legal capacity.** Respect for legal capacity is defined as the right to make decisions for oneself and to have one’s decisions respected by others; it is primarily represented by article 12 of the CRPD (equal recognition before the law).<sup>40</sup> It is the backbone of other human rights and includes the right to be recognized as a person before the law and have one’s decisions legally respected.<sup>41</sup> We searched for keywords such as “legal capacity,” “autonomy,” “supported decision-making,” and “advance care planning.” Overall, 28 (78%) plans mentioned legal capacity. Several included the word “autonomy” in the overarching aims of their plans, demonstrating that governments and ministries acknowledge that people with dementia should be in control of and have freedom of choice in their lives.

*The vision of this plan ... [is that] people with dementia and their caregivers receive the quality*

*care and support they need with dignity, respect, autonomy, and equity. (Dominican Republic)<sup>42</sup>*

Some countries also demonstrated their awareness that supporting people with dementia and their care partners in maintaining autonomy and legal capacity is protected by their own laws and international regulations.

*As a signatory to the Glasgow Declaration, the Welsh Government has previously committed to promote the rights, dignity and autonomy of people living with dementia. (Wales)<sup>43</sup>*

Regarding specific actions to promote and protect the right to legal capacity, countries referred to ensuring that measures for advanced care planning and supported decision-making would be provided.

*Objective delivery ... i. Work towards the development of advance care directives. (Malta)<sup>44</sup>*

**Non-coercive practices.** Coercive care practices are those that go against the wishes of the person receiving care, such as forced admission to services, forced treatment, seclusion, and mechanical, physical, and chemical restraints.<sup>45</sup> They are also practices that are undertaken without the person’s consent. The CRPD protects the rights to freedom from coercion with the following articles: liberty and security of person (article 14), freedom from torture and cruel, inhuman, or degrading treatment or punishment (article 15), and freedom from exploitation, violence, and abuse (article 16).<sup>46</sup> Coercion also encompasses a denial of legal capacity.<sup>47</sup> Twenty-four plans (60%) mentioned coercive and non-coercive practices; however, few plans provided specific actions to ensure that coercive methods are not used within dementia care. Instead, there was mostly a recognition that people with dementia have been and continue to be subjected to harmful practices.

*Dementia will eventually impair the ability to make informed decisions and provide consent. There may therefore be ... uncertainty as to whether a decision is voluntary or if the person displays opposition towards a measure. If the person displays opposition,*

*the measure is considered coercive. (Norway)*<sup>48</sup>  
*8.5. Legal, social and financial assistance to prevent abuse, violence or neglect in the care of the person with dementia. (Mexico)*<sup>49</sup>

**Participation.** Participation refers to people living with dementia (and their care partners) being involved in societal decisions, such as the design and delivery of services and policies regardless of expertise.<sup>50</sup> It also involves the concept of citizenship: having rights, responsibilities, and meaningful opportunities within the wider community.<sup>51</sup> We included “citizenship” as our synonym for this theme. It is guaranteed by article 29 (participation in political and public life) and article 30 (participation in cultural life, recreation, leisure, and sports) of the CRPD.<sup>52</sup> Twenty-four plans (60%) referred to or specifically mentioned participation.

*According to Article 29 of the [CRPD], people with dementia should be able to play an active role in shaping public affairs ... [and] given the opportunity to review the relevance and appropriateness of local planning processes from their perspective ... This will allow people with dementia to be involved ... in the planning of social spaces. (Germany)*<sup>53</sup>

*Stakeholder participation in policy development and legislative changes concerning persons with dementia is ensured through a consultation portal ... What will the situation be in 2030? Active participation of persons with dementia in discussions and decisions concerning this patient group. (Iceland)*<sup>54</sup>

Nineteen countries (47.5%) declared that people with lived experience (both persons with dementia or their care partners) had been involved in the design of the national dementia plan, and some specifically stated how they will continue to involve this population in the implementation of plans.

*The national action plan for dementia was developed ... [with] relevant actors in the field, citizens with dementia, their relatives, and experts and health professionals. (Denmark)*<sup>55</sup>

Table 2 shows further examples of how governments incorporated human rights and the CRPD into their national dementia plans.

## Discussion

This was the first in-depth review of how human rights have been addressed in national dementia plans. Many plans addressed some aspects of basic human rights for people with dementia; in particular, community inclusion was covered in all except one of the plans, and most mentioned developing dementia-friendly communities to achieve this. Perhaps these human rights aspects are easier for governments to promote for people with dementia. Concerningly, many plans did not adequately include non-coercive practices or participation, and the CRPD itself went unmentioned in almost 75% of the plans, despite most of these countries having either signed or ratified the convention. While this lack of specific mention of the CRPD does not on its own indicate that the plans overlooked certain human rights for people with dementia, our review of the content relating to the human rights principles in the CRPD indicates that many plans did not align well with human rights standards. This is vitally important given growing concerns over the human rights of people with dementia. It also suggests a strong need for multisectoral action to protect and promote the human rights of persons with dementia in both policy and practice.

Although our findings suggest that the CRPD may not have been considered when governments developed their plans, our review is also consistent with the work of Rasita Vinay and Nikola Biller-Andorno, who found that social and cultural rights, such as community inclusion and recovery-oriented and person-centered care, were the foundations of national dementia plans.<sup>56</sup> While advanced care planning, increased dementia awareness, and holistic and individualized care were principles strongly considered in the eight plans they reviewed, the provision of alternative care to acute hospitalization was mentioned only sporadically.<sup>57</sup> Our review, alongside that of Vinay and Biller-Andorno, contrasts with the work of Suzanne Cahill, who found that political and civil rights, such as freedom from coercion, were more likely than social and cultural rights to be included in plans.<sup>58</sup> Both reviews, as well as our own, found that governments have placed emphasis on respect and dignity, although

our analysis showed that these terms tended to be used in descriptions around what people with dementia are entitled to rather than specific actions to ensure that these needs are met.

It is important to note that our analysis was more extensive than the other two reviews; we took a comprehensive approach by using the CRPD as a whole rather than using selected items. Additionally, both of these past reviews were of a much smaller scale in comparison to ours: Vinay and Biller-Andorno reviewed eight plans, and Cahill examined ten.<sup>59</sup> Perhaps these reviews were smaller than ours due to the time of their completion. Our review was conducted close to the end of WHO's global action plan target deadlines, whereas the previous reviews were conducted closer to the beginning of the global action plan. Nonetheless, our assessment has revealed similar findings to those of the previous studies, especially when considering that each country tailored its plan to meet its context-specific needs, and therefore it would be expected that visions for the plans and subsequent actions would differ somewhat.

Furthermore, we found that acknowledgments and actions relating to increasing awareness and reducing stigma to achieve community inclusion for people living with dementia were consistently included in national dementia plans, a finding also noted by previous reviews.<sup>60</sup> This is important because stigma and beliefs around dementia are some of the main contributors to human rights denials for people living with dementia.<sup>61</sup> Additionally, our results showed that although participation was mentioned in 60% of the analyzed plans, actions to ensure that this became a part of standard practice were few and far between. This supports the claim by Tim Schmachtenberg et al. that the participation of persons with dementia in planning activities and policies is needed, but in practice is lacking.<sup>62</sup> Our findings also support the recommendations of Nadia Boeree et al., who argue that policymakers must collaborate with people with dementia and their care partners in the development, execution, and evaluation of national dementia plans because it would enhance their effectiveness and overall

usefulness.<sup>63</sup> They also argue that without the involvement of people with lived experience, any of the benefits that materialize from a plan's implementation would not be felt by the people who should benefit most.<sup>64</sup> This echoes the claim that there are considerable gaps between the goals and visions of government policies and the lived experiences of those with dementia.<sup>65</sup> From a human rights-based point of view, the participation of people with dementia (and their care partners) in the design and delivery of national dementia plans is a fundamental right in accordance with the CRPD.<sup>66</sup>

### *Limitations*

To reduce the risk of reviewer bias, each plan was assessed by at least two independent researchers. Additionally, we used publicly available data. That said, not all plans that have been launched were publicly accessible, meaning that we were unable to access eight plans. Moreover, we were unable to translate a further two. The plans missing from our analysis were mainly from the Eastern Mediterranean and Western Pacific WHO regions. Moreover, in order to include as many plans as possible in our review, we relied on a translation website powered by Google Translate rather than translating and then back-translating ourselves; as a result, the translations may have inaccuracies or misinterpretations or may have missed content. Finally, some of the plans included in our review had already, or have since, expired, meaning that their implementation period was over. However, at the time of searching, the included plans were still the most recent plan for those countries, and being publicly available, we chose to include them in the review.

### *Future directions*

Since the completion of our review, several countries—for example, Australia, Brazil, Malta, and Uruguay—have produced new national dementia plans.<sup>67</sup> Further research should be conducted to investigate whether these new plans have a human rights focus, as well as whether future plans of the countries included in this review showcase any changes in their human rights content. Ad-

ditionally, future research could examine the implementation of national dementia plans to assess the extent to which the actions outlined in the plans have been achieved in practice. This research could refer to article 4 of the CRPD, which relates to the general obligations of countries that have ratified the convention. Finally, future work should consider developing a global report on good practice in human rights in dementia care.

### *Implications*

There are substantial implications for policy and practice following our review. First, the results can be used by WHO, ADI, and Alzheimer Europe, among national governing bodies, to advocate for a stronger human rights focus within plans to ensure the protection and promotion of the rights of people with dementia. This review supports WHO efforts to monitor progress on the global action plan targets, as well as ADI efforts to regularly report on the global picture of national dementia plans. ADI recently called for an extension of WHO's global action plan targets to 2035 in its latest *From Plan to Impact* report.<sup>68</sup> The current target is for 146 countries to have a national dementia plan by 2025—and yet, as of ADI's 2024 report, only 38 plans were currently in place, while others had expired and yet others did not have funding for their implementation.<sup>69</sup> Because none of the global targets is on track to be reached by 2025, WHO member states recently discussed a potential extension of the global action plan at the 156th session of the Executive Board.<sup>70</sup> Our review highlights where governments are falling short in complying with the CRPD and indicates how future plans can become more human rights focused.

Policy commitments should not remain mere paper promises—they should be actively implemented with clear accountability measures. Countries are required to report to the United Nations Committee on the Rights of Persons with Disabilities every four years on the measures tak-

en to respect, protect, and promote the rights of persons with disabilities, and it is important that this process also include reporting on the actions taken to safeguard the rights of persons with dementia. At a national level, mechanisms such as national human rights groups, health services (including mental health services), and care quality commissions could integrate the monitoring of dementia-related human rights into their existing functions. Moreover, national and international nongovernmental organizations such as ADI and organizations of persons with disabilities such as Dementia Alliance International can play a pivotal role in monitoring and ensuring accountability.

### *Conclusion*

This review systematically assessed the human rights content of national dementia plans. We found that nearly all of these plans covered basic human rights, especially with regard to the inclusion of people with dementia within the community. However, many plans did not sufficiently align with human rights standards, including the CRPD. There was a lack of specific actions regarding non-coercive practices and ensuring the participation of people with dementia in the design and delivery of services and policies that affect them. This review also has implications for the rights of people with dementia. Significant improvements are needed to guarantee the human rights of people with dementia; therefore, governments can use our findings to better understand the rights of their citizens with dementia and identify actions and frameworks to improve protections for them. Additionally, people with dementia can be encouraged to participate in the implementation of current plans, as well as the design and delivery of future ones. We join calls for a multisectoral effort to be implemented to guarantee the human rights of persons with dementia.



TABLE 2. Examples of narratives reflecting each of the key themes

Theme	Country	Quotation
Respect for legal capacity		
Acknowledgments	Austria	"The strategy aims to create a system in which people affected by dementia and their families and friends: ... • live in a community that promotes ... autonomy to the greatest possible extent" (p. 16)
	Belgium (Wallonia)	"Foster the maintenance of autonomy ... at each stage [of] illness" (p. 4)
	Canada	"Respects choice: The rights of individuals living with dementia to make their own decisions are broadly understood and facilitated" (p. 7)
	Finland	"It is important that everyone can participate in joint decision-making" (p. 23)
Actions	Australia	"Maximise opportunities for people with dementia and their representatives to plan for the future by raising their awareness of options" (p. 15)
	Norway	"To ensure ... greater freedom of choice and codetermination in planning future treatment, the Government will strengthen its efforts to prepare, disseminate and implement advance care planning conversations" (p. 49)
	United States of America	"Action 3.D.8: Develop a Supported Decision-Making Model as an alternative to guardianship" (p. 89)
Non-coercive practices		
Acknowledgments	Canada	"Human rights: Includes the right to life and liberty, freedom from slavery and torture, freedom of opinion and expression" (p. 83)
	Chile	"The risk of neglect and abuse is also increased with an overwhelmed caregiver" (p. 18)
	Cuba	"abuse can manifest itself in different ways ... little attention, abandonment, inadequate nutrition, lack of care, economic abuse and restriction of autonomy, or some more serious, such as physical abuse or sexual abuse" (p. 7)
Actions	Denmark	"Initiative 9: General screening of regulations concerning use of force. DKK 0.5 million [in funding] is allocated to carry out a screening" (p. 9)
	Luxembourg	"Measure: Definition of a formal framework organizing and limiting the use of means of restraint in long-stay institutions for the elderly" (p. 46)
	Malta	"Develop a working partnership, in collaboration with non-governmental organisations and other stakeholders operating in the field, to assess and address abuse in individuals with dementia, their caregivers and family members" (p. 116)
	Spain	"Develop information actions, training and action protocols, aimed at minimizing involuntary restraints, physical or pharmacological" (p. 56)
Participation		
Acknowledgments	Belgium (Flanders)	"Involving the voice of people with dementia at policy level should also be translated into practice by local authorities as an ambition, including in the context of building a dementia-friendly environment" (p. 16)
	Greece	"participation of people with dementia and their caregivers in the planning of services" (p. 17)
	Mexico	"People with dementia and their carers often have a unique perspective on their condition and on life ... they must be involved in the formulation of policies, plans, laws and services" (p. 12)
	Norway	"A key goal is for individuals with dementia and their family members to be involved in decisions that affect them, and to have a say in the design of their own services" (p. 21)
	Scotland	"The best way to deliver better experiences for people is to include them in policy design and delivery" (p. IV)
Actions	Germany	"local authority associations will encourage municipalities to ensure that people with dementia and their relatives participate in planning processes and that their interests are taken into account ... By the end of 2022, the local authority associations will campaign for such participation at municipal level" (p. 29)
	Wales	"We will: • Ensure people with dementia, their carers and families are involved in the development and delivery of dementia education and training" (p. 28)



TABLE 2. *continued*

Theme	Country	Quotation
Community inclusion		
Acknowledgments	Canada	"The strategy will encourage dementia-inclusive communities that support people living with dementia and caregivers in staying involved in their communities and at work for as long as possible" (p. 1)
	England	"people with dementia should be supported to live independently in their own homes for as long as they are comfortable" (p. 39)
	Slovenia	"The standard of care and support for patients should not only include staying in the home environment ... also enable the person with dementia to play a visible and active role in the local community" (p. 8)
Actions	Australia	"Develop communities and workplaces that are dementia friendly" (p. 12) "Support people with dementia in residential aged care facilities to continue to be socially engaged both within and outside the facility (in the broader community)" (p. 21)
	Chile	"Implement daytime support centers for older people living with dementia and their immediate environment, to encourage their social participation" (p. 45)
	Dominican Republic	"Aim: Improve acceptance and understanding of dementias and make the community environment friendly, allowing people with dementia to participate in the community ... Goal: The country has at least one dementia-friendly initiative" (p. 22)
	Kuwait	"Target 3: Creation of social and recreational activities for the elderly ... Combating community isolation and integrating older people into society" (p. 8)
	The Netherlands	"What are we going to do? We want to create opportunities for persons with dementia ... by providing opportunities for doing work, including volunteer activities, for example in Dementalent projects" (p. 14)
Recovery-oriented and person-centered care		
Acknowledgments	Australia	"Timely and accurate diagnosis also ... gives people the power to control their life and plan for their future" (p. 10) and "Community participation for all people with dementia may be facilitated through the use of an enablement approach ... Appropriate service structures may provide assistance to people with dementia to identify and pursue personally important, relevant and meaningful goals in their daily lives" (p. 17)
	Malta	"Empowering individuals with dementia will not only help in challenging stigma but will also encourage social inclusion and integration" (p. 47)
	New Zealand	"Placing the person with dementia, and their needs and wishes, at the centre of care and supporting them to make decisions will maximise their wellbeing and independence" (p. 3)
	Norway	"good dementia care involves seeing the individual and his or her needs and implementing individually adapted services based on the insight into the individual's life story and disease history" (p. 9)
	Scotland	"Our ethos is to empower people living with early and midstage dementia to be the best they can be and to support them to live well with dementia" (p. 12); "Empowerment (International PANEL) - People should understand their rights, and be fully supported to participate in the development of policy and practices" (p. 15); and "person-centred care includes people with dementia being involved in design and delivery of services" (p. 30)
	Sweden	"The support needs to be based on the person's own wishes and remaining abilities" (p. 11)
Actions	Malta	"Develop a series of recommendations that would enhance good quality patient-centred dementia management and care (including dementia-friendly design) in long-term nursing and residential care settings" (p. 89)
	Norway	"Priority area 3: Improved quality of health care services: •prepare guidelines for good patient care pathways ... • prepare a 'toolbox' for person-centered care and milieu therapy" (p. 13)
	United States of America	"Action 3.E.7: Expand resources to support person-centered care" (p. 92)
	Wales	"The team will flex to meet individual needs ... people have the right to individualised and person-centred care. We will continue working with key stakeholders, including people living with dementia and their carers, to ensure that this happens [including]: • Developing individual care plans" (p. 19)

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# “Only on Paper”: Rights vs. Reality for Gender-Based Violence Survivors in Rural Bolivia

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## Abstract

This paper presents testimony from a primary care physician about the challenges of navigating post-assault health service referral options and judicial remedies for adolescent survivors of gender-based violence (GBV) in rural communities in eastern Bolivia. We examine the protections outlined in various international, regional, and national laws; discuss relevant legal instruments and policies that

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aim to safeguard the sexual and reproductive health rights of adolescents; and outline mechanisms for their enforcement. We then apply the availability, accessibility, acceptability, and quality framework to analyze the extent to which post-assault health services and judicial remedies for adolescent survivors of GBV are sufficient, equitable, and effective. Through our application of this framework, we observe that many adolescent survivors likely experience re-victimization and re-traumatization as they navigate a fragmented patchwork of resources following their victimization. Based on this analysis, we argue for the integration of a human rights framework in designing, implementing, and evaluating post-assault care for adolescent survivors of GBV. We also contend that the 2023 ruling by the Inter-American Court of Human Rights in *Angulo Losada v. Bolivia* sets a legal precedent for holding Bolivia accountable for ensuring that adolescent victims of GBV experience their human and constitutional rights in rural, resource-variable communities in Bolivia.

## Introduction

Early one morning in December 2022, Dr. Rojas (pseudonym), a pediatrician in Montero, a peri-urban town in eastern Bolivia, received a WhatsApp message from Fernanda (pseudonym), a 15-year-old girl from a nearby rural community. Fernanda had recently participated in an educational program sponsored by a nongovernmental organization (NGO) that sought to equip adolescents with sexual and reproductive health knowledge (e.g., awareness of their sexual and reproductive health rights, information about menstruation and puberty) and skills (e.g., how to correctly put on a condom, how to ask for consent and establish boundaries).

The program was developed in response to growing concerns from parents about the lack of sexual and reproductive health education in schools, the alarmingly high rates of gender-based violence (GBV), and the increased incidence of sexually transmitted infections (STIs) in the region.<sup>1</sup> At the program's inception in 2019, Bolivia had no universal, state-run comprehensive sexuality education in public schools.<sup>2</sup> At the time, the NGO-sponsored

program was the only source of formal education that young people in the region would receive about sexual and reproductive health and rights. The program included 10 half-day sessions for 20 adolescent girls in rural communities surrounding the peri-urban town where the NGO's main office was located. The program was co-developed by a group of student researchers at a university in the United States and Bolivian clinicians, community health workers, and NGO staff. Dr. Rojas was designated as the contact for program participants.

"I have a few bumps down there," Fernanda's message read.

"Can you come in today?," Dr. Rojas replied.

Fernanda "liked" the message.

Upon Fernanda's arrival, Dr. Rojas escorted her to a makeshift exam room for a pelvic exam. Dr. Rojas documented pelvic pain and signs of genitourinary trauma, including vaginal abrasions, inflammation of the vaginal canal, and ulcerations of the vaginal mucosa. Dr. Rojas summarized that the clinical findings were consistent with a recent traumatic event as well as previous injuries. Dr.

Rojas ordered an STI panel and a pregnancy test. Based on Fernanda's clinical presentation, Dr. Rojas suspected that Fernanda had been the victim of multiple sexual assaults and required both acute and ongoing physical and mental health care, in addition to legal support and other advocacy services.

Dr. Rojas asked Fernanda about her current boyfriend and living situation, reassuring her that she was a safe and supportive person she could talk to about any situation she may be experiencing. Although Fernanda denied experiencing any abuse or violence, Dr. Rojas remained concerned because the presence of genitourinary trauma was clinically inconsistent with Fernanda's explanation, suggesting the possibility of undisclosed sexual violence or abuse.

Dr. Rojas referred Fernanda to the primary-level health facility for follow-up care so that Fernanda could receive a consultation with the doctor responsible for the area. Fernanda later informed Dr. Rojas that she went to the appointment with her mother and received medical treatment for an STI. While Dr. Rojas was relieved that Fernanda received care for her injuries, she was concerned that Fernanda did not access care sooner and that she would not have access to specialized health services if her suspicion of violence was correct.

Dr. Rojas was well aware of the reasons why Fernanda might not choose to disclose that she had been the victim of GBV. For instance, even if Fernanda had disclosed to Dr. Rojas that she was a victim of violence, her registration with the Sistema Único de Salud—Bolivia's universal health insurance program—was not in the municipality of Montero, where Dr. Rojas was based, but in another municipality. As a result, Dr. Rojas needed to first refer Fernanda to the primary health facility nearest to Fernanda's home—about halfway between Fernanda's community and Montero—to receive care. Dr. Rojas later remarked that this bureaucratic barrier was the reason many survivors forgo reporting violence. She elaborated that in her 20 years of experience working in rural communities surrounding Montero, many survivors fear that if they go to the health center nearest to

their community, their privacy and confidentiality will not be protected. Dr. Rojas commented that many survivors fear potential retaliation from their aggressor.

Dr. Rojas also noted that many survivors in the rural communities she serves face significant barriers to obtaining specialized and trauma-informed medical care, health advocacy, and legal services at the local public hospital and *defensoría* (public defender's office). She noted that these barriers may include transportation issues and additional costs associated with services (e.g., printing and notarizing necessary forms). Dr. Rojas explained that the only other referral option was to an NGO that provides temporary emergency shelter, as well as legal and health services, located 130 kilometers from Fernanda's home in the larger metropolitan city of Santa Cruz. She noted that this option was impossible for many of her patients due to the prohibitive amount of time and money needed to travel to Santa Cruz.

Dr. Rojas's reflection on the barriers faced by adolescents affected by sexual violence in the region highlights some of the limitations of primary prevention programming—such as the NGO-provided sexual and reproductive health educational intervention—in preventing GBV victimization among adolescent girls. Her testimony about the challenges in providing accessible post-assault referrals for survivors is particularly alarming given the pervasive GBV throughout the country. Throughout this paper, we use the term “post-assault” to refer to a range of experiences that follow an incident of GBV. We intentionally use the term “assault” and not “rape” to reflect the various forms of harmful and traumatic sexual violence that a survivor may endure but that may not meet the legal definition of rape in Bolivia.

## National and regional trends in gender-based violence

Bolivia has one of the highest rates of GBV in Latin America.<sup>3</sup> Seventy percent of Bolivian women experience sexual or physical violence, and nearly

one-third of adolescent girls suffer sexual violence before the age of 18.<sup>4</sup> Bolivia also has one of the lowest reporting rates of GBV in Latin America due to issues such as “re-victimization, delays in prosecution, and unwillingness by police to cooperate with the justice system.”<sup>5</sup> Additionally, as reported by human rights organizations, the low reporting rates can be attributed to the “justice system’s practice of granting perpetrators of sexual violence impunity for their crimes, especially when committed against underage girls.”<sup>6</sup>

These testimonies and national statistics reflect findings from a recent observational study conducted in two rural communities outside Montero, located in the Obispo Santistevan Province of the Santa Cruz Department.<sup>7</sup> A total of 51.5% (N=104) of adolescent girls and adult women aged 15–35 reported being personally impacted by sexual or physical violence.<sup>8</sup> Among these participants, 72% (N=70) disclosed having been survivors.<sup>9</sup> Only 13 individuals who reported victimization indicated that they had attempted to seek post-assault medical care or legal support. Qualitative results from open-ended survey questions revealed that many survivors refrained from seeking care due to shame, fear of retaliation, the belief that their injuries were not that severe, and the (in)visible costs associated with the services (e.g., transportation).<sup>10</sup> These qualitative findings align with technical reports and other gray literature in the region and are further explored in a later section.<sup>11</sup>

These testimonies underscore the urgent need to critically analyze and document Bolivia’s stated human rights positions regarding the sexual and reproductive health of adolescents, particularly those in rural areas, and how these positions align with or diverge from the lived experiences of adolescents in these communities. The examples presented in this introduction set the stage for a deeper analysis and discussion of the legal protections and rights that are theoretically designed to support and safeguard individuals who are survivors of GBV. While these examples are specific to Dr. Rojas’s experience in assisting adolescents in rural areas outside Montero with referral options, they illustrate challenges that other clinicians may also encounter when provid-

ing referrals for adolescent survivors of GBV in various rural settings across Bolivia, as well as for survivors over the age of 18.

## Human rights framework

The current Bolivian Constitution was adopted in 2009 after work by then-President Evo Morales to reform the Constitution to “end social injustice and inequality.”<sup>12</sup> The Constitution states that Bolivia is “based on the values of unity, equality, inclusion, dignity, liberty, solidarity, reciprocity, respect, interdependence, harmony, transparency, equilibrium, equality of opportunity, social and gender equality in participation, common welfare, responsibility, social justice, distribution and redistribution of the social wealth and assets for wellbeing.”<sup>13</sup> The Constitution incorporates fundamental rights and invokes the hierarchical dominance of the international and regional agreements and treaties to which Bolivia is a party.<sup>14</sup> In this way, the human rights instruments that Bolivia is a party to take precedence over domestic law, and the Constitution should be interpreted in accordance with international and regional human rights treaties.<sup>15</sup> This is significant because it places Bolivia at a higher level of rights obligations than other states that have not constitutionalized the same international and regional legal norms (see Table 1).

### *International human rights treaties*

Bolivia is a signatory—meaning that it is legally bound—to several international human rights instruments that contain protections prohibiting violence against women and girls. Signatories commit to providing health care, policing, and justice for their citizens, including those harmed by sexual violence.

The Universal Declaration of Human Rights, the International Covenant on Civil and Political Rights, and the International Covenant on Economic, Social and Cultural Rights are broad multilateral human rights instruments to which Bolivia is a party. These three formative human rights mechanisms obligate signatories to non-discrimination and the protection of all citizens,

including freedom from violence such as GBV.<sup>16</sup>

The Convention on the Rights of the Child—another treaty to which Bolivia is a party—requires states to “protect the child from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse” and to provide services to ensure investigation, treatment, and other care for cases of suspected violence.<sup>17</sup> The convention also requires states to adhere to standards set by competent authorities to provide safety and health services.<sup>18</sup> It recognizes the rights of the child concerning health care, including preventative care, explicitly requiring states to develop preventative care as well as “family planning education and services.”<sup>19</sup>

As a signatory of the Convention on the Elimination of All Forms of Discrimination Against Women, Bolivia is required to eliminate discrimination against women and girls in all sectors.<sup>20</sup> The convention promotes equal rights for women and girls and commits parties to “take all appropriate measures to eliminate discrimination against women in the field of healthcare to ensure ... access to healthcare services, including those related to family planning,” and to “take all appropriate measures ... to suppress all forms of trafficking in women and exploitation of prostitution of women.”<sup>21</sup> Notably, the convention also provides protections for rural women, specifically ensuring the right of rural women “to have access to adequate health care facilities.”<sup>22</sup>

The international treaties to which Bolivia is a party enforce the Bolivian government’s obligations to ensure that its citizens enjoy the right to live free from violence (including GBV), the right to health, equal rights regardless of one’s gender or status, and rights for children

### *Regional human rights treaties*

Regionally, Bolivia is a party to the American Convention on Human Rights; the Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights; the Inter-American Convention on the Prevention, Punishment, and Eradication of Violence Against

Women (also known as the Convention of Belem do Pará); and regional measures coordinated through the United Nations, such as the Preventing Through Education Declaration. The Additional Protocol to the American Convention explicitly recognizes the right to health, specifying states’ duty to provide their citizens with primary health care as well as programs to meet the “health needs of the highest risk groups” and the impoverished.<sup>23</sup> Adolescents and victims of GBV are considered to be a high-risk group. These two groups often have a disproportionate burden of STIs, among other sexual and reproductive health issues.<sup>24</sup>

The Convention of Belem do Pará affirms that “violence against women constitutes a violation of their human rights and fundamental freedoms, and impairs or nullifies the observance, enjoyment, and exercise of such rights and freedoms” and thus seeks to address that violence.<sup>25</sup> It defines violence as any act, in public or private, that “causes death or physical, sexual or psychological harm or suffering to women.”<sup>26</sup> The convention specifically requires states to take measures to prevent violence and establish legal procedures for remedy.<sup>27</sup> States that have signed the Convention of Belem do Pará agree to provide services to women affected by violence, including sexual violence, and to those impacted by violence, such as their children or witnesses to violence.<sup>28</sup>

In 2009, the same year Bolivia adopted its new Constitution, health ministers from 30 countries in Latin America and the Caribbean, including Bolivia, adopted the Preventing Through Education Declaration, pledging to provide comprehensive sexuality education and sexual health programs.<sup>29</sup> These regional commitments that Bolivia has made regarding human rights, the prevention of violence, and the provision of comprehensive sexuality education and sexual health programs compound upon the obligations it has as a signatory to international human rights instruments.

### *Bolivian progress on obligations*

According to Bolivia’s Constitution, the government must provide comprehensive health care (article 18) and prevent sexual and gender-based vi-



olence (article 15), including by ensuring the sexual and reproductive health rights of rural women and ensuring the rights of youth.

In 1997, the Bolivian government established the Ombudsman's Office (Defensoría del Pueblo), which is tasked with protecting the human rights of Bolivian citizens.<sup>30</sup> The office investigates allegations and complaints of human rights abuses, advocates for individuals whose rights have been violated, and works to improve the legal and institutional framework to better protect human rights across Bolivia.<sup>31</sup> This office has a specialized unit for the defense of children and adolescents (Defensoría de la Niñez y Adolescencia) that provides legal and social support, intervenes in cases of abuse or neglect, and ensures that children's and adolescents' rights are upheld in various contexts.<sup>32</sup>

In 2013, Bolivia passed a law to guarantee women a life free of violence (Law 348), which also enumerated Bolivia's obligations to provide timely comprehensive health and advocacy services for survivors of GBV, ensure access to judicial remedies for survivors of GBV, and furthered the government's obligations to prevent sexual violence. Law 348 also created a government agency tasked with the prevention, investigation, and apprehension of those responsible for acts of violence against women.<sup>33</sup>

In its 2019 report to the United Nations Human Rights Council in preparation for its Universal Periodic Review, Bolivia highlighted its laws and processes for addressing GBV and ensuring women's rights.<sup>34</sup> The report highlighted that Bolivia has "consolidated its regulatory and institutional framework to promote equality and to eradicate violence based on gender and sexual orientation."<sup>35</sup> The report further noted that Bolivia has several government offices and officials focused on combating violence against women, including the Special Office for Combating Violence Against Women, the Plurinational Service for Women and for Dismantling the Patriarchy, the Anti-Violence Squad, the Plurinational Victim Assistance Service, and the Prosecutor's Office for Victims in Need of Priority Care.<sup>36</sup>

Nonetheless, a 2024 report by the Inter-Amer-

ican Commission on Human Rights recognizes that there is a current lack of enforcement in Bolivia on women's right to a life free from violence.<sup>37</sup> The commission views the lack of accountability for GBV as a symptom of the lack of judicial capacity and lack of public trust in a judicial system that has previously been used for political ends.<sup>38</sup> The authors of the report contend that without further developing the mechanisms for achieving these obligations, it is unlikely that Bolivia can ensure access to remedies for survivors of GBV.

Indeed, in 2023, the Inter-American Court of Human Rights issued a ruling stating that Bolivia failed to address sexual violence toward Brisa de Angulo Losada, an adolescent girl in Cochabamba.<sup>39</sup> The court concluded that Brisa's rights to "humane treatment, judicial guarantees, private and family life, equality before the law, judicial protection and children's rights" were violated due to

*the breach of the duty of enhanced due diligence and special protection to investigate the sexual violence suffered by Brisa, the absence of a gender and children's perspective in the conduct of the criminal process and the re-victimizing practices during that process, of the application of criminal legislation incompatible with the American Convention, as well as institutional violence and discrimination in access to justice suffered by the victim due to her gender and status as a child and the violation of the guarantee of a reasonable timeframe.*<sup>40</sup>

This ruling is significant because it establishes an important legal precedent for holding states accountable for systemic failures in addressing GBV and for providing timely, trauma-informed, and culturally responsive judicial remedies for adolescent survivors of GBV. It also provides a legal framework for analyzing gaps in the implementation of state obligations, including gaps in the continuum of services and in the provision and accessibility of specialized health care, advocacy services, and judicial remedies for survivors of GBV.<sup>41</sup>

Our search of both the case name ("Angulo Losada v. Bolivia") and relevant keywords (e.g., "Angulo" and "Losada" separately) across six databases (Lexis+, Westlaw, vLex, Oxford Reports

on International Law, WorldLII, and HeinOnline) revealed that as of April 2025 the Inter-American Court of Human Rights' ruling had not been used as legal precedent in other national or international cases. However, legislative reform is currently underway in Bolivia to comply with the court's ruling, which—in addition to ordering the government to pay reparations to Brisa, to “maintain the criminal complaint against the E.G.A [the perpetrator],” and to “determine the possible responsibility of the officials whose actions contributed to the commission of acts of re-victimization and possible procedural irregularities to Brisa's detriment”—ordered the Bolivian government to

*adapt its protocols or adopt new protocols, implement, supervise, and oversee a protocol for investigation and action during criminal proceedings for cases of children and adolescents who are victims of sexual violence, a protocol on a comprehensive approach and legal medical evaluation for cases of children and adolescents who are victims of sexual violence and a comprehensive care protocol for children and adolescents who are victims of sexual violence, and ... to implement a campaign to raise awareness, aimed at the Bolivian population in general, aimed at confronting sociocultural perceptions that normalize or trivialize incest.*<sup>42</sup>

The proposed legislation also “establishes a series of preventive and access-to-justice measures, including training for prosecutors, forensic doctors, investigators, and judges, who must be provided with specific protocols for caring for underage victims.”<sup>43</sup>

### Rights-based approach to health services and judicial remedies for survivors of gender-based violence

In this section, drawing on the perspective of Dr. Rojas and supported by evidence from other sources, we employ a rights-based approach and utilize the availability, accessibility, acceptability, and quality (AAAQ) framework (see Table 2) proposed by the United Nations Committee on Economic, Social and Cultural Rights to examine the gaps in

access to timely and dignified post-assault health services and judicial remedies for adolescent survivors of GBV.<sup>44</sup> In doing so, we emphasize the need for stronger mechanisms to hold states accountable for ensuring the quality and accessibility of post-assault health services and judicial remedies for survivors in rural communities in eastern Bolivia. We also note areas for future research regarding the availability, accessibility, acceptability, and quality of comprehensive post-assault health services and judicial remedies for survivors of GBV.

#### *Availability and accessibility*

Availability refers to a health system having a sufficient quantity of services, facilities, and supplies needed to provide care.<sup>45</sup> The Committee on Economic, Social and Cultural Rights emphasizes that services must be accessible to all patients regardless of their overlapping social identities—such as gender, sexual orientation, race or ethnicity, and political or religious affiliation—or their ability to pay.<sup>46</sup> Additionally, the committee notes that services must be physically accessible to individuals living in rural or marginalized areas.

To our team's knowledge, as of April 2025, Casa de la Mujer is the only organization in eastern Bolivia providing free, comprehensive, trauma-informed, and specialized medical and psychological services and legal support for survivors of GBV. Even if Fernanda were to report to Dr. Rojas that she was, in fact, suffering from GBV victimization, Dr. Rojas recognized that there were extremely limited publicly run health care services available to survivors in the rural communities surrounding Montero. Reflecting on these limitations of the public health system in rural communities, Dr. Rojas explained:

*They never hire more doctors. They never hire more staff. For example, there aren't even stretchers in the hospitals. There's nothing to provide privacy for the patient, no scheduled times when they can be seen. According to the law, we should have availability. There are no medications for the patients—there's nothing. And the health personnel aren't trained. There are many places where there's only one nurse who handles everything. There's no doctor. So, there's no staff, no budget, no training, and even if*

*there were training, the communities don't allow us to talk about sexual health because it is not convenient for them.*

Dr. Rojas's remarks are consistent with the only known study evaluating Bolivia's universal health care coverage program, called the Single Health System (Sistema Único de Salud).<sup>47</sup> This landmark study found that although access to public health care services increased in the first year of the Single Health System compared to previous years, "human

resources are insufficient, spending at the macro-economic level did not reach recommended levels for universal coverage, and long waiting times, and shortages in medicines and beds, persist."<sup>48</sup>

Additional prior research also supports Dr. Rojas's recognition of the extremely limited—if not nonexistent—comprehensive and specialized services for victims of GBV in Bolivia. For instance, the authors of the US State Department's 2023 report on human rights practices in Bolivia found that although the Bolivian government provides

TABLE 1. Bolivia's obligations under international, regional, and national instruments

Broad obligations	Rights in practice	Source of obligations
Right to live free from violence	Protection of the law Prevention of violence, including sexual violence Prosecution and investigation of violence Services for survivors and their families Access to legal remedies for survivors	Universal Declaration of Human Rights (arts. 7, 8) Convention on the Elimination of All Forms of Discrimination Against Women (art. 6) American Convention on Human Rights (arts. 2, 24, 25) Convention of Belem do Pará Bolivian Constitution (art. 13) Law 348
Equal rights between men and women	Access to health care Participation in society Protection from exploitation Rights of rural women and other marginalized groups	Universal Declaration of Human Rights (arts. 1, 2) International Covenant on Civil and Political Rights (arts. 3, 26) International Covenant on Economic, Social and Cultural Rights (arts. 2, 3) Convention on the Elimination of All Forms of Discrimination Against Women American Convention on Human Rights (arts. 1, 24) Convention of Belem do Pará Bolivian Constitution (arts. 8, 13)
Right to health	Adequate health services Access to the benefits of science Health care services for survivors	International Covenant on Economic, Social and Cultural Rights (arts. 12, 14) Convention on the Rights of the Child (art. 24) Convention on the Elimination of All Forms of Discrimination Against Women (arts. 12, 14) Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights (art. 10) Bolivian Constitution (art. 13) Prevention Through Education Declaration
Rights of children	Accessible education, including education on sexual and reproductive health Adequate health services Protection from exploitation and violence Services for survivors and their families	Universal Declaration of Human Rights (art. 25) International Covenant on Civil and Political Rights (art. 23) International Covenant on Economic, Social and Cultural Rights (arts. 10, 13) Convention on the Rights of the Child American Convention on Human Rights (arts. 17, 19) Convention of Belem do Pará (art. 8) Bolivian Constitution (art. 13) Prevention Through Education Declaration

“access to sexual and reproductive health services for survivors of sexual violence, including emergency contraception[,] postexposure prophylaxis [is] not available.”<sup>49</sup>

Moreover, the availability of judicial remedies for survivors of GBV is limited. For example, according to a 2019 report from the International Human Rights Clinic at Harvard Law School, significant investigative and judicial barriers exist for victims of femicide, a form of GBV.<sup>50</sup> The report details that “Bolivian police investigators struggle to carry out their work in a thorough and timely manner, and systematic roadblocks, such as a lack of resources, corruption, and bias, can undermine their work.”<sup>51</sup> Additionally, the report outlines that “prohibitive costs, delays, and corruption” create barriers for families of the victim who are seeking justice.<sup>52</sup>

In addition to concerns about availability, Dr. Rojas later reflected that many patients in rural areas likely cannot access Casa de la Mujer’s specialized services due to the high travel costs associated with getting to and from their homes. For instance, the public transit route from Fernanda’s community to Montero, where she first met Dr. Rojas, costs 55 Bolivianos, equivalent to US\$8, and takes about two and a half hours for a round trip. A ride to the capital city of Santa Cruz, where Casa de la Mujer’s offices are located, would have been two dollars more, costing 70 Bolivianos and lasting four hours round trip. For reference, the average monthly income in communities surrounding Montero fluctuates between US\$150 and US\$300 per household.

Transportation barriers have been documented by other medical anthropologists working on sexual and reproductive health issues in the region. For example, Carina Heckert, who has worked with individuals living with HIV in communities surrounding Montero and beyond, notes that these individuals often delay or even abandon seeking health care due to high transportation costs.<sup>53</sup>

Previous research has also documented widespread discrimination against and derogatory language toward persons living with HIV, Indigenous Peoples, Bolivians of African descent, women, and individuals who identify as part of

the LGBTQ+ community within the provision of public services, including health care.<sup>54</sup>

Furthermore, the US State Department’s 2023 report on human rights in Bolivia notes that access to post-assault medical services is not equally distributed and that access to such services is “more readily available in urban areas.”<sup>55</sup> The authors of the report also write that “rural areas [lack] access and frequently [rely] on mobile health centers such as those provided by Marie Stopes International.”<sup>56</sup>

Institutional discrimination is also reported in the aforementioned 2019 report on femicide and impunity in Bolivia. The report states that “frequently, inadequately trained judges, prosecutors, and investigators fail to implement the gender-sensitive perspective that Bolivian policies require. Instead, some officials approach their work with a gender bias, engaging in victim blaming and discounting important evidence.”<sup>57</sup> It also notes that Indigenous women who are victims of GBV often experience additional sociocultural and linguistic barriers when attempting to access post-assault judicial remedies.

### *Acceptability and quality*

In addition to concerns about the availability and accessibility of specialized services, Dr. Rojas shared that, in her experience, adolescents often fear that if they seek sexual and reproductive health services in their rural, tight-knit community, their privacy or confidentiality may be compromised. For instance, Dr. Rojas described a scenario that she has seen play out in rural communities like Fernanda’s:

*When adolescents go to a pharmacy to buy a condom, they buy it really quickly, and the whole community finds out. “Oh, so-and-so was buying condoms, for this and that reason.” Then her mom finds out, and it becomes a problem. Access in Bolivia is very complicated because, especially in rural areas, everyone knows each other.*

Dr. Rojas’s comments are consistent with other research in Bolivia, which has documented adolescents’ concerns about privacy and confidentiality when seeking sexual and reproductive health services.<sup>58</sup> This same research has emphasized the



importance of a competent, well-trained, and adolescent-friendly health workforce to assist in increasing adolescents' health care utilization.

Additionally, inconsistent delivery of post-assault health services throughout the country has been documented.<sup>59</sup> Evidence suggests that public institutions tasked with handling cases of sexual violence fail to do so in a timely way.<sup>60</sup> Additionally, research shows that survivors often experience harassment and discrimination when attempting to access post-assault legal support and medical services and that state institutions fail to coordinate work across agencies effectively.<sup>61</sup> Other research has found that survivors and their families often have to navigate confusing and convoluted paths to health care and legal assistance that exist within a context of hypermasculinity (known in Spanish as *machismo*) and other forms of discrimination based on gender and sexuality.<sup>62</sup>

Reflecting on her experience navigating post-assault referral options for survivors of GBV in rural communities, Dr. Rojas expressed frustra-

tion and deep concern about the systemic neglect of survivors' care and institutional apathy. She also hinted at the potential for re-victimization and re-traumatization of survivors as they navigate post-assault health services and judicial remedies:

*There are no psychologists in the health system. So the girl [a survivor of GBV] decided to trust someone, and now the whole system is against her. There are no psychologists to support her, the police blame her, her parents blame her, and the staff don't want to deal with that patient anymore because now, because of her, they have to go to court ... it's very problematic and very complicated.*

This potential for re-victimization and re-traumatization described by Dr. Rojas is an example of "sanctuary trauma," a term coined by Steven Silver in the 1980s.<sup>63</sup> Silver used the term to refer to when a patient expects a safe, protective, and supportive environment (e.g., emergency room or police station) but instead experiences only additional stress, trauma, and violence.<sup>64</sup>

TABLE 2. What would post-assault health services and judicial remedies in Bolivia look like under the AAAQ framework?

	Health services	Judicial remedies
Availability	Sufficient quantity of human resources for post-assault health services (e.g., physicians, psychologists, and advanced practice nurses who have been trained in performing specialized forensic exams) Supplies and medical equipment (e.g., forensic exam kits and post-exposure prophylactic medications) and adequate facilities in which to perform services	Sufficient quantity of human resources for post-assault judicial remedies (e.g., prosecutors and legal advocates who have been trained in working with survivors of GBV) Supplies (e.g., documentation tools) and adequate facilities in which to perform services
Accessibility	No financial, geographic, or linguistic barriers to accessing health services No experiences of discrimination or harassment on the basis of one's age, gender, sexual orientation or gender identity, race or ethnicity, religion, or political affiliation when accessing health services Information about health services that is accessible to diverse patient populations, including communities with unmet literacy needs	No financial, geographic, or linguistic barriers to accessing judicial remedies No experiences of discrimination or harassment on the basis of one's age, gender, sexual orientation or gender identity, race or ethnicity, religion, or political affiliation when accessing judicial remedies Information about judicial services that is accessible to diverse patient populations, including communities with unmet literacy needs
Acceptability*	Health services that are trauma-informed, culturally responsive, and accepted by adolescent victims of GBV	Judicial remedies that are trauma-informed, culturally responsive, and accepted by adolescent victims of GBV
Quality	Evidence-based forensic exams and other post-assault health services that are consistent with international best standards and practices Timely attention Privacy	Timely, trauma-informed judicial processes

\*To our knowledge, no study to date has investigated the perceived acceptability of post-assault health services and judicial remedies for adolescent survivors of GBV in Bolivia. More research is needed to better center the voices of adolescent survivors of GBV and to explore what quality post-assault health services and judicial remedies would mean to them. This would be an important step to ensure that the design and implementation of post-assault resources are informed by and respond to their unique experiences, needs, and perspectives.



Although the concept was originally applied to veterans, “sanctuary trauma” is a useful notion in the context of adolescent survivors of GBV. However, to our knowledge, global health research on post-assault health care and judicial service utilization among survivors of GBV in rural, resource-variable contexts in low- and middle-income countries has not used or applied “sanctuary trauma” as a conceptual or theoretical framework to describe the experiences of survivors as they attempt to access care. Future research ought to apply this framework to examine the ways in which adolescent survivors of GBV may experience trauma as they attempt to access post-assault health care services and judicial remedies.

This review of extant literature about the availability, accessibility, acceptability, and quality of post-assault health care services and judicial services, coupled with Dr. Roja’s testimony, reveals that adolescent survivors of GBV may face barriers preventing them from accessing post-assault resources, which in turn could exacerbate trauma and impede healing. This is even though Bolivia is party to several international agreements guaranteeing sexual and reproductive health care and states in its Constitution that all citizens have the right to these health services.

## Conclusion

Our analysis reveals that despite the assurances made by Bolivian laws and policies to prevent GBV and support survivors in receiving post-assault care, Bolivia is falling short in its attempt to fulfill these broad obligations. As Dr. Rojas poignantly reflected, in Bolivia, “sexual health exists very wonderfully, but it only exists on paper.” The country has yet to meet its commitments concerning GBV, and the human rights of adolescent survivors remain under threat. Moreover, as we show above, adolescent victims of GBV may be experiencing “sanctuary trauma” in their attempts to access post-assault care.<sup>65</sup>

More research is urgently needed on the delivery of health services and judicial remedies for

adolescent survivors of GBV in rural Bolivia. Additionally, there is a need for further investigation into the effects of socio-structural factors (e.g., poverty) on the effectiveness of sexual and reproductive health interventions in resource-variable settings such as rural eastern Bolivia. A better understanding of these factors could inform the development of more targeted and effective policies and interventions.

Lastly, collaboration between NGOs, academic institutions, health care providers, and local communities is essential to address the multifaceted challenges faced by adolescents in accessing sexual and reproductive health services, including post-assault care, and to ensure the fulfillment of sexual and reproductive health rights.

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## Ethics approval

This research was approved by the University of Minnesota Institutional Review Board (STUDY00020590) and (STUDY00017895) and conducted in accordance with the ethical principles of the Declaration of Helsinki. Prior to data collection, informed consent (and assent, where applicable) was obtained from all participants in a language and format they understood. Participants were informed of the voluntary nature of the study, their right to withdraw at any time without penalty, and the measures taken to ensure their confidentiality and privacy. In Bolivia, we also sought institutional- and community-level endorsement for our research. While there is no centralized national institutional review board for nonclinical research in Bolivia, local ethical clearance was obtained through collaboration with municipal health networks and organizational partners. This included sharing study objectives, methods, and intended outcomes with stakeholders and incorporating their input to ensure that the research was culturally appropriate and aligned with the organizational partner's expectations. A faculty member at the Universidad Autónoma Gabriel René Moreno who is a national expert on sexual and reproductive health and rights and GBV also provided input on Voller's dissertation design. This dual-approval process—through the University of Minnesota and Bolivian organizational-based review—was designed to honor both formal institutional protocols and the ethical imperative of community-engaged, respectful research practices.

## Translation

This paper, including all quotations from cases and other Spanish-language material, was translated from Spanish into English by Vanessa Voller.

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## STUDENT ESSAY

# The Case for an Updated Premedical Curriculum in the United States

AUBRIENNE KRYSIEWICZ-BELL

### Abstract

In today's world of stark inequalities, medical education is increasingly recognizing the importance of exposing future physicians to topics such as health equity, social justice, public health, and human rights. A human rights-based approach (HRBA) to medical education centers these concepts as the foundation of equitable and accessible health care systems, comprising professionals who are literate in the social determinants of health and work to combat underlying inequalities. While medical schools and residency programs have preliminarily embraced this approach, the premedical curriculum has remained effectively stagnant since the early 20th century, adopting a narrow focus on the basic sciences and competitive individualism. In this essay, I argue that the premedical years represent a crucial, yet thus far overlooked, time frame in which to cultivate the values, qualities, and career expectations required of physicians under an HRBA to medical education, and critique how the current system generally fails to accomplish this. As a potential solution to realign the premedical curriculum with an HRBA and promote greater synergy within the medical education pipeline, I promote the introduction of premedical service-learning courses, which combine formal instruction in social justice, public health, and human rights with student-led community service projects.

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## Introduction

Recent decades have seen a growing movement to incorporate the social determinants of health, human rights, health equity, and social justice into medical education. The World Health Organization and United Nations (UN) have promoted a human rights-based approach (HRBA) to health care education, a framework that considers health a fundamental human right and emphasizes equality, dignity, and nondiscrimination in the provision of care.<sup>1</sup> Individual scholars, nongovernmental organizations, and medical regulatory bodies such as the Association of American Medical Colleges (AAMC) have issued similar recommendations for the pedagogical integration of these topics.<sup>2</sup> More recently, the COVID-19 pandemic brought renewed emphasis on curricular reform in medical education, and many medical schools and residency programs in the United States have begun teaching the social determinants of health, public health, and social justice topics to physician trainees.<sup>3</sup>

Yet the academic regimen for entry into American medical schools, known as the premedical curriculum, has remained focused on the basic sciences despite commendable advancements in health and human rights training at higher levels of medical education. There has been growing scholarly interest in the premedical experience, and the literature suggests that these years profoundly influence the moral foundation, socialization, and career expectations of future physicians.<sup>4</sup> Students not only gain a scientific foundation during this time but also begin crystallizing their identities in relation to leadership and social accountability. Thus, the mismatch between the biomedically focused, metrics-driven culture of the premedical experience and the humanistic, collaborative, and socially responsive model of care that characterizes modern medicine is increasingly troubling.

Ultimately, the current premedical system is fundamentally out of sync with modern physician values and health care realities, as well as with numerous expert opinions indicating the need for departure from a curriculum that still reflects 20th-century priorities. In the following sections, I critically examine how the US premedical curricu-

lum falls outside of an HRBA to medical education and offer a conceptual framework for reform.

## A rights-based approach to medical education

An HRBA to medical education affirms that health is a fundamental human right, inextricably linked to the realization of other rights and freedoms (e.g., housing, food, education) and asserts that health care systems—and the professionals within them—have a duty to promote equity, dignity, accessibility, and nondiscrimination.<sup>5</sup> This perspective expands the role of physicians beyond their traditional biomedical focus, calling for them to act as social and political advocates for patients.<sup>6</sup> Since the right to health was first enshrined in international documents such as the World Health Organization Constitution and the Universal Declaration of Human Rights in 1948, an HRBA to medical education has been promoted in other global instruments and across the academic literature, indicating a growing embrace of this perspective by medical practitioners.<sup>7</sup>

Two notable documents—the UN Special Rapporteur on the right to health's 2019 report on a rights-based approach to health workforce education and the World Health Organization's *Guidelines for Transforming and Scaling Up Health Professionals' Education and Training*—outline a vision for medical education reform that centers public health, social justice, and human rights.<sup>8</sup> Both reports stress the need to reimagine the goals and methods of health care education amid global epidemiological shifts, widespread economic inequality, and social injustice, in addition to promoting collaborative, community-embedded learning models. The realization of these reforms will require a concurrent shift in how health care professionals view their roles, which should occur “from the selection of students, to the curricula taught.”<sup>9</sup> I believe that this ideological transformation must begin in college as students decide whether to pursue a career in medicine. If we want future physicians to fully espouse and practice the principles of an HRBA to medical education, we must intentionally shape these values and commit-

ments during the formative years of their education.

## The premedical curriculum

Before the 20th century, there were no universal academic prerequisites for admission to medical school. In 1904, the Council on Medical Education was formed to restructure medical education and set admission standards.<sup>10</sup> It oversaw the commissioning of Abraham Flexner, an educational specialist, to assess the state of medical education in the United States and Canada. His famous *Flexner Report*, published in 1910, called for the standardization of curricula and emphasized scientific rigor, setting the blueprint for modern medical education.<sup>11</sup> Notably, his recommendations solidified the now familiar academic regimen for premedical students, including biology, chemistry, physics, and organic chemistry as required courses.<sup>12</sup>

These reforms lent consistency and scientific rigor to the premedical curriculum—an essential overhaul at the time but one that unintentionally cemented a rigid and narrow educational path. Flexner himself noted that medical education should be responsive to changing socio-ecological circumstances.<sup>13</sup> Yet in the 115 years since his report, the only major changes to the premedical requirements have been the addition of calculus and the extension of organic chemistry from one to two semesters.<sup>14</sup> Critiques of the Flexnerian model trace back to only a few decades after the report was published. Recently, the UN Special Rapporteur on the right to health directed attention to the *Flexner Report* as a turning point in medical education, suggesting that over a century later, “it is again time for a paradigm shift, to overhaul the many failings of medical education and its impacts on health systems.”<sup>15</sup>

## Critiquing the premedical curriculum through a rights-based lens

### *Mismatch with physician competencies and public health needs*

One of the most common critiques of the premedical requirements is that they target outdated educational objectives, increasingly disconnected

from the competencies and values of the ideal modern physician. Accordingly, they have come under scrutiny both for the nature and teaching methodology of the material they cover and for the content they fail to include. At most US colleges, premedical science classes are taught in a traditional lecture format and often include hundreds of students, many of whom intend to pursue careers in the sciences other than medicine.<sup>16</sup> Consequently, premedical students learn science concepts devoid of their applicability to medical practice (along with significant extraneous information) and in a way that favors passive learning and memorization over critical thinking and cross-disciplinary application of knowledge.<sup>17</sup> Organic chemistry is the course most frequently cited in studies of attrition among premedical students, prompting many to question “whether a single course should contribute to eliminating persons who might otherwise excel as physicians.”<sup>18</sup>

Overall, there appears to be consensus among the medical education community that the content and format of these required courses do not maximally prepare students for the study of medicine. One critic compared the premedical requirements to hazing rituals for fraternities in that “they both require difficult tasks that contribute little or nothing to the career aspirations of the student.”<sup>19</sup> Some have even argued that courses such as physics and calculus should not be required at all, given the minimal evidence suggesting their relevance to medical practice and the excessive stress and time burden required to succeed in them.<sup>20</sup> Certain pipeline programs, such as the HuMed Program at Mount Sinai School of Medicine, have arisen across the country, offering qualified college undergraduates early acceptance to a medical school without needing to take organic chemistry, physics, calculus, or even the Medical College Admission Test (MCAT). Studies have confirmed that these students performed comparably to their traditionally prepared peers in medical school, observing no significant differences in clerkship honors (except psychiatry, where HuMed students outperformed their traditional peers), overall academic distinctions, or graduation honors.<sup>21</sup>

While basic science subjects of dubious medical relevance continue to be required for admission to most US medical schools, topics including the social determinants of health, human rights, and social justice remain largely overlooked as a foundational element of the premedical experience, despite their clear applicability to modern-day practice. Considering the 21st-century disease climate, dominated by chronic conditions such as cardiovascular disease and cancer, it is essential for physicians to understand the complex social etiologies of these conditions.<sup>22</sup> In the past few decades, robust evidence from the public health literature has suggested that the synergistic interplay of many social determinants of health might contribute more to population health outcomes than do actual health care services, underscoring the importance of a public health perspective in the training of providers.<sup>23</sup> If the premedical curriculum is supposed to lay the scholarly foundation for a future in medicine and assist in the selection of students fit for this profession, it is both disappointing and insufficient for these subjects to be excluded from medical education's modern "renaissance" toward an HRBA.

According to an HRBA to medical education, structural violence (e.g., systemic discrimination, poverty, and housing instability) and direct violence (e.g., trafficking, torture, and physical or sexual assault) both constitute human rights abuses that are deeply responsible for the health disparities reflected in epidemiological data.<sup>24</sup> A commentary written by students at Boston University Medical School noted that within American medical education, the nexus of health and human rights has historically and inaccurately been sequestered within "global health" electives or taught at the will of individual educators.<sup>25</sup> This outdated perspective that patients facing human rights violations exist primarily outside of US borders—and that dedicated instruction about their care is thus not a curricular priority for medical trainees in the United States—is starkly out of touch with clinical realities. As the authors of this commentary describe, patients facing human rights violations

routinely appear in many major teaching hospitals across the United States, especially given today's high incidence of migration, displacement, and transnational crises.<sup>26</sup> Therefore, American medical education can no longer sideline the connection between human rights and health. While some American medical schools and residency programs have begun formally incorporating the social determinants of health and human rights into their training, the premedical curriculum's emphasis on context-free scientific knowledge has endured. The result is a disconnect between the competencies today's physicians need to truly care for the full spectrum of patients (including vulnerable populations) and the current academic barriers to enter this career.

The endurance of a biomedical perspective and the resistance to integrating human rights and social justice into US premedical education does not exist in a vacuum; rather, it reflects a more widespread institutional and ideological resistance to systemic change from within health fields. Decades ago, Jonathan Mann described in his essay "Human Rights and the New Public Health" how traditional public health approaches privilege biomedical and individual-behavior-focused interventions while avoiding the deeper social and political conditions that are truly responsible for disease.<sup>27</sup> He argued that this reluctance was not only due to conceptual inertia but also because departing from the field's status quo would disrupt existing hierarchies of professional authority and move "ownership" of these social problems from the hands of a few experts into the realm of collective responsibility, presenting a more daunting and obscure path toward public health solutions than surface-level, "engineered" interventions.<sup>28</sup> Likewise, premedical education continues to operate within a structurally entrenched, biomedical paradigm that treats science as context-free and health as a primarily individual phenomenon. Reconfiguring its curriculum will require a similarly monumental overhaul of long-established pedagogical structures and an ideological shift in the priorities of medical school admissions.

### *Competitive learning environment and narrow educational focus*

Beyond concerns about the premedical requirements' outdated content, many educators have criticized the social environment and unbalanced educational experience that these requirements directly and indirectly promote. Scholars have long acknowledged the existence of "premed syndrome," first identified in a 1984 report by the AAMC-commissioned Panel on the General Professional Education of the Physician and College Preparation for Medicine.<sup>29</sup> The report describes a culture of immense pressure to excel in the required courses, fierce competition, and an obsessive focus on maximizing admissions metrics.<sup>30</sup>

Despite rhetoric from regulatory bodies and individual admissions committees favoring a "holistic" application review process and a liberal arts education, science grade point averages (GPAs) and MCAT scores remain arguably the most important factors in schools' assessment of students. Although these objective metrics are indeed valid and predictive, many critics have noted that they have been used in unintended ways: "as a surrogate for individual academic excellence and a metric for medical school rankings."<sup>31</sup> Further complicating the issue is that colleges and premedical advisors have an unofficial, conflicting interest in maximizing their institution's acceptance yield to medical school, which can lead them to discourage certain hopeful applicants from applying if their metrics are not high enough to comfortably guarantee acceptance.<sup>32</sup>

Lewis Thomas, a prominent physician and author, has described the degree to which medical school admissions policies perpetuate premed syndrome and silo these students into curricular tracks heavily favoring the sciences. According to Thomas, as long as medical schools emphasize exceptional grades in science prerequisites and high MCAT scores, students will naturally "concentrate on the sciences with a fury" and "live for grades."<sup>33</sup> This sentiment has been echoed by Steven Kanter, who notes that premedical students are keenly aware of how their applications are reduced to numerical metrics—down to the hundredth of a decimal

point—and directly compared to one another.<sup>34</sup> Such a system not only compels them to prioritize these quantitative measures and thus view one another as competition but also communicates to them an inaccurate and incomplete picture of what true excellence in medicine looks like.

Beyond contributing to a stressful learning environment, these pressures also discourage students from pursuing courses that might challenge them in unfamiliar ways. It is unsurprising that premedical students hesitate to venture outside their academic comfort zones and pursue classes that are not required by admissions committees if doing so might risk lowering their GPA.<sup>35</sup> The ultimate purpose of the premedical years has long been a subject of scholarly discussion, and there is consensus that this time frame should be more than a mad race to maximize one's chances of medical school acceptance. Kanter describes an ideal philosophy for premedical education based on the robust literature about this debate, concluding that the premedical curriculum "must go beyond preparing a student to do well on an admission test and in the courses he or she will take in medical school, and must prepare the student to develop into an independent and creative thinker, with a strong moral compass and a commitment to social justice."<sup>36</sup>

The premedical experience is more than just a series of necessary checkpoints and milestones; it is a crucial stage of identity formation and socialization. Students begin internalizing the values and expectations of the medical profession long before they set foot in medical school. This moral and cultural orientation, shaped by implicit messaging from professors, peers, and admissions committees, is part of what has been described as medicine's "hidden curriculum."<sup>37</sup> Frederic Hafferty, a notable medical education researcher, argues that this hidden curriculum extends into the premedical years and that through exposure to it, students' "moral character basically is established prior to entry to medical school."<sup>38</sup> Thus, subsequent schooling in physician values and ethics comes too late to meaningfully shift their existing beliefs and interpersonal manner.



As long as the premedical system continues to reward superior performance in the basic sciences and a hyper-individualistic mindset, the academic and social experiences shaping premedical students' "moral character" will continue to downplay values such as teamwork, open-mindedness, and altruism. At the heart of an HRBA to medical education are professionals who espouse these humanistic values in every interaction with patients and other care providers—people who have both the humility and generosity to de-center themselves from situations and put others first. The current system arguably sets the stage for future physicians to be less team-oriented, cynical about sacrifices made, and focused on individual rather than collective success. If we want future physicians to truly be prepared to meet modern health care's humanistic demands, efforts to actively shape these qualities and values must begin earlier in students' education.

### *Complication of extracurricular time management, fairness, and subjectivity*

It is important to discuss one final, yet slightly less obvious, critique of the premedical requirements that underscores the need for curricular change. Under the current system, students are expected to earn competitive grades in the required courses while simultaneously crafting a résumé of impressive extracurricular activities, including research projects, leadership positions, and volunteer work. These "soft" requirements often represent the avenues through which students demonstrate many of the non-academic competencies expected for incoming medical students, including service orientation, cultural awareness, empathy and compassion, and teamwork and collaboration. These and other qualities are officially promoted by the AAMC's "Premed Competencies for Entering Medical Students" and echoed in many medical schools' mission statements, indicating widespread recognition of their importance to an applicant's preparation for and future success in this career.<sup>39</sup> This prompts the question of why qualities and skills that are so crucial for aspiring physicians and clearly desired by admissions committees are not formally integrated into applicants' education.

Leaving the development of these competencies entirely up to students to do in their free time, without institutional support or structured methods for assessment, introduces several concerns.

First, this system puts academic achievement at odds with extracurricular engagement, forcing students to consistently navigate compromises between the two. Students must learn time management, but the ambiguity surrounding how to balance these official and unofficial requirements unnecessarily burdens students and might even disincentivize their genuine engagement with nonacademic pursuits. When students must spread themselves so thinly under significant time constraints to demonstrate desired physician competencies outside of required coursework, extracurricular activities can often seem like chores—merely another step in "checking all the boxes" required for admission. This is especially true when considering that students are encouraged to prioritize high academic performance first, which often leaves them no choice but to relegate other, possibly more enriching and meaningful pursuits to the periphery. One could consider this yet another negative consequence of the Flexnerian premedical requirements: students are forced to allocate most of their time to GPA optimization at the expense of experiences that might be more intellectually adventurous and spiritually affirming of their decision to pursue medicine. Interestingly, this exact dilemma is cited as part of the justification for Mount Sinai's HuMed Program, which permits, through the elimination of "outdated requirements" and "premed syndrome," the matriculation of students who took more risks academically, pursued independent scholarship, and were overall more "self-directed" than traditional premedical students.<sup>40</sup>

Second, leaving the impetus to acquire these non-academic competencies up to applicants themselves obscures existing inequalities among them. Many of the activities premedical students undertake to demonstrate qualities such as leadership and service orientation require hundreds of hours of unpaid work, and it is grossly unfair to assume all applicants have equivalent time and resources to



do so. For example, students who must work paying jobs or assume caregiving responsibilities outside of school are at a significant disadvantage in their ability to engage in such unpaid ventures. Moreover, applicants who have connections within the medical field or to other prestigious opportunities are clearly at an advantage in securing extracurricular experiences that most aptly demonstrate the desired characteristics of future physicians. Ultimately, this unstructured system favors students with the financial, temporal, and social resources to craft compelling extracurricular narratives—regardless of the actual authenticity, impact, or difficulty of those experiences. The subjectivity this introduces raises serious questions about the soundness and equity of this process. It does not suffice to allow the evaluation of some of the most important qualities, values, and proficiencies for future physicians up to the personal interpretation of admissions committees, especially under a system that favors certain applicants.

It is important to recognize that the AAMC's recent promotion of a competency model for incoming medical students is indeed a step in the right direction. Originally developed in 2011 and updated in 2023 through a joint effort between the AAMC and members of the academic medicine community, these 17 competencies were designed to guide student preparation, provide clarity for admissions committees, and offer flexibility in how students could demonstrate readiness for this career.<sup>41</sup> The UN Special Rapporteur on the right to health even commended this recent pedagogical shift in his 2019 report.<sup>42</sup> Indeed, a growing number of forward-thinking medical schools have adopted this approach and done away with specific curricular requirements. However, the broader implementation of this model has remained inconsistent. As long as most medical schools continue to rely on traditional course prerequisites and the MCAT as key admissions metrics, students will need to follow the conventional prerequisite pathway, regardless of the commendable policies of a few institutions.

Calls for a competency-based approach from medical regulatory bodies and education

committees have fallen under broader appeals for premedical education to be more grounded in the liberal arts, encouraging students to take courses in the social sciences, humanities, public health, and ethics. Again, while admirable steps in the right direction, these calls for reform fall short in one crucial way: the mere encouragement of these academic experiences is not enough. The impetus to take these elective classes or engage in relevant experiences still lies with students, and it is not enough to simply hope that they heed these suggestions. In the same way that proficiency in the basic sciences is achieved through structured frameworks, proficiency in the physician qualities demanded by an HRBA to medical education should likewise be integrated into premedical students' formal academic experience.

### A potential solution: Service-learning courses

Addressing critiques of the current premedical curriculum and aligning it with an HRBA to medical education will require comprehensive reforms. As detailed in previous sections, these shortcomings are due not only to the exclusion of certain necessary material but also to issues with the content, structure, and social environment fostered by the current curricular system. Therefore, simply adding another requirement on public health, social justice, and human rights without restructuring existing coursework would likely exacerbate student stress and competition.<sup>43</sup> While the ultimate solution is outside the scope of this essay, one promising idea supported by the literature and international guidelines is the creation of new interdisciplinary courses that integrate and highlight the most medically relevant components of traditional basic science coursework (e.g., including the appropriate parts of organic and general chemistry in a new, integrated biochemistry class).<sup>44</sup> This approach would eliminate the burden of learning extraneous information, better accommodate the rapid pace of scientific discovery, and liberate scheduling space for non-science electives by reducing the number of required science courses. While there are barriers

to implementing this model, including strains on institutional resources to devise and implement these courses, it represents a promising step in the right direction and should be further pursued.

Ideally, efforts to revamp the existing science requirements in this way would be complementary to another solution proposed herein—one that would effectively address the current premedical system's general exclusion of public health, human rights, health equity, and social justice education. Service learning is a structured educational approach that combines community service with formal academic instruction and personal reflection, aiming to enrich learning experiences, strengthen communities, and cultivate the values of empathy, cultural competency, and civic responsibility among learners.<sup>45</sup> In the context of medical education, service-learning courses enable students to apply academic knowledge to real-world public health issues, deepening their understanding of the social determinants of health and the unique challenges faced by particularly vulnerable patient populations (for example, those who have experienced direct or systemic violence).<sup>46</sup> Such programs have already been introduced at several medical schools, including the Albert Einstein College of Medicine and Tufts University School of Medicine, with great success. Studies of community-embedded social justice learning programs have shown they enhance learners' interpersonal and leadership skills, augment their commitment to working with marginalized populations, and increase their interest in human rights and social justice work.<sup>47</sup>

The success of these programs at the level of medical school sets a precedent for the extension of this model to the premedical years, offering a promising template for a structured, values-driven student learning experience that aligns with an HRBA to medical education. Premedical service-learning courses would include a curricular regimen of topics such as social justice, the social determinants of health, and human rights taught through formal instruction, combined with university-organized opportunities for students to lead service projects that address the needs of local communities and simultaneously demonstrate

competencies such as social responsibility, service orientation, leadership, and cultural awareness. These classes would count as formal academic credits, permitting equal access for all students, and involve assessments, reflective small-group discussions, and presentations of individual projects. Such a multifaceted pedagogical approach would combine elements of the sciences (e.g., quantitative assessment of epidemiological data and population health research) with features of the humanities (e.g., subjective reflection and discourse) to provide a learning experience that enhances rather than limits students' achievement of a liberal arts education. Being encouraged to introspect and discuss service projects with peers would also arguably make these experiences more personally impactful for students, based on the benefits self-reported by learners in studies of similar programs.<sup>48</sup>

The advantages of this proposal are manifold. Foremost, it would enhance continuity between the premedical and medical school phases of physician education, formally enshrining competencies such as service orientation into the premedical curriculum. The promotion of premedical service-learning courses by authorities such as the AAMC would represent tangible action toward ensuring that all students enter medical school with an understanding of health equity, social justice, and human rights. Because proficiency in these topics is increasingly recognized as essential to success as a physician, a more hands-on approach than merely recommending related coursework is needed as students decide whether to pursue this profession.<sup>49</sup> Given the importance of the premedical years in shaping future physicians' identities and values, this period—when students' career goals, social habits, ethical principles, and attitudes toward medicine are actively crystallizing—is the ideal window to introduce such a meaningful intervention. Moreover, ensuring that all premedical students possess a foundational understanding of these topics would improve educational efficiency by reducing the burden on medical schools to teach them from the ground up, much like how introductory biology serves as a springboard for more advanced coursework in medical school.

Premedical service-learning courses would also offer a more equitable and objective alternative to the current way premedical extracurriculars are assessed by admissions committees. Having colleges sponsor and organize opportunities for students to devise and implement service projects would likely reduce the stress of securing extracurricular experiences. It would afford students who possess the leadership, dedication, and enterprise, but lack financial or social resources, an equal opportunity to develop new and impactful community initiatives. Embedding service-learning courses into students' official academic regimen would also mitigate the time conflict between coursework and extracurriculars. This way, students who need to use most of their free time to work a paying job or fulfill family obligations could still demonstrate the nonacademic competencies desired for medical school admission without being at a disadvantage to their peers who have more freedom to pursue such initiatives. Finally, the widespread adoption of comparable service-learning courses across US colleges would permit admissions committees to more objectively evaluate and compare the quality, depth, and personal significance of applicants' service projects and their underlying commitment to community-oriented care.

Although not the complete or final solution, service-learning courses are a promising and feasible step toward realigning the premedical curriculum with the competencies and values espoused by an HRBA to medical education. By integrating student-led community engagement with guided academic instruction and institutional support, service-learning courses offer a more standardized and equitable way for students to cultivate and demonstrate their understanding of the social determinants of health, social justice, and human rights in relation to health care. In addition to reinforcing continuity and efficiency across the medical educational pipeline, service-learning courses' blended educational format would bridge the divide between the abstract understanding of health equity concepts taught in a classroom and their real-world manifestations among vulnerable patient populations. This model thus

offers a concrete pathway for finally transforming long-standing recommendations about the premedical curriculum into truly meaningful reform.

## Conclusion

In 2009, the AAMC assembled a team of scientists, physicians, and educators, known as the Scientific Foundations for Future Physicians Committee, to reexamine the necessary competencies at every stage of medical training. The committee's report called for "new curricula that would create synergies and exciting new learning experiences."<sup>50</sup> Service-learning courses fulfill that vision, offering an innovative, values-driven model that reimagines premedical education not merely as a gateway to medical school but as the foundation for a more diverse, reflective, and socially responsive generation of physicians.

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## VIEWPOINT

# Trump's Banned Words and Disastrous Health Policies

JOSEPH J. AMON

Nearly 60 years ago, comedian Lenny Bruce was arrested for saying “forbidden” words in his stand-up show.<sup>1</sup> A few years later, George Carlin carried on the tradition and was arrested for a routine on the “seven words you can’t say on television.”<sup>2</sup>

What was transgressive then, and what subjected Bruce and Carlin to arrest, is less than shocking today and has, with the election of Donald J. Trump as US president, become normalized and transformed into what has been called “middle-finger politics.”<sup>3</sup>

A big difference, though, is that the words Bruce and Carlin used, which may have offended the conscience of many people (although limited to those paying to see their shows), were not part of a political circus seeking to erase the identities and restrict the human rights and civil liberties of millions of Americans, as well as hundreds of millions of individuals worldwide.<sup>4</sup>

Since his inauguration, President Trump has launched a blizzard of executive orders upending government programs affecting science, public health, the environment, trade, education, sports, and more. As part of these efforts, he has authorized a new list of banned words: gender, transgender, pregnant person, pregnant people, LGBT, transsexual, non-binary, nonbinary, assigned male at birth, assigned female at birth, biologically male, and biologically female.<sup>5</sup>

These are words that Trump demanded be eliminated from the US Centers for Disease Control’s website, erasing not only identities but also critical information on the health status and health inequities of often vulnerable populations. The orders also limit the ability of public health professionals, within the US government and outside of it, to implement programs and conduct research to ensure that everyone’s health needs are met.

On its face, this campaign seems ludicrous and laughable: as archaic as the trumped-up charges against Bruce and Carlin. Have we really stepped back in time to a world where the police, or the US president, is policing language?

The obvious answer is yes, we have.

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But this effort is clearly much greater, and much more powerful, than a couple of comedians pressing against the boundaries of quaint, and often hypocritical, social conventions. Trump's campaign against these words is part of a much larger effort to upend public health and health care in the United States and globally. It is as much a war against words as it is a war against science and against the progress that has been made over decades building global partnerships to advance the right to health.

### Global health and human rights

To understand more of Trump's global impact on health, we need look no further than a news article published on February 3 in *The Standard*, a Kenyan newspaper. The article reported that the United States Agency for International Development had suspended the supply of HIV antiretroviral medicines to the Kenya Medical Supplies Authority "until further notice."<sup>6</sup> Kenya has approximately 1.4 million people living with HIV and, with the support of internationally funded HIV prevention and treatment programs, has seen a sharp decline in new infections, falling from 270,000 new infections in 1992 to 21,000 in 2023.<sup>7</sup> The continuing success of these programs is now at risk.

The nonprofit research organization amfAR estimated that globally the US PEPFAR program supports 271,229 health workers who deliver new supplies of antiretroviral drugs to 222,333 people every day.<sup>8</sup> Among those being reached are 679,936 pregnant people living with HIV and receiving antiretroviral treatment for their own health and to prevent transmission to their children. The organization forecast that during the 90-day US stop-work order, 135,987 babies would acquire HIV. Making matters worse, these children would likely go undiagnosed because infant HIV testing services are also being suspended. Every day of the work stoppage an estimated 1,471 infants would be infected.

Thankfully, two weeks after the announcement of a 90-day "pause" for all US foreign assistance, the US Department of State issued a memo allow-

ing "life-saving HIV care and treatment services," "prevention of mother-to-child transmission services," and payment of "reasonable" administrative costs to continue. Confusion reigns, however, about the details of what is permitted, and funding reportedly remains blocked. The amfAR report also highlighted the stop-work order's impact on critically important public health programs that were related to HIV but were not strictly treatment programs. For example, in 2024, PEPFAR provided post-violence care to more than 1.3 million people, or more than 3,600 survivors of domestic and sexual violence every day, including by providing rape kits, HIV testing, post-exposure prophylaxis, and other essential services. These programs are stalled.

Malaria programs have also been affected. In Kenya, 70% of the population is considered at risk of malaria, and more than six million people are affected each year, mostly children under five years of age and pregnant people.<sup>9</sup> Recent progress against malaria has come from a new vaccine developed over the past four decades through work by the US government's Walter Reed Army Institute of Research and National Institutes of Health, in partnership with the pharmaceutical company GSK, the nonprofit organization PATH, and the Gates Foundation, among others. It has reduced cases of severe malaria and child deaths and increased health care access for children more broadly.<sup>10</sup> Few Americans are likely aware that malaria was endemic in parts of the United States until 1950; but as climate change advances, what are now rare cases of transmission may become more common.<sup>11</sup>

Malaria programs throughout sub-Saharan Africa have shut down mosquito control efforts and suspended shipments of bed nets to protect people from malaria because of Trump's orders. Programs to end maternal mortality lack medicines to stop hemorrhages. Inexpensive treatments, such as oral rehydration salts that treat life-threatening diarrhea, are not being delivered through health systems because of stop-work orders issued by the Trump administration.

Clinical trials have been suspended. Family planning programs halted. While there have been announcements that exemptions exist for some

programs, again confusion reigns, resulting in paralysis as program implementers wait for clarity on whether the exemptions apply to their programs. Meanwhile, thousands of staff experts in these programs and in how to navigate the communities where they are implemented have been furloughed or fired. In Bangladesh, the International Centre for Diarrhoeal Disease Research has laid off more than 1,000 employees.<sup>12</sup>

## Right to health in the United States

These actions “pausing” aid internationally might seem to be consistent with Trump’s campaign slogan of “America First.” But are they?

Trump’s recent executive orders and the actions of his administration also imperil the health of all Americans. Withdrawing the country from the World Health Organization will interfere with its ability to defend the United States against future pandemics. Withdrawing from the Paris Agreement on climate change makes us more vulnerable to the climate-related catastrophes measured in lives and in GDP that are already occurring. Ending diversity, equity, and inclusion programs makes it harder for public health workers to represent and work with the communities they serve and to fight back against misinformation and disinformation.<sup>13</sup> For Trump, who has proposed the blatantly unqualified, anti-science, conspiracy-minded Robert F. Kennedy Jr. to lead the Department of Health and Human Services, that may be intentional. But the impact on Americans, especially those most vulnerable, is inescapable, and affects the enjoyment of the right to equality and nondiscrimination, the right to information and to science, and the right to the highest attainable standard of physical and mental health.

Trump’s orders have especially affected the rights of LGBTQ+ Americans. Discrimination against LGBTQ+ people, particularly transgender people, was getting worse in the United States well before Trump came into office, with some states passing legislation limiting the rights of transgender individuals, especially children. These

laws included restrictions on access to bathrooms, participation in sports, and any discussion of gender and sexuality in schools.<sup>14</sup> As of 2023, 22 states had banned at least some form of gender-affirming health care for children, and five had laws classifying gender-affirming care as a felony.<sup>15</sup>

These policies contradict protections under the International Covenant on Civil and Political Rights, which prohibits discrimination on the basis of sexual orientation or gender identity. As noted by the United Nations Independent Expert on sexual orientation and gender identity following a 2022 visit to the United States, “these actions rely on prejudiced and stigmatizing views of LGBT persons, in particular transgender children and youth, and seek to leverage their lives as props for political profit.”<sup>16</sup>

The right to information on gender and sexuality has also been repeatedly restricted in the United States through bans on educational materials and books in schools and libraries. These bans violate the “freedom to seek, receive and impart information and ideas of all kinds” guaranteed under the International Covenant on Civil and Political Rights and erase the visibility of transgender individuals.<sup>17</sup>

Prior to Trump’s second term, lawmakers in many US states were already attempting to prohibit transgender people from expressing their gender identity by preventing them from sharing their pronouns and restricting discussions of gender identity and these were among the first steps taken by Trump across all federal agencies after he assumed office.<sup>18</sup>

The right to benefit from scientific progress has also been upended by Trump’s actions, impacting the right to health in the United States and globally. Trump’s actions to strip the Centers for Disease Control’s website of information on LGBTQ+ health and to prohibit the collection of information that includes the self-identification of people’s gender identity impedes our understanding of US and global public health challenges and successes. The denial of gender-affirming care for transgender individuals also violates the rights to

health and privacy and can deny the rights to security of person, life, and freedom from cruel and degrading treatment.

## Conclusion

The words used by Bruce and Carlin harmed no one, and the comedians' use of them was to call out hypocrisy and make America a more honest, open, and free country. Trump's forbidden words deny reality and demonstrate ignorance. We should follow in the comedians' vein by using them loudly, openly, and in defense of human rights.

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## VIEWPOINT

# Enforceable Commitments to Global Health Needed to Fulfill Rights

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The recent shifts in global health policy, particularly the United States' sudden retreat from key funding commitments and the Dutch government's decision to defund all projects related to women's rights, reflect a deeper crisis in global health governance.<sup>1</sup> These developments underscore the urgent need to reposition accountability not just as a discretionary moral obligation but as a fundamental legal principle deeply entrenched within international law and global health governance frameworks.<sup>2</sup> The right to health, codified in the International Covenant on Economic, Social and Cultural Rights and operationalized through instruments like the World Health Organization Constitution and the Sustainable Development Goals, imposes obligations on both national governments and international actors to uphold equitable, sustainable health policies. However, rising nationalistic tendencies now threaten to erode this framework, exacerbating vulnerabilities in low- and middle-income countries (LMICs) and undermining the principles of equity, global solidarity, and shared responsibility that are essential for a functional global health system.<sup>3</sup> Addressing this accountability gap requires a firm legal foundation, one that is already articulated in international human rights law.

General Comment 14 of the United Nations Committee on Economic, Social and Cultural Rights reinforces this imperative, emphasizing accountability as central to the realization of the right to health.<sup>4</sup> It underscores that health cannot be sustained solely through domestic efforts but requires collective global action, particularly for resource-constrained countries. At its core, General Comment 14 calls for the establishment of effective accountability mechanisms to ensure that states and other duty bearers uphold their obligations—not only within their borders but also in their extraterritorial engagements.<sup>5</sup>

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This principle is further reinforced by the extraterritorial obligations (ETO) framework, which affirms that states must not only refrain from actions that harm global health but also proactively ensure that their foreign policies, financial decisions, and trade agreements do not undermine health equity worldwide.<sup>6</sup> Yet despite this normative clarity, ETOs remain structurally weak, lacking binding compliance mechanisms, independent oversight, and legal consequences for non-adherence.<sup>7</sup> The absence of such enforcement structures has led to recurrent failures in global health governance, where donor states systematically disengage from financial commitments with impunity, despite the direct transnational consequences of these decisions.

This persistent accountability gap is not merely a technical or procedural deficiency—it represents a fundamental governance failure that threatens the realization of universal health coverage and the broader right to health. The World Health Organization estimates that over 400 million people globally still lack access to essential health services, a number set to rise unless global health financing structures prioritize long-term sustainability over short-term political considerations.<sup>8</sup> Yet rather than strengthening commitments to equity and preparedness, donor states continue to retreat from their obligations, prioritizing short-term domestic interests over long-term global health stability—even as ongoing public health emergencies of international concern such as Mpox, and disease outbreaks like Marburg in Rwanda and the Sudan virus in Uganda, demand sustained global cooperation.<sup>9</sup> This retreat from multilateralism reflects a broader shift toward nationalist approaches that dismantle long-standing commitments to the universal right to health.

The failures of the COVID-19 vaccine rollout illustrated the consequences of an accountability deficit in global health governance.<sup>10</sup> High-income countries monopolized vaccine supplies, while LMICs faced prolonged shortages, resulting in delayed immunization efforts and preventable mortality.<sup>11</sup> This vaccine inequity was a manifestation of a deeper structural failure, where global health

policies continue to be dictated by donor-driven priorities rather than the principles of equity and justice. Without an accountability framework that enforces sustained commitments, global health governance risks becoming a further fragmented system where access to health is dictated by shifting political cycles rather than long-term obligations to universal health rights.

The consequences of this shift extend beyond financial constraints; they reinforce historical injustices, as the same nations that once dictated global health priorities through colonial public health models and structural adjustment programs have now abandoned their obligations under the pretext of national interest.<sup>12</sup> These obligations, however, are not discretionary; they constitute a duty of sustained engagement, recognized under international human rights law. Disregarding these obligations now does not simply create funding gaps—it represents a profound failure of accountability in global health governance that jeopardizes decades of progress in combating infectious diseases, improving maternal health, and advancing universal health coverage.

Another manifestation of this accountability crisis is the persistent inequity in global health research investments.<sup>13</sup> The epistemic injustice embedded in current research paradigms reflects a larger failure of accountability, where knowledge production remains disproportionately controlled by high-income institutions. This results in a system that marginalizes the priorities and expertise of LMIC researchers, reinforcing a model where research agendas, funding allocations, and intellectual property rights are dictated by donor-driven interests rather than responding to local health burdens and systemic inequities.<sup>14</sup> While some research areas, such as pandemic preparedness and malaria vaccine development, have received increased funding, others, including neglected tropical diseases, reproductive health, and decentralized community-driven research models, remain critically underfunded.<sup>15</sup> A truly accountable global health research agenda must dismantle extractive models that prioritize publication metrics over local impact and foster equitable partnerships



that empower LMIC-based researchers as central contributors rather than peripheral actors.<sup>16</sup>

Ensuring accountability in global health requires the institutionalization of binding governance mechanisms that guarantee sustained financial commitments, transparency in health financing, and participatory oversight. The successes of the US President's Emergency Plan for AIDS Relief and the Global Fund demonstrate that when long-term financial commitments are anchored in robust governance structures, they yield measurable public health gains.<sup>17</sup> However, the retreat from these commitments exposes the fragility of a global health system overly reliant on discretionary donor aid, undermining equity and shared responsibility.

Recognizing these vulnerabilities, the African Union Roadmap on Shared Responsibility and Global Solidarity for AIDS, TB and Malaria calls for predictable and diversified health financing to reduce reliance on external donors. It advocates for clear financial sustainability plans, stronger domestic resource allocation, and enhanced accountability from development partners. However, donor disengagement continues to undermine this vision, highlighting the limitations of voluntary commitments and reinforcing the need for binding commitments that ensure long-term health security beyond political cycles.

## Make global health finance legally binding

To operationalize this vision, global health financing must transition from discretionary aid to a legally binding framework that is monitored, enforced, and insulated from political volatility. This requires:

- Institutionalizing binding financial commitments within multilateral legal instruments to prevent unilateral donor withdrawal.
- Embedding accountability mechanisms in treaty-based frameworks, including United Nations resolutions and financial compacts, to transform donor obligations from discretionary contributions into legal commitments.
- Establishing independent compliance mechanisms to track adherence, impose legal consequences for noncompliance, and strengthen enforcement pathways.
- Repositioning LMICs as co-governors of global health funding mechanisms to ensure that financial flows align with epidemiological priorities rather than externally imposed donor agendas.

Without these structural reforms, accountability will remain subject to political discretion rather than legal obligation. While initiatives such as the African Union Roadmap on Shared Responsibility and Global Solidarity lay an important foundation for sustainable health financing, their success depends on enforceable mechanisms that hold donor states accountable. If these measures remain voluntary, the right to health will remain a distant aspiration rather than an enforceable reality.

The future of global health cannot be dictated by shifting political cycles but must be anchored in an unwavering commitment to equity, solidarity, and justice.

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## VIEWPOINT

# Reclaiming Sexual and Reproductive Rights Through a Decolonial Lens

TLALENG MOFOKENG

The world is experiencing unprecedented attacks on sexual and reproductive health and rights (SRHR) that threaten decades of progress.<sup>1</sup> From restrictive abortion laws and gender-discriminatory health care policies to the criminalization of LGBTQIA+ individuals and shrinking civic space for feminist and human rights defenders, the regression is widespread and strategic, part of a systematic effort to reassert control over sexuality and reproduction.<sup>2</sup>

The current backlash points to deeper, structural origins of reproductive control that are embedded in colonial legacies.<sup>3</sup> Colonial regimes exercised power over colonized populations by replacing Indigenous traditional practices with rigid Eurocentric frameworks of gender, race, and sexuality.<sup>4</sup> Colonizers entrenched their authority through political domination and by asserting cultural and moral superiority through Christian missionary values that depicted colonized populations as inferior, uncivilized, and morally corrupt.<sup>5</sup>

The Convention on the Elimination of All Forms of Discrimination Against Women, particularly its articles 12 and 16, remains the key instrument for protecting women's right to decide freely about their bodies, providing legal and ethical grounding for advocacy, litigation, and accountability.<sup>6</sup> However, global efforts to protect this right must also acknowledge the deep-rooted colonial legacies, systemic inequalities, and intersecting forms of oppression that shape reproductive injustices.<sup>7</sup> Integrating a decolonial perspective into SRHR discourse and strategies, therefore, becomes essential to unpack and challenge embedded power structures and to foster more inclusive, locally grounded, and transformative solutions.

## The colonial legacy of control over sexuality and reproduction

Understanding power as a denominator in SRHR means asking hard questions: Who sets the rules around sexuality and reproduction? Whose bodies are policed, and whose desires are ignored? How do global

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health actors today reproduce or challenge these historical patterns?

If we are serious about advancing SRHR, we must confront not only contemporary policies but also the colonial foundations on which many of them rest. Before introducing a decolonial framework, it is imperative to engage with the concept of power—particularly Michel Foucault’s notion of *biopower*. This concept unveils the colonial legacies embedded in global health and reproductive justice systems and interrogates both the overt and subtle mechanisms of reproductive control in the modern era.

Biopower refers to the techniques and strategies through which modern states exert control over bodies, health, and life itself.<sup>8</sup> In the context of reproductive governance, biopower manifests through legal frameworks, health policies, funding mechanisms, and institutional practices that aim to discipline, surveil, and manage reproductive choices and capacities.<sup>9</sup>

The use of colonial-era laws is strong evidence of biopower in the reproductive space. For example, in the colonial era, the British Empire was governed by the 1861 Offences Against the Person Act that criminalized abortion and same-sex relationships, classifying the latter as “unnatural.”<sup>10</sup> Today, Jamaica retains an 1864 version of the colonial law, subjecting offenders of these two “crimes” to lengthy prison sentences.<sup>11</sup>

Another example of the discriminatory use of biopower in the early 20th century occurred in French and British colonies. The French imposed pronatalist policies, repressing contraception and abortion to boost population numbers, whereas the British shifted toward population control influenced by eugenic ideologies and economic rationales, eventually promoting family planning as a development tool.<sup>12</sup> These policies sought to regulate African women’s reproductive lives to serve colonial economic and demographic interests.

Native women in the colonies were subjected to forced sterilizations and non-consensual medical experimentation, illustrating how colonial power operated through control over marginalized bodies.<sup>13</sup> Colonial powers also imposed strict controls not only on the colonized but also on vulnerable

groups within their own ranks. For instance, European children were believed to develop sexual awareness earlier in the tropics, prompting strict oversight, including monitoring and controlling Indigenous adults and children when interacting with European children, to shield them from local influences deemed morally corrupt.<sup>14</sup>

## Neocolonial power and the persistence of reproductive control

Although formal colonialism has ended, power asymmetries persist in new forms, and neocolonial policies continue to wield power over sexuality and reproduction. What once operated through direct governance now functions through more insidious systems. Power is maintained via funding mechanisms that condition development aid on specific gender norms, laws that regulate bodily autonomy, and the continued dominance of Western knowledge systems that marginalize alternative epistemologies.<sup>15</sup>

For example, recent rollbacks in Ghana and the passage of an anti-LGBTQIA+ law in Uganda reflect a disturbing trend of shrinking civic space and heightened control over sexuality and bodily autonomy. In Ghana, the proposed Proper Human Sexual Rights and Ghanaian Family Values Bill criminalizes LGBTQIA+ identities and advocacy, while in Uganda, the Anti-Homosexuality Act imposes severe penalties, including life imprisonment and death sentences in certain cases.<sup>16</sup> These legal norms draw from a long legacy of colonial control over women’s bodies and reproduction, particularly the imposition of rigid family norms and procreative duties that mirror outdated Western ideologies and religious conservatism.

Meanwhile, donors frequently impose conditions that determine which sexual and reproductive health services are morally acceptable and thus “fundable.” For instance, the United States, under the new Trump administration, has reintroduced the Global Gag Rule prohibiting government funding to foreign nongovernmental organizations that provide information on and access to abortion services.<sup>17</sup> In effect, aid becomes a vehicle of control,

reinforcing exclusionary norms and undermining the sovereignty of postcolonial states to define health priorities.

To adequately respond to the scale and complexity of the current backlash requires decolonizing SRHR discourse and practice.<sup>18</sup> This involves recognizing and dismantling colonial power dynamics within global health governance, legal frameworks, and advocacy agendas while centering Indigenous, feminist, and Global South perspectives.<sup>19</sup> A decolonial approach complements the human rights framework and expands its potential for transformation by addressing the historical and structural roots of reproductive oppression.

For example, civil society organizations have been at the forefront of responding to anti-LGBTQIA+ laws rooted in colonial ideologies that institutionalize homophobia and negatively affect health outcomes in Africa. In Uganda, civil society responded to the passage of the Anti-Homosexuality Act by working in partnership with UNAIDS and government ministries to develop an “adaptation plan” that included the creation of safe drop-in centers to allow access to HIV care and services and by engaging law enforcement officials to emphasize the importance of protecting access to HIV prevention and treatment for LGBTQIA+ people.<sup>20</sup>

## Using a decolonial lens in human rights

Human rights-based approaches have played a foundational role in advancing sexual and reproductive health by securing legal protections, affirming bodily autonomy, and challenging discriminatory laws. For its part, the reproductive justice framework, rooted in Black feminist organizing in the United States, highlights the intersections of race, class, gender, and reproductive freedom.<sup>21</sup> Together, these frameworks create a powerful foundation—but to advance SRHR in an inclusive and transformative way, we must go further.

Progress demands a systemic approach that moves from individual-level advocacy and interrogates the broader architecture of power rooted in colonial legacies, geopolitical dominance, patriarchy, and structural racism. These systems continue

to determine whose bodies are controlled, whose voices are amplified, and whose reproductive autonomy is recognized.

The decolonial power lens offers the systemic perspective we need. It reveals that reproductive oppression is not merely the result of individual rights violations but of entrenched systems of control. It calls for the deconstruction and decolonization of power structures—such as global financial structures, donor conditionalities, and epistemic exclusion—that continue to shape global health systems.

Scholars have emphasized that adopting a decolonial lens can lead to better health outcomes and greater equity.<sup>22</sup> But adopting this lens involves going beyond simply being “decolonial” in name—it requires challenging traditional approaches and working toward the genuine sharing of power. It also means shifting where we seek knowledge and leadership, recognizing the value of Black, feminist, and Global South movements, and rethinking the types of knowledge we prioritize.

A decolonial lens is not a rejection of human rights or reproductive justice frameworks but a complement to them. Combining these three frameworks offers a way to transform the institutions, narratives, and power relations that continue to shape who has access to health, and on what terms. It confronts the historical and structural forces that shape reproductive experiences and disparities across contexts and calls for health policies and systems to actively dismantle these structures, not merely treat their symptoms.

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## VIEWPOINT

# The US Administration's Assault on Global Reproductive Health and Autonomy

WINONA XU

Shortly after President Donald Trump's second inauguration on January 20, 2025, he issued an executive order halting nearly all foreign assistance for at least 90 days.<sup>1</sup> Almost immediately, the US State Department sent "stop-work" orders to organizations receiving US funds, forcing clinics to close.<sup>2</sup> Shipments of essential supplies were suspended, and health programs ranging from malaria control to maternal care were disrupted.<sup>3</sup> Simultaneously, the administration not only reinstated but also expanded the so-called Global Gag Rule, a policy that forbids nongovernmental organizations receiving US health assistance from providing or even discussing abortion.<sup>4</sup> Just days later, Secretary of State Marco Rubio instructed US diplomats to rejoin the Geneva Consensus Declaration, an international anti-abortion pact that proclaims "there is no international right to abortion."<sup>5</sup>

These actions constitute a profound attack on reproductive rights. By abruptly freezing aid and restricting speech about abortion, the United States endangers both immediate health services and the broader principle of bodily autonomy, resulting in particularly harmful repercussions for women, girls, and other marginalized groups worldwide.

## Undermining bodily autonomy and the right to health

Access to reproductive health care underpins an individual's ability to make decisions about their body, family, and future. Within days of the freeze, more than 900,000 women and girls had already lost their usual supply of contraceptives; by the tenth day, more than 1.3 million had been denied care.<sup>6</sup> The Guttmacher Institute estimates that a full 90-day pause would leave approximately 11.7 million people without family planning services, thereby triggering an estimated 4.2 million unintended pregnancies and thousands of preventable maternal deaths in 2025 alone.<sup>7</sup>

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This funding freeze constitutes a clear violation of bodily autonomy and the right to health. Under international standards, such as the International Covenant on Economic, Social and Cultural Rights and the Convention on the Elimination of All Forms of Discrimination Against Women, governments are required to promote equitable access to reproductive health care.<sup>8</sup> When the United States, a major funder of such programs, abruptly suspends or places conditions on foreign assistance, communities with the fewest resources experience the most severe impact. Furthermore, sudden interruptions in contraceptive distribution, obstetric care, and other essential health services directly compromise the right of individuals to decide whether, when, and how to have children.<sup>9</sup>

### Disproportionate impact on marginalized communities

Refugees, displaced persons, and individuals living in conflict zones often rely heavily on foreign-funded clinics for prenatal care, gender-based violence response, and emergency obstetric interventions.<sup>10</sup> When these clinics lose funding, services collapse swiftly. Providers must suspend staff, halt deliveries of medical supplies, and close their doors—sometimes with little or no warning. Human Rights Watch warns that President Trump’s abrupt suspension of foreign aid endangers “the health, safety, and livelihoods of millions of people.”<sup>11</sup> It specifically mentions the halting of the President’s Emergency Plan for AIDS Relief (PEPFAR), which is providing support to more than 750,000 pregnant and HIV-positive people to prevent mother-to-child transmission of HIV, as well as preventative care for approximately 850,000 newborns.<sup>12</sup> Disrupting these services violates recipients’ right to health and can be life-threatening, particularly for pregnant individuals, whose compromised immune systems leave them vulnerable to opportunistic infections. According to UNAIDS, more than 2,800 additional HIV infections have already occurred worldwide as a result of the PEPFAR shutdown, underscoring the urgent and far-reaching consequences of this policy decision.<sup>13</sup>

In Uganda, bed-net distribution to pregnant women, a critical component of malaria prevention, has stopped.<sup>14</sup> Pregnant women are particularly vulnerable to the disease, which can lead to preventable adverse complications such as miscarriage, low birth weight, and premature birth.<sup>15</sup> In Zambia, hemorrhage-preventing medications for pregnant women remain stalled in storage.<sup>16</sup> Meanwhile, in South Africa, a 22-year-old participant in a trial testing a vaginal ring to prevent both HIV infection and pregnancy saw her care abruptly halted, exposing an alarming breach of reproductive health protections and bodily autonomy.<sup>17</sup> Public records that might have clarified the scope of these shutdowns have been wiped from the United States Agency for International Development website, compounding a grim history of exploiting communities and other marginalized groups in medical research. Already facing heightened threats to their health and safety, crisis-affected populations lose vital reproductive health care, further perpetuating cycles of poverty. As the Women’s Refugee Commission warns, “This is not about the next 90 days; it’s about a lifetime of consequences for millions of people.”<sup>18</sup>

### The chilling effect of the Global Gag Rule

Although US law (under the Helms Amendment) already bars direct foreign aid for abortions, the expanded Global Gag Rule goes further by restricting even discussion or referrals for legal abortion.<sup>19</sup> If nongovernmental organizations accept US health funds, they must then censor their own services or advocacy. Originally introduced in 1984, the policy has repeatedly proven to reduce access not only to abortion-related care but also to broader health services, because many organizations opt to give up US funding altogether rather than withhold information from their patients.<sup>20</sup>

This chilling effect extends far beyond abortion. Providers worry that discussing post-abortion care or even referring a hemorrhaging patient to the nearest safe facility could jeopardize their funding.<sup>21</sup> Consequently, women are often denied vital medical information, including how to seek

safe care in countries where abortion is legal under specific circumstances. This climate of self-censorship erodes the fundamental principle of informed consent and violates guidelines by the World Health Organization, both of which emphasize patients' right to comprehensive, accurate information about their medical options.<sup>22</sup>

## Rejoining the Geneva Consensus Declaration

Rejoining the Geneva Consensus Declaration further solidifies the administration's alignment with an international bloc that actively seeks to deny reproductive rights. Although nonbinding, the declaration's core assertion—namely that “there is no international right to abortion”—runs counter to established human rights norms affirming the autonomy of women and girls.<sup>23</sup> By positioning the United States alongside countries with restrictive laws on reproductive health, this move may embolden other governments to challenge or weaken existing protections within various United Nations bodies, where the United States has previously threatened to veto resolutions referencing sexual and reproductive health.<sup>24</sup>

Critics argue that this stance undermines the global consensus that reproductive health care, including abortion in certain contexts, is a vital element of the right to health. Countries with fragile health care systems may feel pressured to adopt similar positions in order to preserve future US assistance.

## Eroding decades of progress in global health

For decades, US foreign aid has supported integrated programs focusing on HIV, malaria, tuberculosis, maternal health, and family planning.<sup>25</sup> The sudden mass layoffs triggered by the freeze threaten to reverse these gains. In many settings, skilled local providers who were trained through US-funded programs are forced to find new work elsewhere, fragmenting health care networks that took years to build. Supply chains are similarly affected. Clin-

ical trials on new contraceptive methods or HIV prevention tools remain in limbo, jeopardizing both participants and researchers. Even if funding eventually resumes, it could take months or years to rebuild partnerships, regain community trust and stability, and restore the logistics of medical supply distribution. Overall, these disruptions violate the principle of nondiscrimination in health care by disproportionately affecting populations who can least withstand funding fluctuations. As Doctors Without Borders has warned, “attacks on reproductive health will have devastating consequences worldwide,” especially where alternatives are scarce.<sup>26</sup>

## Call to action

To ensure respect for the human rights of women and girls, and to mediate the harms described above, the following coordinated steps are needed urgently from the administration, Congress, donors, civil society, and private actors. By lifting restrictive policies and investing in locally led solutions, health care systems that have been compromised by harmful regulations can be restored and strengthened.

- First, the administration and Congress should rescind stop-work orders and immediately release congressionally approved funds for reproductive and other health services. Just as important, permanently ending the Global Gag Rule through legislation like the Global Health, Empowerment, and Rights Act will allow continuous access to a full range of reproductive health services and unbiased information.<sup>27</sup> Withdrawing from the Geneva Consensus Declaration is another critical step, since it reaffirms the commitment of the United States to international norms that protect women's autonomy and recognize their right to sexual and reproductive health care.
- Donors, civil society, and private actors can play a transformative role by rebuilding local capacity and reinvesting in health care staffing, supply chains, and comprehensive service delivery. By providing support for locally led organizations

and culturally informed care, community-level health care resources can be restored and enhanced.

- It is important to document the harms caused by both the funding freeze and gag rules, and to seek appropriate avenues of legal and human rights recourse. Through domestic courts and international human rights bodies, advocates can uphold the right to health and the free flow of information. Combining these efforts and sharing responsibility can strengthen health care systems, champion women's autonomy, and protect fundamental human rights.

On both the domestic and international level, President Trump's actions amount to an aggressive campaign against reproductive freedom, dismantling protections and emboldening restrictive policies across populations.<sup>28</sup> The people most in need of care, whether low-income patients at home or marginalized communities abroad, are bearing the brunt of these restrictions. Although advocacy groups have won some early legal battles to stall the onslaught, the administration's trajectory remains uncompromisingly hostile to reproductive autonomy.<sup>29</sup>

As of four months later, the fallout has not abated; the administration has already moved to rescind even fundamental safeguards such as emergency abortion protections in hospitals, a sign that Trump's assault on reproductive health and bodily autonomy is only intensifying.<sup>30</sup>

The repercussions of halting foreign assistance and expanding abortion restrictions are immediate and intergenerational, placing millions at risk of unintended pregnancy, maternal mortality, and diminished bodily autonomy. As overlapping crises such as pandemics, climate change, and ongoing armed conflicts stretch health care systems to their limits, it is urgent that policies reinforce rather than dismantle access to essential care.

Reproductive rights are human rights.<sup>31</sup> Protecting and expanding them now is critical to ensuring the health, dignity, and well-being of women, girls, and marginalized communities around the world.

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## VIEWPOINT

# Diverse Families Under Threat: Reproductive Conservatism

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Assisted reproductive technologies (ARTs) have played a transformative role in expanding the possibilities for diverse family structures. Yet as conservative approaches to reproduction gain influence, these advances are under threat.

In recent years, courts and legislatures around the world have increasingly embraced forms of reproductive conservatism—legal and ideological efforts to reassert control over reproduction by reinforcing normative boundaries about who can become a parent and under what conditions. This phenomenon manifests through two principal mechanisms: first, the restriction of parental rights for those outside heteronormative family structures, particularly LGBTQ+ individuals and single people; and second, the prohibition and even penalization of the use of ARTs. Reproductive conservatism consistently features biological essentialism about kinship, narrow definitions of parenthood, and opposition to the use of reproductive technologies. Aligning with broader conservative ideologies, reproductive conservatism emphasizes tradition, social values, and resistance to progressive shifts in reproductive and family rights.

Appeals to the protection of the “traditional family” frequently frame it as essential to social cohesion, positioning non-normative family models as a threat to societal stability. In this way, there is a global trend aiming to limit the rights of LGBTQ+ families through restrictions on kinship rights and the lack of recognition of parenthood. For instance, in October 2024, the Argentine Supreme Court issued a landmark ruling on surrogacy, rejecting a same-sex couple’s request to be recognized as the sole legal parents of a child born through a surrogacy arrangement, despite mutual agreement with the surrogate.<sup>1</sup> The court reaffirmed that, under current Argentine law, the woman who gives birth is recognized as the legal

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mother, regardless of private agreements.<sup>2</sup> While the absence of a comprehensive legal framework contributes to ongoing legal uncertainty, existing literature indicates that courts had generally ruled in favor of applicants in surrogacy-related cases. In contrast, among the relatively few cases where rectification was denied—including the 2024 decision—same-sex applicants were involved, raising concerns about a pattern of differential treatment.<sup>3</sup>

Bulgaria provides a striking example of the growing influence of reproductive conservatism and its impact on LGBTQ+ rights. In 2021, a same-sex couple, one of whom was Bulgarian, had a child via surrogacy in Spain, with both mothers listed on the birth certificate. However, when they sought Bulgarian identity documents for their child, the Sofia Municipality refused to issue a birth certificate. The authorities cited the absence of information about the biological mother and argued that listing two female parents violated Bulgarian public policy, as same-sex marriages are not recognized in the country.<sup>4</sup> In December 2021, the Court of Justice of the European Union ruled that denying the child the right to one parent or hindering her ability to exercise her right to free movement due to her parents' same-sex marriage would violate fundamental rights under articles 7 and 24 of the Charter of Fundamental Rights of the European Union. As a result, Bulgarian authorities were required to recognize the child as part of the family, and a Bulgarian district court subsequently ordered the Sofia authorities to issue a birth certificate for the child.<sup>5</sup>

However, in 2023, the Supreme Administrative Court of Bulgaria overturned this decision, stating that under Bulgarian law, a mother's identity is determined by birth. The court argued that foreign acts could be recognized only if they do not contradict Bulgarian public order, and since same-sex marriages are not allowed in Bulgaria, the registration of two female parents was not possible.<sup>6</sup> As a consequence, same-sex Bulgarian couples cannot obtain legal recognition for both parents, whether through surrogacy abroad or when one partner undergoes in vitro fertilization and gives birth in

Bulgaria, as only the birth mother will be legally recognized as a parent.

Italy is another example of intensified efforts to curtail the parental rights of same-sex couples, particularly those of non-biological parents. In July 2023, local authorities in Padua began removing non-biological lesbian mothers from birth certificates, aligning with the policies promoted by the government of Prime Minister Giorgia Meloni.<sup>7</sup> This policy shift, which prioritizes biological kinship over social and legal parenthood, resulted in the removal of 27 mothers from birth records.<sup>8</sup> Same-sex couples must now initiate civil lawsuits to obtain legal recognition of their parental status, either through adoption to recognize the second parent or by challenging the legal prohibitions directly.<sup>9</sup> In October 2024, the Italian Parliament expanded these measures by criminalizing citizens who pursue surrogacy abroad, even in jurisdictions where the practice is lawful.<sup>10</sup>

In April 2025, the Spanish government issued a decree banning the direct registration of children born through surrogacy in its civil registry. This decree aims to prevent Spanish nationals from traveling to countries where surrogacy is legal and then attempting to have their parentage recognized in Spain. Under the new regulation, legal parentage will be recognized only in cases of biological parentage or adoptive parentage, and only when a family unit with sufficient legal and social guarantees is established.<sup>11</sup> Surrogacy contracts, whether altruistic or commercial, have been void in Spain since 2006. The new legislation could leave children born through surrogacy stateless.

India passed legislation in 2021 that bans commercial surrogacy, permitting only altruistic surrogacy to married heterosexual couples who have been childless for at least five years.<sup>12</sup> This framework explicitly excludes LGBTQ+ individuals, single parents, and unmarried couples.

In January 2025, a bipartisan bill was introduced in the Chilean Congress aimed at prohibiting gestational surrogacy.<sup>13</sup> The proposed legislation establishes both civil and criminal penalties, including the nullification of surrogacy

contracts and the imposition of criminal sanctions on individuals, agencies, and clinics involved in promoting surrogacy arrangements.<sup>14</sup> Additionally, the bill prohibits egg donation, thereby further restricting access to ARTs that enable diverse family formations.<sup>15</sup> Notably, the bill remains silent on sperm donation, raising concerns regarding gender discrimination in its approach.<sup>16</sup>

In April 2025, the Greek minister of justice announced a reform that, if enacted, will limit surrogacy to women who are medically unable to carry a pregnancy, effectively excluding single men and male same-sex couples from accessing ARTs.<sup>17</sup>

Contemporary restrictions on ARTs and surrogacy are often justified through diverse discourses that serve to reinforce traditional norms surrounding reproduction and family. These justifications obscure the lived realities of LGBTQ+ individuals, single parents, and others for whom access to ARTs and surrogacy is not only a means of family formation but a matter of reproductive autonomy. Denying access to these technologies undermines their right to build families in ways that reflect their identities and life circumstances. This backlash is not merely about regulating technology; it constitutes a broader ideological challenge to reproductive justice, targeting nontraditional kinship models and reasserting state control over who may parent, and under what conditions.

The global spread of anti-surrogacy and anti-ART discourse is not unfolding in isolation. It is deeply intertwined with broader efforts to regulate family formation and curtail reproductive autonomy. These arguments—often framed in the language of human rights or ethics—are increasingly deployed to challenge the legitimacy of same-sex and non-traditional families.

It is crucial to distinguish between the diverse actors and motives driving opposition to ARTs because their underlying objectives and normative foundations vary significantly. Acknowledging these differences is essential for tailoring effective responses to each. For instance, it may be unproductive to engage with those committed to preserving a heteropatriarchal family model, but it is possible and necessary to develop constructive responses to

concerns about the exploitation of women in surrogacy arrangements.

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## VIEWPOINT

# Bodies That Resist: Transgender People's Health and Rights in Colombia

FERNANDE ÁLVAREZ-MOLINA, MAGDA MENESES, ANDRÉS CAMILO RESTREPO MORA, JAVIER GUERRERO, AND CATALINA GONZÁLEZ-URIBE

Colombia is witnessing a period of significant regression in the protection of trans people's rights, marked by the enactment or attempted enactment of discriminatory legislation and a surge in public hostility, amplified in particular through social media. And violence against trans individuals persists. According to the nongovernmental organization Caribe Afirmativo, in 2024 alone, 40 violent acts resulting in the deaths of LGBTIQ+ individuals were reported in Colombia. Of these, 22 involved transgender people.<sup>1</sup> While this piece was being written, on April 4, 2025, Sara Millery González Borja was murdered in the municipality of Bello, Antioquia, a killing that shocked the country because of the torture and public punishment she suffered.

In recent years, the trans movement in Colombia has participated in several initiatives to advocate for their rights, including successfully advocating for a speedy procedure to change the sex identifier on the national ID document in 2015; protecting the right to vote for trans people in 2020; and achieving legal recognition of non-binary people. One important challenge still faced by transgender people in Colombia is access to essential services such as health care.<sup>2</sup> As in other parts of the world, transgender individuals in Colombia face multiple barriers when accessing health care, including fear of discrimination by medical

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and administrative personnel. To address the right to health of trans people in Colombia, in 2024, with the support of senators from the Liberal and Green parties, the trans movement submitted Bill 122, titled “Comprehensive Law on Gender Identity,” before Congress.<sup>3</sup>

This bill proposal is an urgent and necessary response to the historical discrimination, marginalization, and systemic violence experienced by trans and non-binary people in Colombia, as evidenced by the country’s alarming violence statistics. It aims to create a comprehensive framework for the full exercise of trans and non-binary people’s fundamental rights, eradicating injustice and exclusion in both public and private spheres. It emphasizes autonomy and equal opportunity for these individuals and aims to close legal gaps and promote dignified living conditions through adequate protection and historical redress. A key area of focus of the bill is the elimination of barriers to the enjoyment of health and social security by people with diverse gender identities.

The bill proposal is the result of years of organizing and discussion. This organizing intensified in early February 2023 with the launch of “Comprehensive Trans Law Now!,” a campaign that emerged as a collective response to the urgent need for legislation that guarantees the rights of people with diverse gender identities. More than 100 organizations from across the country worked together to begin conceptualizing a draft bill, dividing the work up among specialized subcommittees, including a legal and methodological team that analyzed national and international human rights reports and reviewed legislative experiences from other countries. Later, the collective conducted a nationwide survey, using a snowball sampling method to reach marginalized populations. The consultation gathered data from 1,350 trans individuals, including data on life stages, sex work, rurality, ethnicity, incarceration, and disability. The results were compiled into a report that, combined with previous research done by the Liga de Salud Trans, formed the basis for a first draft of the bill. A national conference was then held in May 2023 in Bogotá, where

allied organizations provided feedback on the bill, and an official draft was finalized.

Finally, on March 31, 2024, with the support of 41 legislators, Bill 122 was formally submitted to Congress, where it is currently undergoing review.

The bill proposal addresses topics such as sexual orientation, gender identity and expression, a life-cycle approach, intersectionality, anti-ableism, and anti-racism. Among the specific areas of focus are the following:

- Health care: Ensuring access to treatment and empathetic medical care.
- Employment: Prohibiting discrimination and promoting decent work conditions.
- Education: Encouraging inclusion and preventing violence.
- Housing: Securing discrimination-free spaces.
- Recognition of care work, exemption from compulsory military service, political and social participation, protection from the effects of armed conflict, and justice, including enhanced penalties for violence against trans people.

Meanwhile, as the bill proposal is being debated in Congress, the trans movement continues to face backlash in response to its legal and policy efforts. For example, in October 2024, nationwide marches were organized by anti-rights groups and conservative politicians to protest External Circular 2024150000000011-5, issued by the National Health Superintendence, laying out guidelines for health care facilities on how to uphold the right to health of Colombia’s trans population. These marches were conducted under the motto “Don’t Mess with Our Kids,” which spread widely on platforms such as X, Instagram, and Facebook. National public figures and celebrities supported the initiative, employing moral panic tactics similar to those seen in other countries. Phrases used in the campaign included the following:

- “What’s wrong is wrong, even if they disguise it as ‘my body, my choice.’”

- “What’s wrong is wrong, even if they disguise it as rights.”
- “What’s wrong is wrong, even if they dress it up as inclusion.”

The anti-trans rights marches took place in 19 cities in Colombia and in New York City, with an estimated 20,000 people participating. Moreover, a year earlier, in 2023, a “Don’t Mess with Our Kids” bill had been introduced in Congress but was shelved due to procedural issues.

These anti-rights efforts all share common goals: to restrict medical treatments, criminalize health care professionals and organizations that support trans minors, and create an environment of fear and self-censorship. They reinforce false and negative beliefs about trans identities, perpetuate stigma and social discrimination, and criminalize support networks. These narratives pathologize trans identities as disorders, despite the medical community and the 11th revision of the International Classification of Diseases no longer classifying them as such, often using cherry-picked or decontextualized references.

In conclusion, trans people in Colombia have faced stigmatizing and violent actions fueled by anti-rights movements that aim to diminish their quality of life and deny them the protection of their rights, all under a discourse of hate and discrimination. Although transformative efforts have been developed by trans organizations, social media has often served as a platform to promote stigmatizing campaigns against these initiatives. Combined with public mobilization efforts, such as marches in major cities, this has contributed to setbacks in key areas such as health, education, employment, and other fundamental rights that should be guaranteed by the state. Nonetheless, there is a glimmer of hope in the country, thanks to Bill 122 of 2024. The fight for this bill proposal illustrates the importance of social movements in sociopolitical contexts where human rights are under threat. If passed into law, it will ensure legal protections for trans and non-binary people, improve these individuals’ quality of life in various domains, and promote a fairer and more equitable society.

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## VIEWPOINT

# Health and Human Rights: Territories in Dispute

JACQUELINE PITANGUY

Health and human rights are part of a political battlefield in which interpretations of religion, culture, science, and judicial systems are constantly disputed. This battlefield also reflects national and international tensions, transnational conflicts, and alliances that affect the incorporation of a rights-based approach to health into laws and public policies, international conventions, and private and public funding for health.

In the 1990s, after the democratization of Brazil and other countries in Latin America following decades of military regimes, the right to health was adopted within a framework of the secularization of political power and accompanied other reforms in constitutions, laws, and public policies. The principles of respect for democracy, pluralism, and diversity were institutionalized.

In Brazil, a new Constitution was enacted in 1988, affirming the right to health as a human right and as a duty of the state. The Constitution established universal and free access to health care by means of a unified public health system, the Sistema Único de Saúde.<sup>1</sup> The new Constitution also assured full equality to women; abolished the previous recognition of the man as the head of the family; and affirmed the right to choose the number of one's children and obligated the state to provide the means to do so.<sup>2</sup> The inclusion of these provisions was due in large part to the country's feminist movement, which had engaged in coordinated advocacy efforts during the constitutional reform process.<sup>3</sup>

However, subsequently in Brazil and elsewhere, the advance of right-wing conservative populist forces has led to the election of presidents that represent a radical right agenda. These leaders include Jair Bolsonaro in Brazil (2019–2023) (who remains a powerful political force even after leaving office because his party has the largest number of representatives in the National Congress), Javier Milei in Argentina (2023–current), Nayib Bukele in El Salvador (2019–current), Donald Trump in the United States (2025–current), and leaders in European countries such as Hungary and Italy.

These governments threaten the fulfillment of the right to health. In some countries, barriers to health care—particularly sexual and reproductive health care—have increased dramatically as a result of changes in laws or funding (both domestic and foreign).<sup>4</sup>

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Issues related to sexuality education in schools, access to contraception, and safe abortion have become central to political parties' electoral platforms and define territories in dispute in parliaments, in justice systems, and in executive branches, while competing for the hearts and minds of populations. Along with gender, reproductive rights has become a central issue in debates on democracy, civil rights, and social justice. Gender identity is a battlefield challenging societal norms.<sup>5</sup>

While the debate on abortion in countries with secular governments, such as Brazil, should be based on the premise that unsafe abortion contributes significantly to high rates of maternal mortality and is a violation of the right to health, it instead incorporates moral and religious arguments that feature strong patriarchal perspectives on women's autonomy and on gender roles and power in the family, education, workforce, and politics.

Among the many threats to health and human rights, this culture war over gender and reproductive rights is one of the most pressing in Brazil. The extreme right strategically promotes a binary narrative that divides all debate into order or disorder and classifies the world as either good or evil. On one side are those who proclaim themselves to be representatives of the good: defenders of Christian values, of religion, of the homeland, of national sovereignty, of the family, and of childhood. This side often denies climate change, is skeptical of science generally, and fears "gender ideology" and trans youth.

The "evil side" includes feminist movements, health and human rights defenders, LGBTQ+ movements, Black rights movements, migrants, Indigenous Peoples, academics, scientists, and proponents of multilateralism.

Such a binary narrative hinders democratic debate about social and economic rights, including the right to health. This narrative favors authoritarian models that have no place for political disputes, since opponents are portrayed simply as enemies of what they define as culturally and socially correct. No room is left in these far-right political movements for negotiation or consensus-building.

The extreme right also includes religion and

the word of God in its political debates. It generates polarization, intolerance, and hatred, leading to a collective cognitive dysfunction, with an accompanying loss of rationale and critical perspective in the way politics is approached. When narratives are presented as God's will, many people, particularly those under the influence of evangelical leaders, become fearful of questioning them. People are exposed to multiple conspiracy theories and general disinformation, full of hate and anger, through social media and in speeches by religious authorities and political leaders. Fake news has become a major asset in the political landscape and is used particularly when the adversary is portrayed as an evil to be annihilated.<sup>6</sup>

The panic arising from not knowing what is true or culturally acceptable, exacerbated by fake news, threatens not only democratic institutions but also the right to mental and physical health and well-being of women, men, and children. Fake news spread by a government is a violation of human rights.

These extreme narratives do more than affect individual health—they shift public health policies. One example is the anti-vaccination position of the Bolsonaro administration, which promoted disinformation suggesting that COVID-19 vaccines could result in more serious physical harm than the virus itself. A study on political and socioeconomic factors in the context of COVID-19 found that municipalities that supported Bolsonaro in the 2018 elections had worse mortality rates than others, even when allowing for other structural inequalities.<sup>7</sup>

As a result of disinformation and poor management of the Ministry of Health, and despite Brazil's extensive public health system that had the means to provide excellent vaccination coverage, the vaccine delays and general mistrust resulted in low vaccination rates and an extremely high number of COVID-19 deaths (over 700,000).<sup>8</sup> This number is probably an underestimate due to failures in classifying the causes of death, particularly in the first year of the pandemic. A fear of vaccination persists today, even with a new administration that has engaged in campaigns to overcome the mistrust.

The challenges in responding to this cultural and political war in Brazil are immense. Civil society organizations, social movements, universities, sectors of the government, and the media are attempting to grapple with them. In order to restore our rights, we need to identify strategies that can dismantle barriers such as:

- The lack of effective regulation of social media that amplifies misinformation and renders the internet dangerous.
- The increasing use of religion as a political strategy to influence the legislature, particularly on issues related to abortion and LGBTQ+ rights. Brazil has many lawmakers who represent evangelical churches and impede legislation promoting access to abortion and the rights of women and girls more generally.
- The advance of neoliberalism along with social inequality and poverty.

These and other social and political factors demand a coordinated response, from advocacy efforts aimed at regulating digital platforms, to rebuilding collectives and community organizations in order to overcome individual isolation and lessen people's vulnerability to fake narratives. We also need to educate people about their health and human rights in schools, universities, and communities, and fight back with counternarratives promoting the values of science, diversity, democracy, pluralism, vaccines, and inclusion.

The task is daunting and complex, but necessary. I suggest we follow Pandora's lead, and together open the box to let the evil out, while holding on to hope.

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## VIEWPOINT

# Advocating for Reproductive Rights in Northern Ireland: Access to First-Trimester Screening

FIONA BLOOMER, SUZIE HEANEY, AND CLAIRE LOUGARRE

Authoritarian populist governments around the globe are attacking reproductive rights as part of political strategies to reinforce traditional gender roles and gain legitimacy among certain electorates. However, various coalitions of academics, nongovernmental organizations, and medical professionals have helped protect reproductive rights in challenging political contexts, giving hope to those wishing to follow suit. In this viewpoint, we outline our efforts to advocate for universal access to first-trimester antenatal screening in Northern Ireland, a country where religion and politics have long weighed on women's ability to make decisions over their reproductive health.

Northern Ireland, a part of the United Kingdom (UK) where abortion used to be unlawful in all circumstances unless the life of the pregnant woman was at risk, decriminalized abortion in 2019 and authorized it under several circumstances, including in cases of "severe fetal impairment or fatal fetal abnormality."<sup>1</sup> However, region-wide access to abortion services was not achieved until 2022.<sup>2</sup> As outlined by Fiona Bloomer and Emma Campbell, the use of human rights law was instrumental in the push for legislative reform, with international and national human rights bodies playing active roles throughout this process.<sup>3</sup> Despite the furthering of reproductive rights in this context, some aspects of pregnancy care in Northern Ireland remain subpar and dissociated from any human rights language, resulting in discrimination against women (and pregnant persons). This is the case for first-trimester antenatal screening, a service routinely offered to all pregnant women across the UK but (un)surprisingly, not in Northern Ireland.

Starting on these premises, our interdisciplinary research team met in 2023 to discuss how to best advocate for the availability of this service in Northern Ireland. We agreed to draft a policy brief outlining the impact of this situation on pregnant women, its human rights ramifications, and the need for a more co-

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herent social policy. It was published in June 2024.<sup>4</sup>

First-trimester screening allows the detection of three of the most common chromosomal abnormalities: trisomy 13 (Patau syndrome), trisomy 18 (Edwards syndrome), and trisomy 21 (Down syndrome). All three trisomies lead to higher incidences of miscarriages, stillbirth, and neonatal and infant mortality. Such incidences are particularly high for trisomies 13 and 18, both considered “fatal fetal abnormalities,” whereas trisomy 21 is considered a “serious fetal abnormality” given the significant lifelong health issues it results in. First-trimester screening policies are recommended by the World Health Organization and, in the UK, by the National Institute for Health and Care Excellence and by the Royal College of Obstetricians and Gynaecologists.<sup>5</sup>

In the UK (excluding Northern Ireland), pregnant women are routinely offered a screening test called “the combined test,” consisting of an ultrasound scan and blood test at 11–14 weeks’ gestation, with 90%–95% accuracy. Another test is available: a blood test analyzing cell-free DNA. This test, called noninvasive prenatal testing (NIPT), is carried out from 10 weeks’ gestation, with >99% accuracy, although it is often accessed privately. In Northern Ireland, however, the reality is very different: some hospitals offer screening via a blood test (the “quadruple test”), but practice is inconsistent and the test is performed later (14–20 weeks’ gestation) and is of lesser quality. NIPT can be accessed privately, but knowledge about its availability is low, and the financial cost is high (average £400). As a result, in Northern Ireland, most fetal abnormalities are diagnosed following the anomaly scan, which typically occurs at around 19–21 weeks’ gestation.

During the writing of our policy brief, we conducted two roundtables: one with bereaved families who had received a diagnosis of fatal or severe fetal abnormalities, and one with medical professionals involved in fetal medicine and maternity care. The harrowing stories shared by families and medical professionals all pointed toward the same conclusion: early diagnosis is crucial to minimize trauma for everyone involved. These discussions prompted us to stress in our policy brief that the absence of

first-trimester antenatal screening results in later diagnoses, causing significant distress for pregnant women (and for health professionals), who are obliged to make (or support) decisions on whether to terminate or continue a pregnancy during the second half of gestation.<sup>6</sup>

Our research suggests that the absence of first-trimester antenatal screening breaches several human rights for women living in Northern Ireland: their human right to health, their right to privacy, and their right to be free from cruel and inhuman treatment, all of which are protected by various treaties ratified by the UK.<sup>7</sup> It also suggests that since this service is primarily targeted at pregnant women, its absence results in gender discrimination for five reasons. First, this situation exposes women to preventable mental and physical harm related to late diagnoses of fetal abnormalities (such as increased risk of trauma, limited choices around abortion methods, and having to make decisions—often hurried—around feticide and palliative care). Second, women deciding to terminate their pregnancies due to fatal or severe fetal abnormalities must do so at a later stage, forcing them to disclose personal details to persons aware of the pregnancy by then. Third, women deciding to continue their pregnancies in such circumstances are unable to prepare themselves and their family for the possibility of pregnancy loss, infant death, or becoming a carer for a disabled child until week 20+ of gestation. Fourth, the anomaly scan is not as accurate as first-trimester screening for certain conditions, resulting in some women receiving a diagnosis only at birth or through an investigation following a stillbirth or late miscarriage. Fifth, because trisomies 13, 18, and 21 result in disabilities likely to require regular care, a task most often performed by mothers, women are unable to access what is likely to represent life-changing information.<sup>8</sup>

To raise awareness among the public and politicians, we shared our policy brief with the BBC’s Northern Ireland health correspondent in mid-2024 and suggested that they could speak confidentially with families who had expressed an interest in doing so. A few months later, the BBC published a story exploring how the absence of

early pregnancy screening services was affecting women in Northern Ireland.<sup>9</sup> Using our policy brief and the BBC news story, we then contacted the Northern Ireland Assembly Committee for Health to discuss our research findings. After this meeting, the committee asked Northern Ireland's minister for health to explain why there had been a delay in the provision of screening services. The outcome of this was a commitment to expedite action, but no time frame was confirmed.

We are currently writing a second policy brief to continue raising awareness of the issue to ensure that pregnant women in Northern Ireland have access to better care. To conclude with the words of a parent we spoke with:

I trusted the [physicians] and hospitals to do the right thing because I wasn't aware of any reason why I shouldn't. I was 36 and I was not offered any test. Much to my distress, I was led blindly to a scan at 21 weeks, where you have more limited options and risk complications to your physical and mental health. It is also incredibly distressing to have to act quickly in those emotionally charged circumstances.

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## VIEWPOINT

# Breaking Barriers: Strengthening Health Equity in Sub-Saharan Africa Through Improved Local Pharmaceutical Production

STUART SSEBIBUBBU, DENIS KIBIRA, AND ADRIANO LUBANGA

## Introduction

The right to health, enshrined in international human rights frameworks, remains elusive for millions in sub-Saharan Africa due to persistent barriers to accessing essential medicines. More than 70% of medicines used in the region are imported, leaving countries vulnerable to global supply chain disruptions, price volatility, and external political pressures.<sup>1</sup> The COVID-19 pandemic magnified these inequities because vaccine and medicine nationalism disproportionately disadvantaged African nations.<sup>2</sup>

The overreliance on external pharmaceutical markets undermines not only health security but also African states' agency in protecting their populations' well-being.<sup>3</sup> Strengthening local pharmaceutical production is not just a development priority; it is imperative for the fulfillment of human rights.<sup>4</sup>

African nations lack strong pharmaceutical industries to address the continent's disease burden due to systemic underinvestment, restrictive trade agreements, and intellectual property barriers. The Agreement on Trade-Related Aspects of Intellectual Property Rights has hindered technology transfer, limiting local manufacturers' ability to produce generic life-saving drugs.<sup>5</sup> These barriers sustain monopolistic control and keep medicine prices unaffordable for many communities.

The consequences have been dire. In the early 2000s, millions of Africans living with HIV were denied timely access to affordable antiretroviral therapy due to patent protections.<sup>6</sup> South Africa's legal battle against pharmaceutical companies to secure generic antiretrovirals remains a landmark case in global health justice.<sup>7</sup>

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Africa's recent struggle to access COVID-19 vaccines further exposed persistent inequalities, as wealthier countries stockpiled doses while African nations faced delays and shortages.<sup>8</sup>

Emerging shifts in global health aid, such as the closure of the United States Agency for International Development (USAID) in several African countries, now threaten the continuity of essential medical supply chains and weaken local procurement systems.<sup>9</sup> USAID has historically played a key role in financing HIV/AIDS treatment, malaria drugs, and other essential medicines.<sup>10</sup>

### Community impact: A rights-based crisis

The right to health is inextricably linked to the right to access essential medicines. Yet shortages across Africa disproportionately impact vulnerable populations, especially women, children, and those in rural and low-income communities.<sup>11</sup> Health emergencies and outbreaks further strain fragile health care systems, as seen during the Ebola crisis, when delayed access to critical medications and vaccines increased mortality rates.<sup>12</sup>

Chronic illnesses such as diabetes and hypertension are becoming more prevalent, yet shortages of insulin and antihypertensive medications exacerbate preventable complications and deaths.<sup>13</sup> For example, in Nigeria, inconsistent access to insulin limits treatment options for diabetic patients, increasing mortality rates. With 3.5 million Nigerians living with diabetes—a number projected to rise to 8 million by 2045—insulin remains costly, consuming 29% of a minimum-wage earner's monthly income.<sup>14</sup> This reflects a broader issue: as Raffaella Ravinetto et al. have noted, even century-old essential medicines such as insulin remain inaccessible to many due to monopolistic pricing and weak procurement systems.<sup>15</sup> These barriers reflect systemic failures to prioritize the right to equitable access over commercial profit.

### Local production as a human rights imperative

A human rights-based approach to access to med-

icines requires investing in local pharmaceutical production. There is growing momentum in Africa to reduce dependency on foreign pharmaceutical markets. The World Health Organization's mRNA technology transfer program, launched in 2021, established a development hub in South Africa and engaged 15 partner producers across middle-income countries.<sup>16</sup> In 2023, the African Vaccine Manufacturing Accelerator was launched with US\$1 billion in funding to scale up vaccine manufacturing on the continent.<sup>17</sup> Such initiatives are promising steps in the right direction. Yet they are not sufficient on their own.

While these manufacturing initiatives signal international support, meaningful transformation requires deeper political and financial commitments from African governments, structural policy reforms, and alignment across regional blocs. This includes fully leveraging TRIPS flexibilities, harmonizing regulatory standards through the African Medicines Agency, and operationalizing the Pharmaceutical Manufacturing Plan for Africa, including its road map for the regional production of 24 priority medicines.<sup>18</sup>

### Additional measures to ensure accountability

Ensuring accountability in medicine access demands the monitoring of shortages, of price gouging, and of policy effectiveness. Governments must shift from rhetoric to action by investing in local pharmaceutical production and creating supportive regulatory and economic environments. This includes promoting inter-regional trade and removing barriers to the free movement of medicines across African borders. Several mechanisms can help track and challenge these barriers alongside initiatives to strengthen the pharmaceutical ecosystem:

- Increased involvement of civil society organizations, similar to the collaborative efforts seen during the campaigns on access to HIV/AIDS treatment, is crucial. Organizations such as Health Action International and the Treatment



Action Campaign (South Africa) have been instrumental in holding governments and pharmaceutical companies accountable for issues such as access to essential medicines and fair pricing, achieving notable successes through litigation and public pressure.

- Strengthening agencies such as the African Medicines Agency can help monitor drug quality, affordability, and production standards, ensuring that local manufacturing meets global benchmarks. As Ravinetto et al. emphasize, strong regulatory systems are essential not just for ensuring safety but also for protecting against the harms of substandard and falsified medicines, which often disproportionately affect low-income populations.<sup>19</sup>
- Governments should support private pharmaceutical companies through public-private partnerships, access to affordable financing, tax incentives, and guaranteed offtake agreements that reduce market risks and ensure sustainable demand for locally manufactured medicines, anchored in empowering African-led enterprises to solve African health challenges.
- The strengthening of pharmaceutical and biotechnology training institutions through curricular reforms, regional learning exchanges, industry-academia partnerships, and internship programs leveraging established model institutions is essential to developing a skilled workforce capable of sustaining local medicine production in the region.
- Enhancing grassroots monitoring by integrating digital reporting tools, building community health worker capacity, and establishing feedback loops with regulators to ensure data on stockouts, treatment disruptions, and medicine affordability drives responsive policy and procurement decisions.
- International human rights law, including United Nations mechanisms and the African Court on Human and Peoples' Rights, should serve as a tool for challenging unjust trade policies and ensuring equitable access to medicines.

- Governments must commit to transparent procurement processes to avoid corruption and inefficiencies that worsen medicine shortages.

## Conclusion

Reliance on imports undermines health security and deepens health injustice. Strengthening local pharmaceutical production is crucial to ensuring equitable access to life-saving medicines and upholding the right to health for all. African governments, international policy makers, and global health organizations must work collaboratively to dismantle structural barriers, support sustainable medicine production, and reaffirm their commitment to health equity. Without urgent action, millions will remain at the mercy of an unjust global health order that prioritizes profit over people.

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## VIEWPOINT

# A Tax on the World's Ultra-Rich to Fight Hunger and Disease

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On April 1, 2025, *Forbes* published a list of a record 3,028 billionaires worldwide, including 902 in the United States, 516 in China, and 205 in India. Their total net worth was US\$16.1 trillion, up nearly US\$2 trillion from 2024.<sup>1</sup> Meanwhile, children and adults are dying of hunger and disease amid humanitarian crises around the world, from Afghanistan and Burma, to Gaza and Yemen, Sudan and the Democratic Republic of Congo, Haiti and Venezuela. In Sudan alone, hundreds of children starve to death every week.

It is time to marry these two realities to the benefit of humankind by ending this starkest of denials of the dignity of every person and our fundamental equality. We propose a tax on the world's richest people, with the revenue directed to United Nations and partner agencies that are addressing the needs of people who require international assistance to meet their food and other core needs. Ours is ultimately a modest proposal, an approach that could be expanded from meeting immediate humanitarian needs to reducing the financing gap for achieving the storied goal of ending hunger throughout the world and other development and human rights priorities.

United Nations humanitarian assistance appeals—collectively known as the Global Humanitarian Overview (GHO)—cover areas including food security and nutrition, together by far the largest single component, along with health, multipurpose cash, education, emergency shelter, protection, and water, sanitation, and hygiene. Heading into 2025, these appeals—most covering single countries but several addressing regions—aimed to cover about 190 million of some 305 million people in urgent need of humanitarian assistance and protection.<sup>2</sup>

In addition, every year the World Food Programme (WFP) issues its own appeal, which partially over-

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laps with the GHO but also includes funding not incorporated into the GHO (such as for countries without overall humanitarian appeals but in which WFP operates). All told, WFP is targeting 123 million people for support in 2025, yet in the countries where WFP operates, 343 million people (60% of whom are women and girls) are experiencing acute hunger—phase 3 or higher of the Integrated Food Security Phase Classification.<sup>3</sup> (Each phase, from 1 to 5, with 5 being famine, has its distinct metrics, including mortality, food consumption, nutritional status, and coping strategies.<sup>4</sup>)

A major reason that neither the GHO nor WFP target all in need is inadequate funding. Yet even funding for those targeted for support consistently falls short. In 2024, the United Nations sought US\$49.5 billion in humanitarian assistance to cover more than 40 separate appeals, with similar needs heading into 2025 (US\$47.4 billion).<sup>5</sup> The 2024 GHO was just under 50% funded.<sup>6</sup> The 2024 WFP appeal received 46% of required funding.<sup>7</sup> Prospects of improvements are dim as the United States slashes foreign assistance and as increased defense spending and economic stagnation in Europe further threaten development assistance. Contributions for both appeals are well behind those reported at this time last year; at the end of March 2025, WFP announced that it may need to curtail humanitarian assistance for 58 million people this year, nearly half of the total number of people it is supporting.<sup>8</sup>

Recent developments have created a fertile environment for the tax we propose. Asking billionaires to channel billions to humanitarian assistance, and emergency food aid in particular, has precedent. In 2021, WFP Executive Director David Beasley appealed directly to Elon Musk on Twitter, asking him to contribute US\$6.6 billion to WFP to enable it to meet the needs of 42 million people experiencing emergency or catastrophic levels of hunger (Integrated Food Security Phase Classification phases 4 and 5). Musk responded positively, with the proviso that WFP had to provide a plan on how it would spend the money. WFP did just that, but Musk never even acknowledged Beasley's follow-up.<sup>9</sup>

There are also two precedents for a global

agreement on taxing the wealthy. First came a 2021 agreement, negotiated through the OECD, for countries to impose a minimum 15% tax on corporations. Then, at last November's G20 summit, leaders agreed to "engage cooperatively to ensure that ultra-high-net-worth individuals are effectively taxed."<sup>10</sup> Their final communiqué offers a glimpse of the cooperation the leaders envisaged: "exchanging best practices, encouraging debates around tax principles, and devising anti-avoidance mechanisms, including addressing potentially harmful tax practices."<sup>11</sup> Advancing this effort is on this year's G20 agenda.<sup>12</sup>

An influential report commissioned by last year's G20 Brazilian presidency offered specifics.<sup>13</sup> The idea was to increase billionaires' effective income tax rate so that it would make billionaires' effective tax rate no lower than that of middle-class taxpayers, resulting in a tax equal to 2% of billionaires' wealth. Those already paying this level would face no extra tax; those paying less would pay extra to reach this level.

Such a tax scheme would raise US\$200–250 billion annually, and an additional US\$100–140 billion if extended to people with a minimum net wealth of US\$100 million (centi-millionaires). Notably, with a 7.5% annual pre-tax rate of return on their wealth (after inflation), these super-rich individuals would still see their wealth increase by an average of 5.5% annually after taxes. The report's author, Gabriel Zucman, offered proposals for avoiding several of the main pitfalls of any taxes calculated based on wealth.<sup>14</sup>

A tax on the ultra-high-net-worth individuals to boost funding for humanitarian assistance would help states raise the funds required to meet one aspect of their human rights obligations. States are obliged to meet people's urgent food and other humanitarian needs, necessary to help fulfill corresponding rights such as the rights to food, health, clean water and sanitation, and education. Critically for our purposes, with our focus on people who are reliant on the international community to help meet their most basic needs, the requirement that states act to fulfill these rights extends to states' extraterritorial obligations. The

International Covenant on Economic, Social and Cultural Rights obliges governments “to take steps, individually and through international assistance and co-operation ... to the maximum of [their] available resources” toward fully realizing people’s rights.<sup>15</sup> This obligation extends even to states not party to the convention. Through the preeminent instrument of international law, the United Nations Charter, states have assumed the responsibility “to take joint and separate action” to achieve “universal respect for, and observance of, human rights and fundamental freedoms for all.”<sup>16</sup>

Where states are unable or unwilling to secure those rights, other states must step in. Otherwise, “universal respect for, and observance of, human rights” is unachievable. Nowhere does this obligation more clearly fall on the international community than meeting all people’s core humanitarian needs. Humanitarian assistance represents only a small portion of states’ extraterritorial obligations, which extend to development assistance and other forms of cooperation. Yet as General Comment 14 of the Committee on Economic, Social and Cultural Rights makes clear, humanitarian assistance is a priority: “Each State should contribute to this task to the maximum of its capacities,” prioritizing vulnerable and marginalized groups.<sup>17</sup>

A reasonable starting point for discussion for a tax dedicated to humanitarian assistance would be a tax equivalent to 0.2% of wealth, or a tenth of what was put before last year’s G20. Applied to all billionaires globally, this would raise US\$23.5–29.4 billion, and another US\$11.8–16.5 billion if also charged to centi-millionaires. At the low end, US\$23.5 billion would be about half of the 2025 GH0. Move the tax up to 0.3% and extend it to centi-millionaires, and it would raise at least US\$52.9 billion. With even only meager government donations, this would fully meet the combined need of the GH0 and WFP’s separate appeal, the latter of which was US\$16.9 billion for 2025.<sup>18</sup>

This year’s G20 should commit to such a tax, or at least to establishing a fast-tracked process to reach an agreement. Yet countries need not wait for a G20 agreement to establish a tax on ultra-high-net-worth individuals; they could create

momentum for such a tax by establishing one for their own taxpayers.

Beyond its inherent benefits, an initial tax for humanitarian assistance could also serve as a trial run for a larger G20-agreed tax directed to national treasuries. The G20’s interest in a billionaires’ minimum tax raises the hope of G20 leadership on our proposal. This year’s G20 Summit—with South Africa taking the lead—holds particular promise. WFP and other humanitarian agencies are facing record shortfalls. Africa has more than its share of humanitarian emergencies; South Africa could claim the mantle of African solidarity. And with fewer billionaires than almost any other G20 country, South Africa’s government may face less pressure to avoid new taxes on ultra-high-net-worth individuals. The United Kingdom also holds potential as a leader, a way to compensate for its own cuts to official development assistance.

Humanitarian leaders within the United Nations system—such as the WFP’s executive director, the High Commissioner for Refugees, and the Under-Secretary-General for Humanitarian Affairs—could propose such a tax to the G20; their calls would not be easily dismissed.

A tax on ultra-high-net-worth individuals will not stop wars, save our environment, or buttress democracies. But until we can begin to repair our world, it would bring some hope and relief to hundreds of millions of people who are the greatest victims of humankind’s present failings. And perhaps it could serve as a stepping stone to confronting our more vexing challenges.

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## VIEWPOINT

# Maintaining the Right to Health: A Democratic Process in Taiwan

TSUNG-LING LEE AND YI-LI LEE

Taiwan, with a population of 23.56 million, implemented a nationwide single-payer health care system in 1995—the National Health Insurance (NHI)—which has achieved 99.9% universal health coverage.<sup>1</sup> The NHI has an average monthly premium of approximately US\$42 (the average annual income in Taiwan is around US\$22,000) and combines accessibility, affordability, and widespread availability for Taiwanese citizens, residents, and eligible foreigners. The premium is calculated at 5.17% of monthly income, lower than neighboring countries South Korea (7%) and Japan (10%), which have similar aging demographical patterns and single-payer systems. The NHI provides comprehensive coverage, encompassing inpatient and outpatient care, pharmaceuticals, dental services, traditional Chinese medicine, mental health day care, and home-based medical services. To ensure health equity, the NHI exempts low-income households from paying health premiums. Depending on occupation and income, health premiums range from 30% to 100% of the health service cost. Overall, health premiums contribute 89% of the NHI's annual budget, with the government's contribution statutorily capped at 36%. Taiwan's spending on health of 6.54% of GDP remains below the OECD average of 9.2%.<sup>2</sup> Attempts to increase health premiums are politically controversial and unpopular.<sup>3</sup>

Although the NHI Act mandates the participation of all citizens and eligible foreigners, the Enforcement Rules of the National Health Insurance Act—a complementary administrative rule to the NHI Act—establishes a suspend-and-resume mechanism for residents living overseas more than six months. This mechanism exempts long-term overseas residents from insurance payments while abroad, benefiting approximately 210,000 Taiwanese living overseas.<sup>4</sup>

Taiwan's NHI system operates primarily through privately run hospitals that generate revenue by offering out-of-pocket health services to attract private patients while also receiving NHI reimbursements from those who use their national health insurance. For inpatient care covered by the NHI, patients are

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responsible for co-payments ranging from 5% to 30% of their hospitalization costs.

While the system delivers comprehensive health services at affordable premiums, high utilization rates have sparked ongoing concerns about its sustainability and potential bankruptcy. Two potential solutions have been proposed: reducing costs by restricting coverage or increasing revenue through higher insurance premiums. However, both options lack political viability because the public and government strongly oppose any reduction in coverage or increase in premiums.

In addition, the affordability and accessibility of the NHI comes at a human cost: health care workers endure long hours and low wages to maintain the system's sustainability. The nurse-to-patient ratio is 1:8.6, compared to 1:4 in the United States, and doctors work longer hours—averaging 59.8 hours per week versus 49.6 hours in the United States. Physicians and hospitals are reimbursed through a point system based on services rendered. This fee-for-service model has resulted in outpatient visits surpassing the OECD average, at 14.12 admissions per 100 persons, placing considerable strain on the health care workforce.

### Use of the NHI by expatriates

When the NHI was first introduced in 1995, no one anticipated the surge in international travel and health care tourism that would follow. As health care costs have risen in other countries, Taiwan's wealthy (and aging) expatriates have taken advantage of Taiwan's high-quality, low-cost health services through the suspend-and-resume mechanism. They are able to return to Taiwan for relatively cheaper health services, including non-emergency procedures and annual health screenings.

For instance, knee surgery that costs around US\$50,000 in the United States is available for less than US\$5,000 in Taiwan's NHI.<sup>5</sup> This scheme enables expatriates to contribute minimally while enjoying full services as local residents, and some hospitals have embraced this trend, offering services that cater to returning overseas residents who are often retirees with the financial means to travel

comfortably. Overseas patients can choose to either make co-payments under NHI coverage or pay out of pocket. Under the NHI, hospitals are reimbursed based on the services they provide; thus, a financial incentive exists to perform more procedures to increase their profit margins. However, doing so dilutes the point values for all service providers since the total NHI budget remains fixed.

While the health services used by expats through the suspend-and-resume scheme constitute a relatively small portion of total usage, government data suggest that NHI loopholes are systematically exploited by overseas residents whose per-procedure costs often exceed those of domestic residents, indicating strategic use of NHI services by expatriates.<sup>6</sup> Overall, this is placing additional financial constraints on the NHI system, while raising questions of fairness. A key factor behind the financial crisis is the failure of premium growth to keep pace with rising medical expenses. Other major contributing factors include a rapidly aging population, low co-payments, and the broad scope of covered services.<sup>7</sup>

Since the NHI operates as a social insurance system designed to protect all participants equally, the suspend-and-resume mechanism undermines the principle of equitable risk-sharing across all beneficiary groups. It has created a dual-tier structure whereby expatriates receive subsidized health care while making selective financial contributions, while domestic residents pay consistent premiums regardless of usage. This arrangement places a disproportionate financial burden on domestic residents, who effectively bear the medical expenses incurred by overseas residents. This unintentional structure is also straining the health workforce, with nursing shortages presenting a particular concern.<sup>8</sup>

### Constitutional Court and democratizing health

In 2022, a landmark Constitutional Court ruling declared the suspend-and-resume scheme unconstitutional and ordered the National Health Insurance Administration (NHIA) to review and

propose reforms.<sup>9</sup> The case involved a Taiwanese expatriate whose health insurance premium was suspended during her time abroad. During her annual visits to Taiwan, her premium automatically resumed, resulting in an overdue payment of US\$70. Not wanting to pay premiums during her brief visits home, the plaintiff challenged the constitutionality of the suspend-and-resume scheme in the Constitutional Court.

The court acknowledged that mandatory participation in the NHI is necessary for the government to fulfill its responsibility to provide health care for all. However, rather than addressing overseas citizens' health care obligations regarding pooled resources, the court based its decision on the legal doctrine of *Gesetzesvorbehalt* (legal reservation), adopted from German constitutional law. This doctrine acts as a check on government power by requiring that significant decisions affecting citizens' rights and obligations be passed through the legislature. Since the suspend-and-resume scheme operated solely through an NHIA administrative ruling, the court deemed it unconstitutional. In other words, the court held that the legislature, rather than administrative agencies, must make decisions about how to meet health needs fairly across diverse populations.

While it appeared that the Constitutional Court ruled on a technical ground without addressing the substantive issues of the case, its decision carries important implications for understanding the right to health. In particular, since Taiwan's Constitution does not explicitly recognize this right—incorporating it instead through article 22—the court's decision is noteworthy. Under article 22, the substance of the right to health, including health care, remains open to interpretation. Based on *Gesetzesvorbehalt*, the Constitutional Court established that decisions about meeting various health needs must undergo public deliberation, meaning that decisions regarding fair health care access and financing must be subject to public negotiation and democratic accountability.

For Taiwan, this represents a positive development—it not only recognizes health as an

intrinsic moral good but acknowledges that health care distribution across a diverse population must be determined through democratic deliberation. Through this nuanced interpretation, the court reinforced both the legal foundation and moral imperative of democratizing health through the national health care system. The system creates equality of opportunity by requiring public input and democratic processes to guide health care governance.

## Implementation of the ruling

After the Constitutional Court's ruling, the NHIA amended the Enforcement Rules of the National Health Insurance Act and set an end date of December 2024 for the suspend-and-resume mechanism. After that end date arrived, the NHIA deliberately chose not to propose any legislative amendments to Congress. This administrative inaction effectively resulted in the complete abolition of the scheme. Eliminating the suspend-and-resume scheme means an increase of 1.18% (an additional US\$70.59 million) in the NHI's annual revenue, a small—but meaningful—step toward (re)establishing fairness in the system.<sup>10</sup>

Public sentiment supported the administration's inaction, largely due to widespread concerns about systemic abuse of the NHI system.<sup>11</sup> While the suspend-and-resume mechanism had long faced criticism by scholars and practitioners prior to the Constitutional Court's ruling, public support peaked following a high-profile case involving Huang An, an aging Taiwanese entertainment personality who had settled in China. Despite consistently promoting pro-China rhetoric through his public platform, Huang regularly returned to Taiwan to access health care services—behavior widely viewed as exploitative.<sup>12</sup> The public recognized that managing the finite financial pool required fairness, sustainability, and shared responsibility, acknowledging that consistent contributions were essential to maintain Taiwan's health care system.

The sustainability of the NHI requires both political and legal commitments and continuous

financial contributions from all participants. While the Constitutional Court did not directly address the question whether overseas residents are required to contribute, it affirmed that the right to health, expressed as universal health coverage, must use democratic processes to determine fair access.

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## VIEWPOINT

# Local Advocates in the United States Make Slow but Steady Progress on Water Affordability

MARTHA F. DAVIS

In 2014, in the midst of the financial crisis in the US city of Detroit, the city began systematically shutting off water service to tens of thousands of low-income households that were behind in paying their water bills.<sup>1</sup> The implications for public health were profound.<sup>2</sup> Families were unable to bathe, wash clothes or dishes, or rinse food items.<sup>3</sup> Parents feared losing their children to the Children's Protective Services because of unsafe home environments, or losing their homes to bank liens and foreclosure. And some of the shutoffs were based on incorrect city records, affecting people who were not behind with their payments at all, but who had to live without running water while trying to fight city hall to have it restored.<sup>4</sup>

Building on Detroit's long history of activism spanning issues from labor rights to civil rights to welfare rights, the affected communities and their allies banded together to call attention to the underlying problems: the rising cost of water and sanitation in a city marked by extreme racial segregation and economic inequality. Grassroots activist groups such as the People's Water Board Coalition, We the People of Detroit, and the Detroit Water Brigade framed the immediate issue as a violation of the human right to water—a right that the United Nations (UN) had formally recognized just a few years earlier, in 2010.<sup>5</sup> Several UN Special Rapporteurs spoke out on the issue and even visited the city to draw attention to the inhumanity of shutting off water service for people who could not afford to pay the rising costs.<sup>6</sup> Some local Detroit advocates traveled to the UN headquarters to raise the issue directly before the international community.<sup>7</sup> Federal lawsuits brought further attention to Detroit's actions.<sup>8</sup>

Meanwhile, the people affected by shutoffs had to get by. Neighbors helped one another access water, sometimes finding ways to reverse the shutoffs and other times sharing water jugs and bottles.<sup>9</sup> Using the press, social media, academic research, policy analysis, and plain old organizing, activist groups kept the pressure on the city and the State of Michigan to find a long-term solution to the water unaffordability crisis.

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This was not a speedy process. For years, city leaders resisted, rejecting promising affordability plans developed by experts in the field.

Ironically, the COVID-19 pandemic, for all of its negative impacts, made clear that change was possible. Like many other communities around the country, Detroit implemented a moratorium on water shutoffs.<sup>10</sup> The city found other ways to close its financial shortfall. And when the pandemic sputtered out and the moratorium was lifted, city leaders were no longer able to argue that shutoffs were the only way to handle unaffordable water bills.

In 2022, after years of focused organizing and community pressure, activists in Detroit finally achieved their goal of establishing a workable water affordability plan. Called the “Lifeline Plan,” the program offers residents fixed monthly rates from US\$18 to US\$56, depending on the household income, and also removes past water debt based on a household’s income and water use.<sup>11</sup> Similar plans are in effect in Philadelphia, Baltimore, and DeKalb County, Georgia. At the end of 2024, more than 26,700 Detroit residents were enrolled in the Lifeline Plan, with most paying US\$18 per month for their water service.<sup>12</sup>

However, this hard-won success in Detroit is not the end of the saga. Only about one-third of eligible households applied for the Lifeline Plan, and many households falling just above the threshold still need assistance. For those households, water shutoffs remain a threat. Further, the Lifeline Plan depends on continued state funding; it is funded through 2025, but its long-term stability is not clear.<sup>13</sup>

In late 2024, Michigan activists led a focused effort to enact a statewide water affordability plan, but their efforts fell short. The comprehensive water affordability bill introduced in the Michigan Legislature would have capped water bills at 2% of the average annual household income in a water provider’s service area for households with incomes up to 135% of the federal poverty level. For households with incomes between 135% and 200% of the federal poverty level, bills would have been capped at 3% of the average household income in the area. The

proposal would also have allowed tenants to request that bills be in their name, so that they are not dependent on a landlord to maintain water access.<sup>14</sup> However, despite bipartisan support, the bill was not adopted before the legislature adjourned for the year.

So yes, it is still a glass that is only half full, but the local activism in Detroit and other Michigan communities is having an effect. And the years of advocacy mean that the issue cannot be ignored. The Michigan Legislature will not reconvene until June 2025, but water affordability figures prominently in the proposed budget released by the state’s governor, Gretchen Whitmer. Among the priorities outlined in her budget are plans to invest in state funding for water affordability, underscoring a pressing issue facing residents around the state.<sup>15</sup> Indeed, a 2023 study by Public Sector Consultants concluded that household water was unaffordable for about 30% of Michigan residents, including 25% of Michigan seniors.<sup>16</sup>

In sum, while there is much more to do and the work continues, the long-term, grassroots-led advocacy to recognize and honor the human right to water in Michigan has made a difference. The issue is being constructively addressed in Detroit, and it is being teed up for serious consideration at the state level. In fact, a bipartisan water affordability bill was reintroduced in the Michigan State Senate in April 2025.<sup>17</sup> Going forward, the State of Michigan has the opportunity to serve as a pioneering model for other states in the United States confronting the growing human rights challenges of water access and affordability.

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## VIEWPOINT

# Let All Children Eat

THOMAS POGGE

The billionaires fight a two-front war. Within the United States, they fight to convert the country into an enduring plutocracy in which their wealth will enable them to dominate the three branches of government forever. Internationally, they utilize the vast military, economic, and diplomatic power of the US government to expand their dominion: to structure the global trade and financial systems to their extractive advantage and to modify or disable any states and other organizations that resist their agenda.

This war has entered a new phase with President Trump's second term: his administration is openly disregarding constitutional constraints on presidential power; and the United States is openly flouting fundamental rules of the rules-based international order by threatening to annex foreign territories (with ethnic cleansing, in the case of Gaza), for example, and by imposing sanctions on supranational officials for doing their jobs.<sup>1</sup>

The US elites who opposed Trump are now either scrambling to share in the spoils of his victory, or else denouncing him as a threat to justice and human rights. The denunciations are insincere, as the leaders of the Democratic Party were equally willing to sell their services when they had the chance, though they did so with tedious lip service to morality. Thus, it was Bill Clinton who—on behalf of intellectual property-heavy US corporations—imposed the TRIPS Agreement on the developing world, ensuring that its peoples would have to pay heavy road tolls to patent holders in the Global North for the privileges of partaking in advanced agriculture, globalized business communications, and the manufacture and use of new pharmaceuticals.<sup>2</sup> Millions have died because they could not afford life-saving medicines that generics firms would manufacture and sell very cheaply if patent enforcement didn't prevent them from doing so. The Clinton administration also slashed development assistance by 20% in real terms between 1991 and 2001, reducing it from 0.20% of US gross national income to 0.11%—even while the US enjoyed a rich peace dividend from the fall of the Soviet Union, and even though the rich countries had promised 0.7%.<sup>3</sup> It refused to pay US dues to the United Nations (UN), causing CNN founder Ted Turner to step in with a US\$1 billion donation in 1998. It pushed the International Monetary Fund and World Bank to impose struc-

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tural adjustment programs on indebted developing countries. And it promoted bilateral treaties that allow US multinationals to sue foreign states for compensation when their profit expectations are disappointed on account of improving protections for workers, the environment, or the country's natural wealth.

Faced with the billionaires' broad onslaught and rapid advance, the instinctive reaction is to protect one's family and local community and to save with rearguard actions what can be saved of the rest of the world. Perhaps philanthropists and foundations can replace some of the domestic funding felled by the Department of Government Efficiency's ax, thereby preserving important medical research, legal aid, scholarships, national park services, etc. Perhaps private or public funds can be found to fill gaps left by sudden withdrawals of US funding for health, nutrition, and education abroad.

### Create a clear countermodel: School meals

Such efforts are important. But they will not stop the plutocrat-driven pandemic of national selfishness. To do so, we must—alternative both to Trump's discarding of morality and to his predecessors' instrumentalizing it to accumulate soft power—create a clear countermodel that anticipates a world governed by rules and procedures grounded in a shared recognition of basic human needs and rights.

A globally universal school meals program is a realistic, unambiguous, highly visible first step that can unite a broad range of morally motivated actors. Wherever healthy food is lacking, each child should have a full, healthy meal, locally sourced, on every school day. Strongly backed by human rights and the Sustainable Development Goals (SDG) maxim "leave no one behind," this is a widely recognized imperative, given humanity's enormously enhanced technological, economic, and administrative capacities.

The proposed program would serve many SDGs: by eradicating poverty (goal 1) and hunger (goal 2), and by promoting health (goal 3), educa-

tion (goal 4), and access to decent work (goal 8), it reduces social and economic inequalities (goal 10), promotes responsible consumption and production (goal 12), and creates fairer, more inclusive societies (goal 16) through an international partnership (goal 17) in which experiences are shared and reliable needs-based support is available to all lower-income countries to enable and incentivize their participation.

States adopted the SDGs at the UN in 2015 without any understandings on responsibilities—on who was supposed to do what to achieve the goals. Relishing immediate praise for setting lofty goals, adopting officials were content to risk future disappointments as problems for their successors. Many may have thought that the SDGs would largely realize themselves through ordinary economic growth and naturally rising technological and administrative capacities. But mounting inequality and violence around the world, and COVID-19, have dashed this hope. We are behind schedule on 83% of the SDG targets, and on 35% we have made no progress at all, even retrogressing in half of the latter.<sup>4</sup>

The fight to end undernourishment is emblematic. The UN Food and Agriculture Organization reports that the number of food-insecure people is up nearly 50% since 2015.<sup>5</sup> The agency also estimates for each country the bare minimum cost of a healthy diet—US\$2.63 per person per day in the United States in 2022—and finds that nearly three billion human beings still cannot afford such a diet.<sup>6</sup> This while the purchasing-power-adjusted per capita gross world product has reached US\$63 per person per day.<sup>7</sup> Children are especially affected. Malnutrition impairs their development and thus their future health and performance. Add to this that 250 million children are out of school as many impoverished and often highly indebted families put their children to work.<sup>8</sup> Some 160 million children are engaged in wage work, many others help their families with household chores or farm labor, and others live in war zones or, as girls, are not allowed to go to school.<sup>9</sup>

This colossal waste of human potential is a crime against humanity when we could so easily

reduce it. School meals promote children's mental and physical development and thereby their future opportunities and performance. They motivate parents to send their kids to school. They raise the family's nutritional status and inculcate healthy eating habits. Locally sourced, they create jobs and build agricultural and administrative capacity. They also enable states, using the power of procurement, to move producers toward more sustainable agricultural practices. All this is supported by ample evidence drawn from the 418 million children who are already getting them.<sup>10</sup>

The chief obstacle is the financial condition of the often heavily indebted low- and lower-middle-income countries, in the former of which, thus far, only 18% of primary school children receive meals.<sup>11</sup> As an opportunity and incentive, the proposed program should guarantee that each country willing to initiate, enhance, or expand a domestic school meals scheme will receive the needed support for doing so.

The proposed program would advance a central ambition of the Global Alliance Against Hunger and Poverty, which the G20 launched in 2024 on the initiative of Brazil's President Lula da Silva. School meals are one of its six "2030 Sprint" priorities.<sup>12</sup> Linked to this Global Alliance and in collaboration with the World Food Programme, a broad-based School Meals Coalition has already been formed and could be upgraded to take on crucial clearinghouse functions: calculating the need-based financial support due various lower-income countries and the capacity-based contributions from participating higher-income countries, while also setting standards of adequacy for national school lunch schemes, monitoring and auditing them, and maintaining a repository of data and best practices from such schemes around the world.<sup>13</sup>

At an estimated average cost of US\$64 per child per year, the annual cost of the proposed program might in time reach as high as US\$40 billion.<sup>14</sup> If subsidies averaged 50%, the high-income countries would have to contribute US\$20 billion per year—or less, if China also agreed to contribute. Their average burden would then be around 0.025% of gross national income, or US\$12 per person per

year on average, with variations reflecting differences in national per capita incomes. Who could possibly resent such a small contribution when it achieves so much for so many children around the world?

Some high-income governments would refuse, at least initially, their international human rights obligations notwithstanding.<sup>15</sup> This gap might be filled privately via the Ted Turner model: through donations by firms, foundations, and philanthropists, as well as through bequests. Over time, the program might build an endowment that would help cover its expenses and help smooth out fluctuations in receipts and disbursements.

A small step for the affluent, the proposed global school meals program would be a very big step forward for the world's children—and a significant milestone on the path to a world order whose rules are grounded in shared moral commitments. It would moreover be a magnificent capstone to four consecutive years of Southern leadership of the G20, which have also seen the admission of the African Union as the 21st—and first-ever added—member. Despite all the distractions, let us get this program started in 2025! To achieve this, we must mobilize a broad range of citizens to demand that their governments advance and support this significant and symbolic initiative without delay.

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## VIEWPOINT

# From Dependency to Sovereignty

BEATRICE WERE AND VANESSA OKUMU-MCCARRON

Uganda has been a pioneer in combating HIV, spearheading a multi-sectoral response coordinated by the Uganda AIDS Commission.<sup>1</sup> Between 1990 and 1995, through its AIDS Control Program and collaboration across ministries, civil society, and communities of people living with HIV, Uganda achieved significant progress, reducing HIV prevalence among pregnant women from 30% to 15%.<sup>2</sup> This established Uganda as a global benchmark, and the success attracted more development partnerships. Today, 95% of people living with HIV in Uganda—including over 90% of pregnant women—receive life-saving antiretroviral treatment.<sup>3</sup> These accomplishments are a testament to Uganda’s unwavering courage in the face of an existential threat.

While celebrating these achievements, Uganda must address a critical vulnerability: its heavy reliance on foreign aid for health financing. According to the World Bank, donor aid constitutes over half of Uganda’s annual health budget; meanwhile, the government of Uganda contributes only 8%, private community-based insurance schemes cover another 8%, and households are left to cover the remaining 33% through out-of-pocket payments.<sup>4</sup> Donor funding accounts for 85% of HIV financing and over 90% of the malaria budget, starkly contradicting the country’s Abuja Declaration pledge to allocate 15% of its annual national budget to health.<sup>5</sup> By outsourcing health financing to external actors, Uganda is abdicating its obligation to ensure the right to health for its people, treating health as a charity or privilege rather than a fundamental human right.

## The perils of dependency

*“Give someone the power to feed you, you give them the power to starve you.”*  
—African proverb

For decades, foreign aid has been crucial in financing life-saving treatment and prevention efforts. However,

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the Trump administration's recent freeze on foreign aid has exposed the fragility of this dependence. The unpredictability of such aid leaves critical programs vulnerable, destabilizing communities that depend entirely on them. Without immediate action in Uganda, decades of progress are at risk of unraveling, potentially triggering a national crisis whereby millions are exposed to increased infections and mortality.

### *AIDS: Ghost of the 1990s is knocking at the door*

The US President's Emergency Plan for AIDS Relief (PEPFAR) and the United States Agency for International Development fund HIV prevention, testing, and sexual and reproductive health programs, including antenatal care, early infant diagnosis, and treatment. As reported by PEPFAR, as of September 2022, nearly all 1.3 million people living with HIV in Uganda were receiving PEPFAR-supported antiretroviral therapy. This averted approximately 500,000 HIV infections, including among 230,000 infants, and prevented 600,000 HIV-related deaths.<sup>6</sup>

The Trump administration's abrupt freeze on foreign aid represents a reckless abdication of international obligations. By reneging on commitments, the United States undermines decades of global health progress, disregarding principles of shared responsibility underpinning global health security. The cuts are especially alarming given the interconnected nature of health, where epidemics can rapidly escalate into global crises, as seen with COVID-19. These actions erode trust in international partnerships and set a dangerous precedent for abandoning critical health initiatives, consequently undermining the very foundations of international cooperation. US leadership in global health is both a moral and a strategic imperative, vital to safeguarding lives and global stability, as emphasized in the United Nations General Assembly Special Session on HIV/AIDS Declaration of Commitment on HIV/AIDS.<sup>7</sup>

Between 2010 and 2022, the mother-to-child transmission rate in Uganda dropped by 77%, a milestone now in danger.<sup>8</sup> Uganda is systemically ill-equipped to make up the loss of funding, risking

a resurgence of new infections due to shortages in antiretroviral medications and human resources, and risking the emergence of drug-resistant HIV, which is five to ten times costlier to treat. Heavy dependence on now-suspended external financing jeopardizes Uganda's ability to fulfill its people's right to health.

Interruptions in antiretroviral therapy heighten the risk of AIDS-related complications for HIV-positive pregnant and breastfeeding women and are likely to cause a resurgence in mother-to-child transmission. This could heighten Uganda's rates of AIDS-related infant mortality, reawakening the anguish of the 1990s.

The looming plight threatens the achievement of the 95–95–95 global targets for testing, treatment, and viral suppression—a roadmap for ending AIDS by 2030. Notably, UNAIDS reported in 2023 that by 2021, Uganda was nearing these goals, with 89% of people living with HIV aware of their status, over 92% on antiretroviral therapy, and 95% of those on treatment virally suppressed.<sup>9</sup>

### *Tuberculosis: A silent reaper poised to strike*

Insufficient health funding also risks propelling tuberculosis—already the leading cause of death among people living with HIV—into a crisis of drug resistance, further burdening Uganda's fragile health system. The World Health Organization estimates that 91,000 Ugandans contract tuberculosis annually, that 2% have multidrug-resistant tuberculosis (MDR-TB), and that more than half of tuberculosis-related deaths occur among people living with HIV.<sup>10</sup> Untreated tuberculosis accelerates the progression of HIV into AIDS. The United States funds tuberculosis prevention and treatment programs. Disruption caused by the freeze will lead to a lack of medicines, leaving many people untreated and enabling them to spread tuberculosis to others, causing a surge in new infections. Additionally, those already on treatment may miss their doses, increasing the risk of developing resistance to first-line drugs. These individuals can then spread drug-resistant strains to the public, exacerbating the crisis. This cycle of non-adherence and drug resistance will further strain Uganda's



health care system and undermine global efforts to combat tuberculosis. This exposes the public to MDR-TB, which costs 20 times more to treat than drug-susceptible tuberculosis. Uganda lacks the capacity to manage MDR-TB outbreaks, increasing the likelihood of a public health crisis. Donor funding enables 90% of tuberculosis patients to be tested for HIV, and vice versa. The freeze will decimate this synergy and undermine the investments made in prevention, treatment, and care.

### *Malaria: A prolific serial killer on the loose*

Malaria, Uganda's leading cause of death, endangers nearly the entire population: it accounts for 30%–50% of outpatient visits and 15%–20% of hospital admissions, primarily affecting children under five and pregnant women.<sup>11</sup> Malaria in pregnancy increases risks of fetal complications and maternal mortality, hindering progress toward Sustainable Development Goal 3.<sup>12</sup> With nearly 90% of the country's malaria budget reliant on foreign aid, prevention and treatment programs now face potential disruption. Without this aid, households will bear the full out-of-pocket costs of malaria treatment, deepening the crisis as stockouts occur and families struggle to afford care.<sup>13</sup>

Inadequate investment has exacerbated disparities, with households covering approximately 70% of the cost of malaria treatment and management regardless of their socioeconomic status. The funding freeze intensifies this inequity, shifting the entire burden onto the public. This contravenes World Health Organization standards on universal health coverage and the International Covenant on Economic, Social and Cultural Rights, which mandates equitable and affordable health care as a fundamental human right.<sup>14</sup>

### *A system in collapse*

Uganda's health system is already overwhelmed, with infrastructure crumbling and communities being ravaged by preventable, treatable, and manageable diseases such as HIV, as well as curable ones such as tuberculosis and malaria. The COVID-19 pandemic exposed critical gaps in the health system's infrastructure, demonstrating the urgent need for

transformative investment. The freeze will compel an ill-equipped Uganda to fight a tripartite pandemic (HIV, tuberculosis, and malaria), reversing decades of progress toward epidemic control.

Without urgent action, the consequences could surpass those of the 1990s epidemic, exacerbated by drug-resistant strains. Uganda cannot withstand the human and socioeconomic toll of such a catastrophe.

Persistent underinvestment in health grossly contravenes Uganda's obligation to uphold the right to health as enshrined in national, regional, and international frameworks.<sup>15</sup> This perpetuates systemic violations of the population's rights to health, life, and dignity.

### Call to action

Averting this crisis demands a robust strategy by the Ugandan government to resolve the glaring systemic shortfalls and to create a resilient and self-sustaining health system.

- *Prioritization of health financing:* Reallocate components of the national budget toward an immediate contingency plan to manage this state of emergency.
- *Domestic financing:* Urgently mobilize funds to offset the freeze and sustain life-saving HIV, tuberculosis, and malaria programs. Explore innovative financing mechanisms, such as the AIDS Trust Fund and national health insurance, to reduce household out-of-pocket costs.
- *Access to essential medicines:* Invest in local pharmaceutical production to reduce external reliance and prevent stockouts.
- *Accountability:* Publish real-time data on the rapid response strategy for transparency and the meaningful participation of the public, civil society, and private partnerships.

The cost of inaction is immense—not only in terms of lives lost but also because it will perpetuate a cycle of epidemics and a crumbling health system, deepening the country's reliance on donor aid. This

crisis has potential to escalate into a regional catastrophe, similar to other pandemics such as Ebola and COVID-19.

In the 1990s, Uganda proved that political will, innovation, and multisectoral engagement could overcome the most daunting health challenges. Today, similar stewardship is urgently needed to galvanize a collective regional response and avert disaster. Prioritizing health funding by investing in people's well-being is transformational and could again inspire other countries in the region.

Foreign aid, while invaluable, often comes with strings attached that promote donors' agendas rather than Africa's priorities. True sovereignty cannot coexist with overreliance on external support.

Recognizing health as a human right obligates governments to ensure available, accessible, acceptable, and high-quality prevention and treatment services, as articulated in article 12 of the International Covenant on Economic, Social and Cultural Rights.<sup>16</sup> The abrupt cessation of US funding is irresponsible; in response, Africa must accelerate a unified, robust, and sustainable health agenda rooted in equity and innovation.

Africa must build and resuscitate its health systems to make them resilient enough to ensure that the health of its people no longer hinges on the whims of foreign aid and where the phrase "African solutions to African problems" becomes a lived reality.

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