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SPECIAL SECTION  
CHILDREN'S RIGHT TO HEALTH

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## EDITORIAL

# Foreseeable Harms and Children's Right to Health

MICHAEL GARCIA BOCHENEK

Children worldwide face challenges threatening their human right to health. The Ebola outbreak, the dismantling of the United States Agency for International Development (USAID), increasing environmental exposure to toxic metals such as lead, mercury, and arsenic, and restrictions on children's sexual and reproductive health services are undermining gains made through decades of investment in education, health care, and protection from exploitation.

In May 2026, an Ebola disease outbreak caused by the Bundibugyo virus was spreading rapidly in Ituri and Nord Kivu Provinces, in the east of the Democratic Republic of the Congo (DRC). By May 25, more than 900 suspected cases and at least 220 suspected deaths were reported—one-quarter of whom were children.<sup>1</sup> Cases have also been reported in Kampala, Uganda, as well as in Goma, one of the largest cities in eastern DRC.<sup>2</sup>

The virus spread undetected for months.<sup>3</sup> While there are multiple reasons for the delay, public health experts have questioned whether US foreign aid cuts and the closure of USAID in 2025 hindered the early detection of, and response to, the virus.<sup>4</sup> USAID had funded surveillance, contact tracing, and similar initiatives in the DRC and elsewhere in East Africa, much of which was cut.<sup>5</sup> Cuts in US funding also suspended planned improvements to water and sanitation in eastern DRC.<sup>6</sup>

When the administration of President Donald Trump cancelled these programs, a senior USAID official estimated that the result would be up to 18 million additional cases of malaria per year; 200,000 children paralyzed with polio annually; one million children not treated for severe acute malnutrition; and more than 28,000 new cases of infectious diseases such as Ebola and Marburg annually. The official also warned of a significant increase in child mortality in 48 countries.<sup>7</sup> US funding cuts are being felt broadly, with cuts in prevention services leading to declines in testing, reduced access to pre-exposure prophylaxis, and interruptions in outreach and treatment. The US approach is also increasingly transactional: For instance, the US government offered to restore health aid to Zambia through a bilateral aid agreement, but on the condition of securing US access to its minerals, according to leaked records obtained by the *New York Times*.<sup>8</sup>

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The DRC and other countries on the continent have considerable expertise in the treatment of Ebola and other infectious diseases. But rapid and scaled-up logistical support is crucial in responding to an outbreak. Until last year, the United States supplied the bulk of that support. As Salim Abdool Karim, who heads the Africa Centres for Disease Control and Prevention's emergency committee, said, "Who else can bring 20 trucks in a matter of three days, have drivers, have fuel?"<sup>9</sup>

### Foreseeable harm

To the extent that May's Ebola outbreak is a chronicle of deaths foretold, it is not unique. Pollution is another context that can have foreseeably devastating consequences for the health of children and adults. Unfortunately, examples abound of government failures to address pollution, particularly toxic contamination from mining and other extractive industries.

In Ethiopia's Oromia region, for instance, the operators of the Lega Dembi gold mine failed for years to act on media reports of pollution from the mine, and the Ethiopian government allowed the mine to reopen in 2021 after a three-year suspension without taking effective measures to reduce pollution.<sup>10</sup> Water and soil downstream of the mine have high concentrations of heavy metals, including mercury, arsenic, and lead.<sup>11</sup> After the mine reopened, a study found dangerous levels of these metals in cow's milk in the area close to the mine.<sup>12</sup>

For years, people living near the mine have reported a disproportionate incidence of ill health and disabilities, particularly among newborn children. Summarizing these accounts, the Kontomaa Darimu Alliance, together with Northwestern University's human rights law clinic, reported to the United Nations (UN) Committee on the Rights of the Child:

*Rates of miscarriage, stillbirth and infant mortality are uncommonly high. Many infants have been born with severe physical and developmental abnormalities that shorten life expectancy and compromise quality of life, including deformed limbs, paralysis, and mental incapacity. Local*

*people, including children, have suffered debilitating health issues, including tumors, headaches, skin conditions, and vision problems.*<sup>13</sup>

In another example, the harmful mining, removal, and processing of lead-contaminated waste at and near a former industrial lead and zinc mine and smelter in Kabwe, the capital of Zambia's Central Province, have caused mass child lead poisoning. Decommissioned in 1994, the mine has never been cleaned up; instead, its estimated 6.4 million tons of lead-bearing waste have attracted new businesses that are moving the waste to different locations across town for extracting and processing zinc and other minerals. Lead dust blows to residential areas, contaminating homes, yards, schools, and roads and exposing up to 200,000 people to a toxic metal with no safe level of exposure.<sup>14</sup> A 2018 study found that over 95% of children living near the former mine had elevated lead levels in their blood, and about half of these children urgently required medical treatment.<sup>15</sup> In April 2026, several residents of Kabwe, together with a pan-African legal group and a Zambian nongovernmental organization, brought a complaint to the African Committee of Experts on the Rights of the Child over the Kabwe lead contamination, accusing the Zambian government of violating their rights.<sup>16</sup>

The list goes on. In Brazil in 2019, four months after a mining company pressured auditors to certify the safety of a dam at an iron ore mine despite obvious risks, the dam collapsed, releasing several million cubic meters of toxic mine sludge and killing at least 270 people.<sup>17</sup> In Ghana, exposure to mercury and other toxic metals in the context of mining has caused grave health risks for local communities.<sup>18</sup> In Peru, 8.5 million children are exposed to a daily risk of contamination from heavy metals, the country's ombuds office has found.<sup>19</sup>

In fact, "toxic contaminants are ubiquitous today," the UN Special Rapporteur on the right to a clean, healthy, and sustainable environment has observed, particularly in "sacrifice zones"—"extremely contaminated areas where vulnerable and marginalized groups bear a disproportionate burden of the health, human rights and environmental consequences of exposure to pollution and haz-

ardous substances.”<sup>20</sup> The UN Special Rapporteur on the implications for human rights of the environmentally sound management and disposal of hazardous substances and wastes has also observed that children face higher levels of exposure and are more sensitive to toxics and pollution, warning of “a ‘silent pandemic’ of disability and disease associated with exposure to toxics and pollution during childhood, many of which do not manifest themselves for years or decades.”<sup>21</sup>

### Callous disregard

There are obvious differences between US aid cuts to infectious disease surveillance, prevention, and response efforts in Africa, on the one hand, and government failures to regulate extractive industries that operate on their territory, on the other. Regulation, accompanying monitoring for compliance, and other due diligence measures are often critical means of protecting the right to health and other human rights, and when a government fails to take steps to prevent and remediate pollution and other environmental harm, it breaches its international obligations.<sup>22</sup> Whether states have a legal obligation to provide aid to other governments is far more contested.<sup>23</sup> But these scenarios share a common element of flagrant carelessness.

There is no reason to believe that the officials who ordered aid cuts or who, in the words of then-Department of Government Efficiency head Elon Musk, “spent the weekend feeding USAID into the wood chipper,” intended to harm children and adults.<sup>24</sup> But they had warning of the likely consequences of these cuts, meaning that there is ample reason to conclude that they simply did not care. Put a different way, they regarded health risks as acceptable collateral consequences of their policy agenda.

In much the same way, governments that fail to effectively regulate mining and other industries are too often treating people as acceptable casualties in pursuit of profit.

### Collateral harms to children

Government tolerance for harms to children is trending. Notably, governments with an anti-rights agenda have promoted policies that hurt children and their human rights. Russia and other states have used false narratives that seek to set ideas of “parental rights,” “traditional family,” and “protecting children” against child rights in general and, in particular, children’s sexual and reproductive rights.<sup>25</sup> In the United States, elsewhere in the Americas, and in parts of Europe, the framing of issues as “parental rights” is being used to block sexuality education, gender-affirming care, and education on racism and to roll back child labor laws.

The US government’s forcible family separations from 2017 to 2019 are a stark example of harm to children in the name of other policy ends. “We need to take away children,” then-Attorney General Jeff Sessions told federal prosecutors in May 2018, instructing them to carry out what he and other senior officials described as a deterrent to future irregular migration, even though he and the other architects of the policy knew or should have known that forcible family separation and the detention of children would inflict serious and potentially irreparable harm.<sup>26</sup>

The Trump administration’s more recent “mass deportation” policy, under which some 400,000 people have been apprehended in immigration enforcement operations in the interior of the United States, shows similar disregard for children’s well-being. The Brookings Institution estimated in May 2026 that the mass deportation effort had separated more than 100,000 children, three-quarters of them US citizens, from their parents since January 2025.<sup>27</sup>

### Children’s right to health

Human rights treaties, notably the International Covenant on Economic, Social and Cultural Rights and the Convention on the Rights of the Child, set forth robust guarantees of the right to health. States commit under the covenant to promote children’s

healthy development, ensure healthy occupational and environmental conditions, and prevent, treat, and control disease, among other steps.<sup>28</sup> To implement children's right to health, the convention calls on states to provide children adequate and nutritious food and safe drinking water, ensure that families have appropriate prenatal and postnatal care, and guarantee access to education and health information for "all segments of society," among many other measures.<sup>29</sup>

In principle, if not in practice, health services should be available to everyone. The covenant calls on states to create "conditions which would assure to all medical service and medical attention in the event of sickness."<sup>30</sup> Under the convention, states "shall strive to ensure that *no child* is deprived of his or her right of access to ... health care services" and "take appropriate measures ... to ensure the provision of necessary medical assistance and health care to all children."<sup>31</sup>

As with other economic, social, and cultural rights, the right to health is subject to "progressive realization," meaning that states are given time to implement the right in light of resource constraints, as long as they are "mov[ing] as expeditiously and effectively as possible" by taking steps on their own as well as through international cooperation and assistance.<sup>32</sup> The UN Committee on Economic, Social and Cultural Rights, the expert group charged with interpreting the covenant and monitoring its compliance, has observed that this means that "depending on the availability of resources, States should facilitate access to essential health facilities, goods and services in other countries, wherever possible and provide the necessary aid when required."<sup>33</sup>

Companies, in turn, have a responsibility to ensure that they do not cause or contribute to rights abuses, including abuses of the right to health, in line with the UN Guiding Principles on Business and Human Rights and other standards, notably those set by the Organisation for Economic Co-operation and Development. Specifically, companies should take steps to identify, prevent, and mitigate their human rights and environmental impacts. Where companies have caused or contributed to

human rights abuses—including by failing to use leverage over a supplier to mitigate its impact to the greatest extent possible—they should help remedy them.<sup>34</sup>

\* \* \*

As these examples illustrate, policies and practices by government and corporate actors can have dire consequences for children's health and their enjoyment of other rights. In recognition of the need for research and analysis on these topics, beginning with this issue, *Health and Human Rights* will contain a regular section dedicated to children's right to health. This section will include contributions that examine child health and development issues through the lens of human rights and children's right to health, bearing in mind the international legal framework outlined above and the UN Committee on the Rights of the Child's specific guidance on children's right to health.<sup>35</sup> Papers, perspective essays, viewpoints, and other contributions to the section might, for example, present primary research findings concerning children and their families' access to and the availability of appropriate, quality health care; discuss the impact of social, political, or other underlying determinants of health and development on children; examine children's participation in health care and decision-making; highlight the particular situation of children in conflict and humanitarian crises; and offer case studies of rights-based approaches to children's health and development.

## References

1. World Health Organization, "WHO Director-General's Remarks at the Virtual Ministerial Briefing on the Bundibugyo Ebola Outbreak" (May 25, 2026), <https://www.who.int/news-room/speeches/item/who-director-general-s-remarks-at-the-virtual-ministerial-briefing-on-the-bundibugyo-ebola-outbreak-25-may-2026>; Save the Children, "DRC: One in Four Confirmed Ebola Deaths Are Children Underscoring the Urgent Need to Protect Them" (May 27, 2026), <https://reliefweb.int/report/democratic-republic-congo/drc-one-four-confirmed-ebola-deaths-are-children-underscoring-urgent-need-protect-them>; R. McCabe, L. Ebbarnez, S. Okware, et al.,

“Estimation of the Size of the Outbreak of Ebola Disease Caused by Bundibugyo Virus in the Democratic Republic of the Congo: May 20, 2026 Update,” Imperial College London (May 20, 2026).

2. L. Chutel, Y. Zhuang, and E. Livni, “Ebola Outbreak in Central Africa Could Last Months, W.H.O. Says,” *New York Times* (May 19, 2026), <https://www.nytimes.com/2026/05/20/health/ebola-congo-united-states-trump.html>.

3. J. Rigby and O. L. Poidevin, “Ebola Likely Circulating in Congo for Two Months, Outbreak to Grow, WHO Says,” Reuters (May 20, 2026), <https://www.reuters.com/business/healthcare-pharmaceuticals/who-says-139-suspected-ebola-deaths-congo-outbreak-numbers-expected-rise-2026-05-20/>.

4. B. Doran, “Defunded and Exposed: How US Aid Cuts and Broken Trust Fueled the 2026 Ebola Crisis,” *Infection Control Today* (May 26, 2026), <https://www.infectioncontrolday.com/view/defunded-exposed-how-u-s-aid-cuts-broken-trust-fueled-2026-ebola-crisis>; A. Mandavilli and S. Nolen, “Efforts to Contain Ebola May Have Been Hindered by Lack of U.S. Involvement,” *New York Times* (May 20, 2026), <https://www.nytimes.com/2026/05/20/health/ebola-congo-united-states-trump.html>.

5. A. Mandavilli, “How Foreign Aid Cuts Are Setting the Stage for Disease Outbreaks,” *New York Times* (March 7, 2025), <https://www.nytimes.com/2025/03/07/health/us-aid-funding-disease-outbreaks.html>.

6. R. Ombuor, R. Chason, L. Weber, and L. H. Sun, “Ebola Responders Say Aid Cuts by Western Nations Left Them Ill-Equipped for Outbreak,” *Washington Post* (May 21, 2026), <https://www.washingtonpost.com/world/2026/05/21/ebola-responders-say-aid-cuts-under-trump-left-them-unprepared-outbreak>.

7. A. Mandavilli, “U.S.A.I.D. Memos Detail Human Costs of Cuts to Foreign Aid,” *New York Times* (March 2, 2025), <https://www.nytimes.com/2025/03/02/health/us-aid-cuts-deaths-infections.html>.

8. S. Nolen, “U.S. Considers Withholding H.I.V. Aid Unless Zambia Expands Minerals Access,” *New York Times* (March 16, 2026), <https://www.nytimes.com/2026/03/16/health/zambia-hiv-aid-minerals-trump.html>.

9. Mandavilli and Nolen (see note 4).

10. Human Rights Watch, “Ethiopia: Companies Long Ignored Gold Mine Pollution” (April 26, 2023), <https://www.hrw.org/news/2023/04/26/ethiopia-companies-long-ignored-gold-mine-pollution>.

11. W. M. Fereja, A. Legesse, L. Kenea, et al., “Assessment of Heavy Metal Levels in Surface Water, Sediment and Agricultural Soils Around the Abandoned Laga Dambi Gold Mine, Ethiopia,” *Scientific Reports* 15 (2025).

12. W. M. Fereja, C. M. Abda, and A. A. Labena, “Assessment of Heavy Metal Levels in Cow’s Milk and Associated Health Risks in the Vicinity of the MIDROC Laga Dambi

Gold Mine in Ethiopia,” *Journal of Trace Elements in Medicine and Biology* 86 (2024).

13. Kontomaa Darimu Alliance and Center for International Human Rights of Northwestern University Pritzker School of Law, *Additional Information to Supplement September 2024 Report on Ethiopia’s Violations of the Rights of Indigenous Guji Children in Communities Near the Lega Dembi Gold Mine Submitted to the Committee on the Rights of the Child* (December 2025).

14. Human Rights Watch, *Poisonous Profit: Lead Waste Mining and Children’s Right to a Healthy Environment in Kabwe, Zambia* (2025); Human Rights Watch, “We Have to Be Worried”: *The Impact of Lead Contamination on Children’s Rights in Kabwe, Zambia* (2019), <https://www.hrw.org/report/2019/08/23/we-have-be-worried/impact-lead-contamination-childrens-rights-kabwe-zambia>.

15. S. Bose-O’Reilly, J. Yabe, J. Makumba, et al., “Lead Intoxicated Children in Kabwe, Zambia,” *Environmental Research* 165 (2018).

16. IHRDA, “IHRDA Files Major Case on 100-Year-Old Kabwe Lead Poisoning Before African Children’s Rights Body” (April 16, 2026), <https://ihrda.org/en/ihrda-files-major-case-on-100-years-old-kabwe-lead-poisoning-before-african-childrens-rights-body/>.

17. Senado Federal (Brazil), Comissão Parlamentar de Inquérito, *Relatório* (June 2019), <https://legis.senado.leg.br/atividade/comissoes/comissao/2246/mna/relatorios>.

18. M. A. Adombila, “Ghana Communities Face Hazardous Toxin Levels Linked to Mining, Study Warns,” *Reuters* (September 23, 2025), <https://www.reuters.com/sustainability/climate-energy/ghana-study-warns-hazardous-toxin-levels-linked-mining-artisanal-gold-output-2025-09-23/>.

19. Human Rights Council, *Report of the Special Rapporteur on the Human Rights to Safe Drinking Water and Sanitation, Pedro Arrojo Agudo*, UN Doc. A/HRC/54/32/Add.2 (2023), para. 6; Defensoría del Pueblo (Peru), *En defensa de las personas expuestas a metales pesados, metaloides y otras sustancias químicas: Los impactos de la contaminación ambiental*, Informe de adjuntía no. 19-2021-DP/AMASP-PI (2021), <https://www.defensoria.gob.pe/wp-content/uploads/2021/12/Informe-de-Adjuntia%CC%81a-N%C2%Bo-19-2021-DP-AMASPPI.pdf>; *Case of the Inhabitants of La Oroya v. Perú*, Inter-American Court of Human Rights, judgment of November 27, 2023.

20. Human Rights Council, *The Right to a Clean, Healthy and Sustainable Environment: Non-Toxic Environment*, UN Doc. A/HRC/49/53 (2022), paras. 1, 12.

21. Human Rights Council, *Report of the Special Rapporteur on the Implications for Human Rights of the Environmentally Sound Management and Disposal of Hazardous Substances and Wastes*, UN Doc. A/HRC/33/41 (2016).

22. Committee on the Rights of the Child, General Comment No. 26, UN Doc. CRC/C/GC/26 (2026).

23. See, e.g., E. Pribytkova, "Are There Global Obligations to Assist in the Realization of Socio-Economic Rights?," *New York University Journal of International Law and Politics* 379 (2022).

24. E. Musk (@elonmusk), X post from February 3, 2025, <https://x.com/elonmusk/status/1886307316804263979>.

25. See, e.g., R. Thoreson, "From Child Protection to Children's Rights: Rethinking Homosexual Propaganda Bans in Human Rights Law," *Yale Law Journal* 124 (2015).

26. Office of the Inspector General, US Department of Justice, *Review of the Department of Justice's Planning and Implementation of Its Zero Tolerance Policy and Its Coordination with the Departments of Homeland Security and Health and Human Services*, Report No. 21-028 (January 2021, rev. April 2022), p. 39; Human Rights Watch, Texas Civil Rights Project, and Lowenstein International Human Rights Clinic, "We Need to Take Away Children": *Zero Accountability Six Years After "Zero Tolerance"* (Human Rights Watch, 2024), pp. 97-104.

27. M. Jordan and J. Adelson, "Over 100,000 Family Separations in Deportation Push, Report Estimates," *New York Times* (May 18, 2026), <https://www.nytimes.com/2026/05/18/us/brookings-institution-report-family-separations.html>.

28. International Covenant on Economic, Social and Cultural Rights, G.A. Res. 2200A (XXI) (1966), art. 12(2)(a)-(c).

29. Convention on the Rights of the Child, G.A. Res. 44/25 (1989), art. 24(2).

30. International Covenant on Economic, Social and Cultural Rights (see note 28), art. 12(2)(d) (emphasis added).

31. Convention on the Rights of the Child (see note 29), arts. 24(1), 24(2)(b) (emphasis added).

32. Committee on Economic, Social and Cultural Rights, General Comment No. 3, UN Doc. E/1991/23 (1990), para. 9.

33. Committee on Economic, Social and Cultural Rights, General Comment No. 14, UN Doc. E/C.12/2000/4 (2000), para. 39.

34. Guiding Principles on Business and Human Rights, UN Doc. A/HRC/17/31 (2011); see also Organisation for Economic Co-operation and Development, *Responsible Business Conduct*, <https://www.oecd.org/en/topics/responsible-business-conduct.html>.

35. Committee on the Rights of the Child, General Comment No. 4, UN Doc. CRC/GC/2003/4 (2003); Committee on the Rights of the Child, General Comment No. 15, UN Doc. CRC/C/GC/15 (2013); Committee on the Rights of the Child, General Comment No. 20, UN Doc. CRC/C/GC/20 (2016).

## VIEWPOINT

# Balancing Protection and Autonomy: Adolescent Sexual Rights and the Limits of Criminal Law in Kenya

MOURICE ONYANGO OKUON AND RITA BABIRYE

A recent ruling by the High Court of Kenya in *HSO, AMO TA & Another v. Attorney General and 3 Others* on May 20, 2026, has exposed the tension between the duty to protect children from exploitation and the constitutional limits of such protection.<sup>1</sup> The court was faced with the question whether the prosecution of adolescents engaging in consensual, noncoercive, and non-exploitative sexual relations is constitutional. The petitioners argued that such prosecutions are discriminatory because they target boys as the perpetrators and girls as the victims. Their central argument, however, was that the impugned sections of the Sexual Offences Act (SOA) limited the rights of adolescents without meeting the proportionality and justification tests envisioned by the Kenyan Constitution.

Kenya's Constitution defines a child as any person under the age of 18, in line with the Convention on the Rights of the Child.<sup>2</sup> The SOA builds on this definition by providing that a child lacks the capacity to consent to sex.<sup>3</sup> This statutory rule has informed the prosecution of defilement cases in Kenya, including cases involving adolescents whose sexual relations are alleged to be consensual, noncoercive, and non-exploitative.

Several considerations support strong legal protections against the sexual exploitation of children. First, children are more susceptible to manipulation and abuse. Second, there is evidence that exploitative sexual conduct causes significant harm to children in Kenya.<sup>4</sup> Third, children in Kenya continue to face sexual abuse in the form of defilement and indecent acts, among others.<sup>5</sup> A 2015 study of adolescents aged 13–17 found that 27% of respondents had experienced indecent touching by classmates, 21% by strangers, and 19% by neighbors.<sup>6</sup> Against this backdrop, coercive, nonconsensual, and pressured sexual encounters may also occur between close-in-age adolescents, underscoring the need for legal protection within adolescent sexual relationships.

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Article 53(2) of the Constitution mandates the state to consider the best interest of the child in all its actions.<sup>7</sup> The primary legal instrument for protecting children from sexual abuse and exploitation is the SOA, which criminalizes defilement and attempted defilement under sections 8 and 9, respectively. Section 11 prohibits any indecent act with a child, while section 43(4)(f) provides that children lack the capacity to consent to sexual conduct.<sup>8</sup> These provisions establish a strict liability regime in which any sexual conduct with a person under the age of 18 in Kenya is a crime.

But what happens when one adolescent consents to sex with another adolescent in circumstances that are noncoercive and non-exploitative? The SOA does not distinguish between such situations and the coercive, exploitative, and nonconsensual conduct it is intended to guard against. The result is the blanket criminalization of adolescent sexual activity irrespective of the circumstances in which it occurs. The rationale for this can be found in section 43(4)(f) of the SOA, which provides that a child has no capacity to consent to sex. Without the necessary qualifications, this provision outlaws any sexual relations involving a child, even if such relations are between consenting adolescents in non-exploitative and noncoercive environments. As the *HSO* judgment recognized, however, the protection envisioned by this provision must be interpreted in full consideration of children's rights to dignity, privacy, and autonomy.<sup>9</sup>

### The court's reasoning in *HSO*

While the SOA rightly protects children and punishes sexual abuse against them, applying it without regard to constitutional rights risks turning adolescents into perpetrators. In effect, the absence of a legislative mechanism distinguishing adult predation from consensual peer intimacy means that adolescents who engage in consensual sexual relationships may face the same criminal consequences as adults who prey on children. Such blanket criminalization is problematic, as the United Nations Committee on the Rights of the

Child has noted, particularly because adults who engage in consensual sexual conduct are not punished in the same way.<sup>10</sup>

Before the *HSO* judgment, Kenyan courts had considered this issue, albeit inconclusively. In *P.O.O. (A Minor) v. Director of Public Prosecutions*, the High Court observed that adolescents in consensual relationships should be counseled instead of criminally sanctioned.<sup>11</sup> Similarly, the Court of Appeal in *Wambui v. Republic* found fault in the incarceration of adolescents arising from consensual relationships.<sup>12</sup>

In *HSO*, the court interrogated whether sections 8, 9, 11, and 43(4)(f) of the SOA satisfied the proportionality test under article 24 of the Constitution—which outlines the test for the limitations of rights provided in the Bill of Rights—when applied to consensual peer relationships between adolescents. In essence, the court sought to determine whether limiting the rights of adolescents—including their rights to dignity, privacy, nondiscrimination, and reproductive health care—met the proportionality test. It found that blanket criminalization failed the minimal impairment requirement because it extended criminal sanction beyond conduct involving coercion, capturing consensual adolescent relationships. The court therefore ruled that sections 8, 9, 11, and 43(4)(f) of the SOA were unconstitutional insofar as they criminalized consensual, noncoercive, and non-exploitative sexual conduct between adolescents of similar ages.

### The road ahead: Adolescent sexual and reproductive health and rights and the need for reform

While the judgment is timely, the court's failure to set a timeline for implementation creates uncertainty as to when the government should publish guidelines on handling cases of consensual, noncoercive, and non-exploitative sexual conduct between adolescents. Even more glaring is the court's failure to resolve the issue of "close in age proximity" in the context of peer sexual relations

among adolescents. Instead, it left that determination to Parliament.

It is important to note that nonconsensual, coercive, and exploitative sexual relations involving adolescents remain punishable under the SOA. The *HSO* judgment did not invalidate this. Rather, it recognized, first, that under the doctrine of evolving capacities, adolescents are entitled to exercise autonomy and should not be punished for doing so. Second, it highlighted the urgent need for Kenya to reconsider its approach toward adolescents' access to sexual and reproductive health services. As the court noted, adolescents in Kenya are sexually active and must be protected through access to sexual and reproductive health information and services free from discrimination. Essentially, this is a call for the removal of the parental consent requirements standing in the way of adolescents' access to health services.

Although Kenya has comprehensive guidelines and policies on adolescent health care, including the National Reproductive Health Policy 2022–2032, they still require parental consent before minors can receive reproductive health services.<sup>13</sup> This requirement is informed by section 9, read in conjunction with section 8, of the Health Act, which requires consent from a minor's guardian before any health service is provided.<sup>14</sup>

In light of the *HSO* ruling, it is clear that adolescents in Kenya should be able to access sexual and reproductive health services and information free from structural and legal barriers. Such access is essential to protecting adolescents from the risks associated with sexual relations, including teenage pregnancy, sexually transmitted infections, and sexual and gender-based violence. Kenya should therefore consider lowering the age of consent to medical services, as was recently done in Rwanda.<sup>15</sup>

## References

1. *HSO, AMO TA & Another v. Attorney General and 3 Others*, High Court of Kenya, judgment of May 20, 2026.
2. Constitution of Kenya (2010), art. 260; Convention on the Rights of the Child, G. A. Res. 44/25 (1989), art. 1.
3. Sexual Offences Act (2006), sec. 43(4)(f).
4. T. Mutavi, M. Mathai, M. Kumar, et al., "Psychosocial

Outcomes Among Children Following Defilement and the Caregivers Responses to the Children's Trauma: A Qualitative Study from Nairobi Suburbs, Kenya," *African Journal of Traumatic Stress* 5/1 (2016).

5. M. W. Mwangi, T. A. Kellogg, K. Brookmeyer, et al., "Perpetrators and Context of Child Sexual Abuse in Kenya," *Child Abuse & Neglect* 44 (2015).
6. *Ibid.*
7. Constitution of Kenya (2010).
8. Sexual Offences Act (2006).
9. United Nations Children's Fund, *Growing with Rights: Understanding and Supporting the Evolving Capacities of the Child* (2026).
10. Committee on the Rights of the Child, General Comment No. 24, UN Doc. CRC/C/GC/24 (2019), para. 12.
11. *P.O.O. (A Minor) v. Director of Public Prosecutions & Another* (Constitutional Petition 1 of 2017) [2017] KEHC 8341 (KLR).
12. *Wambui v. Republic* (Criminal Appeal 102 of 2016) [2019] KECA 906 (KLR).
13. Ministry of Health, *The National Reproductive Health Policy 2022–2032* (2022).
14. Health Act (2017).
15. D. Lutasingwa, A. Higirow, A. Favina, et al., "Lowering the Age of Consent for Contraception: Legal Reform in Rwanda," *Lancet Obstetrics, Gynaecology, & Women's Health* 2/2 (2026).



## VIEWPOINT

# Denying Pediatric Gender-Affirming Health Care Is a Human Rights Violation

SWARUPA DEB

This viewpoint critically analyzes contemporary global opposition to pediatric gender-affirming care (GAC) as a regulatory ideology that justifies human rights violations against transgender children. Pediatric GAC is a developmentally appropriate support for children undergoing gender transition that includes interventions such as puberty blockers and hormone replacement therapy.<sup>1</sup> However, recent medico-political shifts have invoked statutory restrictions, institutional retrenchment, and the reorientation of clinical guidelines to limit or withdraw access to pediatric GAC, citing uncertain medical outcomes and child protection concerns.

The Cass Review, for instance, argues against pediatric GAC, emphasizing the limited quality and longitudinal depth of evidence supporting puberty suppression and hormonal interventions, as well as uncertainty regarding long-term outcomes.<sup>2</sup> The American Society of Plastic Surgeons invokes insufficient risk-benefit data, procedural irreversibility, and minors' limited capacity to provide informed consent.<sup>3</sup> Queensland's suspension of puberty blockers for minors emphasizes risk assessment and highlights potential threats to children's health.<sup>4</sup> Similarly, Alberta's most recent legislative restrictions on pediatric GAC insist on harm to minors' well-being.<sup>5</sup>

Resonant precautionary logics are emerging within Indian medico-judicial-public discourse as well. They problematically frame the expansion of pediatric GAC as a "mistake," appealing to medical caution and aligning with international trends.<sup>6</sup> Read symptomatically, these oppositions reveal how protectionist language and institutionalized medical hesitation are consolidated as regulatory rationality to justify the denial of equal health care for trans and gender-diverse children.

Such extraordinary medical scrutiny around pediatric GAC reveals symbolic weight attached to the concept of gender itself. Scholarship, both seminal and recent, has demonstrated that gender identity, unlike other aspects of psycho-physiological development, continues to be treated as a foundational principle of social order. It operates as a structuring logic that organizes power, status, and intelligibility.<sup>7</sup> Consequently, interventions that appear to destabilize binary gender norms are experienced not merely as a

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biomedical risk but as a civilizational threat. From this perspective, engaging directly with counter-arguments that invoke “documented risk” and “systemic evidence reviews” to justify restrictions or deferral of GAC is important.<sup>8</sup>

Historically, transgender encounters with medicine have been organized less around care than around classification, risk assessment, and the management of gender variance as a problem to be solved.<sup>9</sup> Within this history, assessments of harm have been unevenly distributed, and evidentiary standards concerning GAC have been subjected to heightened scrutiny. Medical scholarship continues to remain internally differentiated in this context, with one body of research evidencing significant psychosocial and mental health benefits for trans youth, and another body of medical epistemology emphasizing evidentiary uncertainty, potential long-term risks, and caution.<sup>10</sup> The irony here thus lies in the inversion of medical reasoning: “Uncertainty” and “documented risk,” which should typically function as a catalyst for clinical refinement and innovation, are instead mobilized in GAC as a justificatory basis for denying rights. Ergo, the core disagreement concerning GAC is not over the necessity of caution itself but over how caution is unevenly applied and whose interests such applications ultimately serve.

Against this backdrop, I argue that the contemporary opposition around pediatric GAC cannot be understood as a narrow medical dispute. Rather, it is a convergence of multiple regimes of power, including biomedical authority, juridical paternalism, developmental psychology, and deeply sedimented cultural anxieties around gender non-conformity. Within this convergence, structural discrimination against transgender children is (re) produced in ways that systematically generate and sustain disadvantage. This discrimination operates not only through the denial of services but through the unequal distribution of risk and recognition within health care regimes. It is in this precise context that human rights commitments to the best interests of gender-diverse children are critically strained, through the epistemic-moral disqualification of the “child” as a knowing subject.

## Childhood, incapacity, and the politics of protection

Across regulatory and clinical contexts, children's self-reports are frequently approached with caution and presumptions of diminished capacity and are often filtered through adult interpretations of risk and protection. This dynamic becomes especially pronounced in the case of gender-diverse children, resulting in the systematic invalidation of their capability and right to articulate gendered experiences, distress, and needs.

Human rights jurisprudence in this context offers a nuanced account of childhood and agency. The Convention on the Rights of the Child explicitly rejects the idea that children are merely passive recipients of protection.<sup>11</sup> Rather, it advances a model of *evolving capacities* (article 5), according to which children's ability to participate in decisions affecting them increases over time. Importantly, this framework dismisses the binary distinction between complete autonomy and total incapacity, instead acknowledging that children's capacity to participate meaningfully in decisions that affect them develops relationally and contextually.

The Committee on the Rights of the Child further elaborates this principle in its General Comment 20 on the implementation of the rights of the child during adolescence.<sup>12</sup> It highlights adolescents' entitlement to participate meaningfully in decisions concerning their health, bodily integrity, and medical treatment, emphasizing that states must move beyond protectionist paternalism and ensure access to appropriate, rights-respecting health care services. Read together, these provisions underline the *best interests of the child* principle that mandates all decisions concerning children to prioritize their well-being and development—not as an exception to protection, but as integral to it.

In juxtaposition, anti-GAC arguments represent a selective application of the principle, repeatedly treating it as a risk-management tool, devaluing present and ongoing harm. This approach departs from the fundamental principles of human rights jurisprudence, which emphasize children's lived experience, psychological well-being, social belonging, and sense of self above all else. This is

crucial in the case of gender-diverse children, who are continually required to justify their entitlement to care and credibility—entitlements that are contingent on conformity to dominant gender norms and imagined futures of normalization.

Thus, what appears as an appeal to medical caution is in reality a structural failure of rights realization. The failure arises from a clinical structure so rigidly organized around standardization and normative assumptions about gender and childhood that it actively disables the forms of knowledge most necessary for caring for gender-diverse children. When health care, a fundamental human right, is structured in this manner, access to care is no longer realized as a right but rendered conditional. For gender-diverse children, this results in continued invalidation of their dignity, suffering, and aspirations, which are treated as illegible and unworthy of medical care. The vulnerabilities, anxiety, and depression of gender-diverse children, therefore, actually arise from regulatory and social constraints and not from their embodied identity, as commonly presumed.

### Against protective harm

Engaging critically with pediatric GAC is not merely a debate over clinical protocols. It is about medical decision-making that differentially recognizes and restricts fundamental rights to health, bodily integrity, and dignity, thereby effectively violating them under the guise of ethical health care regulation. The harm intensifies when these regulations presume that clinical objectivity, risk assessment, and evidence standards operate independently of social contexts.

This presumption is analytically untenable given that health care has always been socially and culturally embedded. Medical knowledge is produced within institutional norms, regulatory regimes, and moral frameworks. These structures shape how risk is defined, whose experiences are considered credible, and which lives are recognized as legitimate subjects of care.<sup>13</sup> They not only influence care practice but also significantly structure its ethical and legal boundaries. Appeals that India

too should align with “international consensus” on pediatric GAC thus presume that scientific evidence is context-free and universally transferable; they obscure how local legal frameworks, institutional capacities, and social norms shape risk, eligibility, and access to care.

When discrimination-free health care is withheld in the name of ethical regulation, the outcome is not mere medical caution or risk assessment but an immediate violation of the universal human rights to life, equality, and freedom of expression. Such regulations redistribute harm into the lives of young children, impacting their everyday realities as they concern access to education, social adjustment, peer pressure, and self-image. This viewpoint thus calls for the recognition of gender-diverse children as present rights holders, entitled to dignity and participation in decision-making concerning their health care, rather than as future contingencies to be governed.

### References

1. L. Ha, “Further Defining Gender Affirming Care December,” *AAP Journals Blog* (December 22, 2023), <https://publications.aap.org/journal-blogs/blog/27752/Further-Defining-Gender-Affirming-Care>.
2. H. Cass, *Independent Review of Gender Identity Services for Children and Young People: Final Report* (2024), <https://webarchive.nationalarchives.gov.uk/ukgwa/20250310143933/https://cass.independent-review.uk/home/publications/final-report/>.
3. S. Christy, “US Plastic Surgeons Group Advises Delaying Gender Surgery Until Age 19 Due to Insufficient Evidence,” *Reuters* (February 3, 2026), <https://www.reuters.com/business/healthcare-pharmaceuticals/us-plastic-surgeons-group-advises-delaying-gender-surgery-until-age-19-due-2026-02-03/>.
4. D. Melissa, “Queensland Ban on Puberty Blockers for Gender Dysphoria to Continue Until at Least 2031, LNP Announces,” *Guardian* (December 19, 2025), <https://www.theguardian.com/australia-news/2025/dec/19/queensland-ban-puberty-blockers-gender-dysphoria-2031>.
5. T. Laura, “Alberta Has Restricted Access to Gender Based Medical Care for Trans Youth. Will the Rest of Canada Soon Follow?,” *Healthy Debate* (January 21, 2026), <https://healthydebate.ca/2026/01/topic/alberta-gender-based-medical-care/>.
6. “Gender Reassignment Surgery on Children Is an Invasion of Rights Enshrined in Constitution: Kerala

HC,” ANI (August 8, 2023), <https://www.aninews.in/news/national/general-news/gender-reassignment-surgery-on-children-is-an-invasion-of-rights-enshrined-in-constitution-kerala-hc20230808213114/>; J. Nilekani, “Many countries are rethinking gender treatment for kids. India should too,” *Times of India* (January 3, 2026), <https://timesofindia.indiatimes.com/blogs/toi-edit-page/many-countries-are-rethinking-gender-treatment-for-kids-india-should-too/>.

7. K. K. Means and T. Morgenroth, “The Ubiquity of the Gender/Sex Binary: Power and Status in Social Psychology,” *Frontiers in Social Psychology* 2 (2024); C. West and D. H. Zimmerman, “Doing Gender,” *Gender and Society* 1/2 (1987).

8. Cass (see note 2); Nilekani (see note 6).

9. S. Stryker, *Transgender History: The Roots of Today's Revolution*, 2nd edition (Seal Press, 2017).

10. L. Crabtree, K. J. Connelly, J. T. Guerriero, et al., “A More Nuanced Story: Paediatric Gender-Affirming Healthcare Is Associated with Satisfaction and Confidence,” *Journal of Adolescent Health* 75/5 (2024); K. McDeavitt, J. Cohn, and C. Kulatunga-Moruzi, “Paediatric Gender Affirming Care Is Not Evidence-based,” *Current Sexual Health Reports* 17 (2025).

11. Convention on the Rights of the Child, G.A. Res. 44/25 (1989).

12. Committee on the Rights of the Child, *General Comment No. 20, UN Doc. CRC/C/GC/20* (2016).

13. A. B. Sideman and N. Razon, “Extra/ordinary Medicine: Toward an Anthropology of Primary Care,” *Social Science and Medicine* 346 (2024).

## VIEWPOINT

# Schools Under Fire: Armed Conflict and the Vulnerability of Childhood

JÚNIA APARECIDA LAIA DA MATA AND SAYED ABDUL BASIR SAMIMI

### The attack on a girls' school in Minab

On February 28, 2026, during coordinated US–Israeli air strikes against Iran, a girls' school in Minab, southern Iran, was struck with guided weapons alongside 12 structures in an adjacent Islamic Revolutionary Guard Corps compound; Iranian authorities reported 156 deaths in the school attack, including students, teachers, and civilians.<sup>1</sup> The Global Coalition to Protect Education from Attack condemned the strike, emphasizing that military operations must adhere to proportionality, distinction, and precaution to safeguard the right to education.<sup>2</sup> A subsequent legal analysis in *Just Security* noted that reports of a preliminary US military inquiry attributed the strike to a targeting error based on outdated intelligence, raising concerns about verification, precaution, and accountability under international humanitarian law (IHL).<sup>3</sup> The attack also drew attention at the 61st session of the United Nations Human Rights Council, where the Global Coalition to Protect Education from Attack stated that schools are civilian objects and that attacks on education may violate IHL and international human rights law (IHRL).<sup>4</sup> Beyond immediate casualties, attacks on educational spaces threaten children's rights to education, protection, and physical and mental health.

Iranian authorities blamed the strike on US and Israeli forces, while US and Israeli officials denied deliberately targeting the school and stated that reports of civilian harm were under investigation.<sup>5</sup> These differing accounts reinforce the need for independent investigation and accountability under IHL, given questions about target selection, outdated intelligence, and verification.<sup>6</sup> They also reflect a broader pattern in contemporary conflicts, where disputes unfold alongside military operations while children remain exposed to risks to their safety, well-being, and development.

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Furthermore, the attack raises gendered implications, showing how armed conflict can intersect with inequalities and expose girls to specific vulnerabilities. In many conflict settings, girls' access to education is already fragile. When girls' schools become targets or are rendered unsafe, consequences may extend beyond casualties, reinforcing educational exclusion, early marriage, and socioeconomic marginalization, while undermining conditions necessary for physical, psychological, and social well-being.

### Humanitarian consequences

This attack occurred amid a regional escalation marked by rising child casualties, disrupted education, displacement, damaged infrastructure, and immediate and long-term impacts on women and girls.<sup>7</sup> Reports and literature show that, in armed conflict, children, women, and girls face higher risks of death, injury, malnutrition, displacement, and physical and mental illness, affecting their rights to health, protection, and development.<sup>8</sup>

When military operations, including aerial attacks and explosive weapons, occur near civilian areas, they can disproportionately harm civilians and damage essential infrastructure, including schools, homes, and health facilities.<sup>9</sup> Children are particularly vulnerable because of their developmental stage, dependence on adult protection, and exposure to both the direct and indirect effects of hostilities.<sup>10</sup> As a result, children face increased risks of death, injury, long-term psychological trauma, educational disruption, and adverse developmental outcomes, with lasting implications for their physical and mental health.<sup>11</sup>

Attacking civilians and civilian objects, including schools, may constitute a violation of IHL and IHRL and may amount to a war crime when attacks are intentionally directed at buildings dedicated to education that are not military objectives.<sup>12</sup> Such attacks also engage states' obligations to protect children's rights to health, education, and development under IHRL. Beyond the immediate loss of life and injury, attacks on educational spaces and the destruction or military use of schools

produce sustained disruption to learning and dismantle education systems, leaving children without access to safe schooling.<sup>13</sup>

This compromises not only physical safety but also children's cognitive, emotional, and social development, since conflict-related trauma, displacement, and unsafe learning environments undermine social-emotional development and cognitive functioning and weaken educational outcomes.<sup>14</sup> In addition, when education is denied through violence, it is not merely an interruption of a service: it becomes an assault on children's human dignity and on the conditions needed for holistic development and recovery during and after conflict, including their long-term well-being.<sup>15</sup>

### An ethical debate

The effects of prolonged exposure to violence can produce intergenerational consequences, since unprocessed trauma, successive grief, and structural deprivations may compromise children's development and reverberate in cycles of social vulnerability and psychological suffering across generations.<sup>16</sup>

This vulnerability is not only personal or psychological; it is also political and structural. Human geography scholarship understands childhood and youth not as fixed biological stages but as dynamic social processes shaped by global political and economic conditions, including neoliberal agendas that shift risks and weaken public support for social reproduction.<sup>17</sup> Children's lives, bodies, and everyday micro-histories are therefore "folded into" broader transformations of power, land, resources, and material conditions, producing vulnerabilities that are social, bodily, and environmental.<sup>18</sup> When schools are bombed and children become direct victims of military offensives, the rupture between ethical rationality and the strategic logic guiding political decisions becomes evident.

From a human rights perspective, attacks on schools raise an ethical question that goes beyond military justification: whether children can ever be treated as acceptable collateral harm in political or strategic disputes. A human dignity-centered

approach rejects this logic and emphasizes that attacks on education are not merely legal breaches but assaults on children's dignity, psychosocial well-being, and future potential.<sup>19</sup>

Ultimately, the attack on the girls' school in Minab illustrates how contemporary armed conflicts continue to erode the moral and legal boundaries that should protect civilian life. When educational spaces, associated with safety, learning, and the future, become targets of military violence, consequences extend beyond immediate casualties. Such acts undermine not only IHL but also children's rights to health, education, and dignity and the broader social commitment to protect childhood. Protecting children and educational institutions must remain a nonnegotiable legal, ethical, and human rights priority. Failing to uphold these principles risks normalizing warfare in which children, especially girls, bear the deepest costs.

## References

1. Amnesty International, "USA/Iran: Those Responsible for Deadly and Unlawful US Strike on School That Killed Over 100 Children Must Be Held Accountable" (March 16, 2026), <https://www.amnesty.org/en/latest/news/2026/03/usa-iran-those-responsible-for-deadly-and-unlawful-us-strike-on-school-that-killed-over-100-children-must-be-held-accountable/>.
2. Global Coalition to Protect Education from Attack, "Statement by GCPEA on Attacks on Schools in Iran" (March 6, 2026), <https://us2.campaign-archive.com/?u=4bd5fe1f61eea29e76411b24e&id=8796462215>.
3. J. N. Orenstein, "When Intelligence Fails: A Legal Targeting Analysis of the Minab School Strike," *Just Security* (March 26, 2026), <https://www.justsecurity.org/134350/legal-analysis-minab-school-strike/>.
4. Global Coalition to Protect Education from Attack, "GCPEA News: Protecting Education from Attack at the 61st Session of the Human Rights Council" (April 15, 2026), <https://protectingeducation.org/news/gcpea-news-protecting-education-from-attack-at-the-61st-session-of-the-human-rights-council/>.
5. L. Cooper, "Iran Claims US and Israel Attacked a Girls' School. This Is What Is Known About the Strike," ABC News (March 2, 2026), <https://www.abc.net.au/news/2026-03-02/iran-girls-school-strike-minab-explained/106404558>; K. Singh, "US Says It Wouldn't Deliberately Target School After Iran Said Over 160 killed in Strike," Reuters (March 2, 2026), <https://www.reuters.com/world/us-says-it-wouldnt-deliberately-target-school-after-iran-said-over-160-killed-2026-03-02/>.
6. Orenstein (see note 3).
7. UNICEF, "Child Casualties Rise Amidst Deepening Middle East Conflict" (March 11, 2026), <https://www.unicef.org/press-releases/child-casualties-rise-amidst-deepening-middle-east-conflict>; UN Women, "Impact of the Recent Military Escalation in the Middle East on Women and Girls" (April 10, 2026), <https://www.unwomen.org/en/news-stories/statement/2026/04/un-women-statement-on-the-impact-of-the-recent-military-escalation-in-the-middle-east-on-women-and-girls>.
8. UNICEF (see note 7); UN Women (see note 7).
9. United Nations Office for Disarmament Affairs, "Explosive Weapons in Populated Areas," <https://disarmament.unoda.org/en/our-work/conventional-arms/explosive-weapons-populated-areas>.
10. A. Kadir, S. Shenoda, and J. Goldhagen, "Effects of Armed Conflict on Children," *Pediatrics* 142/6 (2018).
11. Save the Children, *Stop the War on Children: Pathways to Peace* (2023).
12. UNICEF, "Declaração do UNICEF sobre o impacto da escalada militar nas crianças no Oriente Médio," (March 1, 2026), <https://www.unicef.org/brazil/comunicados-de-imprensa/declaracao-do-unicef-sobre-o-impacto-da-escalada-militar-nas-criancas-no-orientemedio>; K. Akbariavaz and P. Moslemzadeh Tehrani, "The Role of International Law in Protection Against Attacks on Children's Education Rights in Armed Conflict," *Journal of Politics and Law* 13 (2020).
13. Akbariavaz and Moslemzadeh Tehrani (see note 12); L. Nyathi, "When Bullets Threaten the Pursuit of Knowledge: Reclaiming Children's Right to Education in Armed Conflict Through a Human Dignity-Centred Approach Under IHRL and IHL," *International Review of the Red Cross* (2026).
14. L. Jacobs and M. M. Dollebo, "Editorial: Education in Times of War and Displacement," *Perspectives in Education* 43/2 (2025).
15. Nyathi (see note 13).
16. D. Devakumar, M. Birch, D. Osrin, et al., "The Intergenerational Effects of War on the Health of Children," *BMC Medicine* 12 (2014).
17. S. Ruddick, "The Politics of Aging: Globalization and the Restructuring of Youth and Childhood," *Antipode* 35/2 (2003).
18. S. Hadfield-Hill and C. Zara, "Children and Young People as Geological Agents? Time, Scale and Multispecies Vulnerabilities in the New Epoch," *Discourse: Studies in the Cultural Politics of Education* 41/3 (2020).
19. Nyathi (see note 13).



## VIEWPOINT

# Crime Is Not the Beginning: Health Rights and Adolescent Criminalization in Conflict-Affected Colombia

FELIPE AGUDELO-HERNÁNDEZ AND JAVIER DÍAZ-AMAYA

When a conflict-affected adolescent appears before a juvenile judge in Colombia, the hearing often comes at the end of a much longer trajectory of harm. Many adolescents have already endured displacement, confinement, hunger, school interruption, family rupture, coercive control by armed actors, and untreated psychological distress. Their contact with the justice system thus reflects not an isolated act but the cumulative effects of prolonged exposure to violence, deprivation, and state neglect. In many cases, criminalization becomes the point at which the state finally confronts a life it has long failed to protect.<sup>1</sup>

That is the central human rights problem. The right to health does not end with clinical care following recruitment into armed groups, detention, or punishment. For conflict-affected adolescents, health is inseparable from protection, food, education, housing, territory, and dignity across the life course. A rights-based lens changes the question. Instead of asking only how to “correct” adolescents after they enter punitive systems, it asks what was denied in childhood and adolescence that made punishment more likely in the first place.<sup>2</sup>

In Colombia, this is not an abstract concern. In the department of Chocó, armed conflict and institutional neglect overlap in ways that make the problem difficult to evade. The International Committee of the Red Cross reported that in 2023 Chocó accounted for 44% of the country’s confined population, with direct effects on access to food, education, and health care.<sup>3</sup> The Ombudsperson’s Office later reported 6,898 cases involving violations of fundamental rights in the department in 2024.<sup>4</sup> Research on child recruitment in Colombia shows that children and adolescents are drawn into armed dynamics where coercion, economic vulnerability, weak state presence, and illicit economies converge.<sup>5</sup> These are the conditions in which many

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adolescents are socialized before the state encounters them through punishment.

In Colombia, adolescents aged 14–17 who are accused of or found responsible for crimes enter the Criminal Responsibility System for Adolescents (abbreviated as SRPA in Spanish), a specialized framework established by the Code of Childhood and Adolescence. Formally, the SRPA is pedagogical, specific, and differentiated from the adult criminal system, and it is intended to guarantee restorative justice, truth, and reparation. Judges may impose a warning, rules of conduct, community service, assisted liberty, placement in a semi-closed setting, or, in limited cases, deprivation of liberty in a specialized center. All sanctions are legally defined as protective, educational, and restorative.<sup>6</sup>

This pattern reflects abandonment as much as resilience. The language of resilience can become politically convenient because it shifts attention away from states as duty bearers and onto the capacity of marginalized communities to survive repeated harm.<sup>7</sup> Adolescent suffering is often framed primarily as an individual mental health problem, obscuring the political and moral conditions that produce distress. The more distress is detached from those conditions, the easier it becomes for institutions to prioritize screening, diagnosis, correction, and treatment while leaving structural remedies aside.<sup>8</sup> An adequate response therefore requires confronting the conditions in which these adolescents have grown up, including war, deprivation, and institutional neglect.

That formal architecture matters because the problem is not that Colombian law openly endorses punishment over rights. The problem is the gap between formal design and lived sequence. Although the Colombian juvenile justice framework is formally rights based and restorative, conflict-affected adolescents often encounter state authority only once multiple rights failures have already accumulated. In that sense, the system risks functioning as a late response to long-standing neglect rather than as a form of early protection.<sup>9</sup> What many conflict-affected adolescents learn from the justice system is therefore not protection but hierarchy. Published research with justice-involved youth

shows that legal institutions are often experienced less as spaces of rights realization than as punitive settings marked by weak voice, low trust, and limited respect. Under those conditions, young people learn that justice is something done to them, not something that protects them.<sup>10</sup> In conflict-affected settings, that distinction matters. A state that arrives late and mainly through sanction teaches a lesson about law that no civic education campaign can easily undo.

Critical children's rights scholarship helps explain this pattern. In highly unequal settings, the formal recognition of rights often provides limited protection in everyday life. Conflict-affected children frequently encounter institutions through categories of suspicion, punishment, and control, even when legal frameworks recognize them as rights holders. By the time rights-based language reaches them, much of its protective force has already been weakened by prolonged exposure to violence, exclusion, and institutional neglect.<sup>11</sup> In this context, juvenile justice systems often operate as mechanisms for managing inequality after harm has accumulated, rather than as institutions capable of preventing it.

A more serious response would move upstream. Governments should treat forced displacement, recruitment exposure, confinement, school exclusion, food insecurity, family incarceration, and barriers to care not merely as predictive risk factors but as rights-deprivation indicators that should trigger specific state duties. The difference is functional rather than semantic: "Risk factors" describe the probability of later harm, while rights-deprivation indicators identify failures of protection that require a public response. In this sense, the path from diagnosis to action becomes clearer. School interruption should trigger school-retention and school-protection measures, and recruitment exposure and confinement should trigger territorial protection, humanitarian access, and safe mobility. Likewise, food insecurity should trigger nutritional and income support, and family rupture or incarceration should trigger family-based accompaniment and community reintegration.

Colombian law already requires the state to guarantee children's rights, prevent their violation, restore them when breached, and ensure that sanctions are implemented with protective and educational guarantees.<sup>12</sup> Fulfilling these obligations demands more than the provision of mental health care or the management of adolescent conduct. Sustained disengagement from violence depends on institutions that are credible, reciprocal, and dignifying, as well as on communities that are prepared to receive adolescents without reproducing stigma and exclusion.<sup>13</sup> Reintegration, therefore, should be understood as a broader social and institutional process grounded in rights, protection, and recognition.

This is also the direction already set by international human rights law. General Comment 15 understands the child's right to health as interdependent with the wider set of rights protected under the Convention on the Rights of the Child. General Comment 24 makes equally clear that every child accused of or recognized as having infringed the penal law must be treated in a manner consistent with dignity and worth.<sup>14</sup>

For conflict-affected adolescents in Colombia, this standard defines the minimum conditions for prevention, recovery, and non-repetition. Rights require effective protection before young people enter punitive systems, not simply once harm has already accumulated. When state action begins only after judicialization, institutions reinforce a pattern in which prior neglect is recast as an individual problem to be managed. In this sense, the delayed activation of rights reflects a broader failure of protection, recognition, and accountability.

The human rights community should be clearer about the stakes. Youth crime in conflict-affected settings should be understood as evidence of what happens when unprotected childhoods are later managed through punishment. Crime is not the beginning. That is precisely why punishment cannot be the answer.

## References

1. J. L. Goldhagen, S. Shenoda, C. Oberg, et al., "Rights, Justice, and Equity: A Global Agenda for Child Health and

Wellbeing," *Lancet Child and Adolescent Health* 4/1 (2020); N. Hughes, M. Ungar, A. Fagan, et al., "Health Determinants of Adolescent Criminalisation," *Lancet Child and Adolescent Health* 4/2 (2020); C. G. Victora, F. P. Hartwig, L. P. VIDALETTI, et al., "Effects of Early-Life Poverty on Health and Human Capital in Children and Adolescents: Analyses of National Surveys and Birth Cohort Studies in LMICs," *Lancet* 399/10336 (2022).

2. Goldhagen et al. (see note 1); Hughes et al. (see note 1); Victora et al. (see note 1).

3. International Committee of the Red Cross, "Balance humanitario Colombia 2024" (April 3, 2024), <https://www.icrc.org/es/document/colombia-balance-humanitario-2024>.

4. Defensoría del Pueblo, "Cerca de 7.000 casos de derechos fundamentales vulnerados atendió la Defensoría en Chocó en 2024" (May 26, 2025), <https://www.defensoria.gov.co/-/7000-casos-de-derecho-vulnerados-atendio-choco>.

5. M. Hurtado, Á. Iranzo Dosdad, and W. F. Rodríguez, "Labor Markets in Contexts of War: Recruitment and Trafficking of Child Soldiers in Colombia," *Colombia Internacional* 114 (2023); W. Ortiz-Jiménez, "Reclutamiento forzado de niños, niñas y adolescentes: De víctimas a victimarios," *Encuentros* 15/1 (2017).

6. Ley 1098 de 2006, arts. 139, 140, 177, 178, 187; Instituto Colombiano de Bienestar Familiar, "Sistema de Responsabilidad Penal para Adolescentes – SRPA," <https://www.icbf.gov.co/programas-y-estrategias/proteccion/sistema-de-responsabilidad-penal-para-adolescentes-srpa>; Instituto Colombiano de Bienestar Familiar, *Manual Operativo de las Modalidades que Atienden Medidas y Sanciones del Proceso Judicial – SRPA* (July 25, 2024), <https://www.icbf.gov.co/manual-operativo-de-las-modalidades-que-atienden-medidas-y-sanciones-del-proceso-judicial-srpa-v4>.

7. J. Sedky, "Resilience Is No Substitute for Justice," *WBUR Cognoscenti* (2025), <https://www.wbur.org/cognoscenti/2025/11/21/development-donor-sector-humanitarian-aid-human-rights-un-jehane-sedky>; L. Cosgrove, "Addressing the Global Mental Health Crisis: How a Human Rights Approach Can Help End the Search for Pharmaceutical Magic Bullets," *Health and Human Rights* 27/2 (2025).

8. Sedky (see note 7); Cosgrove (see note 7).

9. Ley 1098 de 2006; Instituto Colombiano de Bienestar Familiar, "Sistema de Responsabilidad Penal para Adolescentes" (see note 6); Instituto Colombiano de Bienestar Familiar (2024, see note 6).

10. S. C. Enujioke, M. C. Aalsma, C. G. Meagher, et al., "Perception of Procedural Justice Amongst Previously Incarcerated Youth: Procedural Justice in Incarcerated Youth," *International Journal of Offender Therapy and Comparative Criminology* 69/6–7 (2025); M. J. Bernuz Beneitez and E. Dumortier, "Why Children Obey the Law: Rethinking Juvenile Justice and Children's Rights in Europe Through Procedural Justice," *Youth Justice* 18/1 (2018); E. L. Portillos, A. A. Peguero, J. C. González, et al., "C'mon—You Should Know

the Rules, Man': Latinx Youth's Perceptions of Procedural Justice and Chronic Punishment," *Urban Education* 60/10 (2025).

11. D. Reynaert, W. Vandenhole, A. Twum-Danso Imoh, and V. Llobet, "Critical Children's Rights Studies: An Introduction," in V. Llobet, D. Reynaert, A. Twum-Danso Imoh, and W. Vandenhole (eds), *Critical Children's Rights Studies: A Research Companion* (Routledge, 2025).

12. Ley 1098 de 2006, arts. 41, 177–178.

13. Goldhagen et al. (see note 1); Cosgrove (see note 7); J. Garbarino, A. Governale, and D. Nesi, "Vulnerable Children: Protection and Social Reintegration of Child Soldiers and Youth Members of Gangs," *Child Abuse and Neglect* 110 (2020); T. S. Betancourt, D. L. Thomson, R. T. Brennan, et al., "Stigma and Acceptance of Sierra Leone's Child Soldiers: A Prospective Longitudinal Study of Adult Mental Health and Social Functioning," *Journal of the American Academy of Child and Adolescent Psychiatry* 59/6 (2020).

14. Committee on the Rights of the Child, General Comment No. 15, UN Doc. CRC/C/GC/15 (2013); Committee on the Rights of the Child, General Comment No. 24, UN Doc. CRC/C/GC/24 (2019).

# Evaluation of the United States' Permitless Concealed Carry Laws and Child Health in the ECHO Cohort

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## Abstract

Firearms are the leading cause of death among children in the United States (US). As of 2023, half of US states had enacted laws allowing permitless concealed carry of firearms. Our cross-sectional study evaluated the association between permitless concealed carry laws and child general health using data from the nationwide Environmental influences on Child Health Outcomes (ECHO) Cohort collected between 2003 and 2023. Children aged 1–21 years with caregiver- or self-reported general health status were included. Secondary outcomes included child internalizing and externalizing behaviors and child stress. Regression models estimated the association of exposure to state-level permitless concealed carry laws six months prior to each outcome, adjusted for individual- and area-level covariates. One-fifth (20.9%) of the sample (n = 11,325) lived in states allowing permitless concealed carry of a handgun. Children living in these states were 25% less likely (OR: 0.75, 95% CI: 0.60, 0.95) to report excellent/very good general health and had psychological stress scores 0.21 standard deviations higher ( $\beta = 0.21$ , 95% CI: 0.10, 0.31) than children in other states. There was no statistically significant association with internalizing or externalizing behavior scores. Our study found that children living in states that allow permitless concealed carry of firearms had worse general health and higher stress, suggesting the need for policy changes to address gun violence as a public health and human rights crisis.

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## Introduction

The United States (US) has the highest rates of firearm ownership and firearm-associated homicide among high-income countries. Recent reports show a civilian firearm ownership rate of 120.5 per 100 people in 2017 (compared to 34.7 per 100 people in Canada) and a firearm-associated homicide rate of 5.4 per 100,000 population in 2023 (compared to 0.72 per 100,000 population in Canada).<sup>1</sup> During the COVID-19 pandemic, firearm ownership became more widespread in the United States, with 75

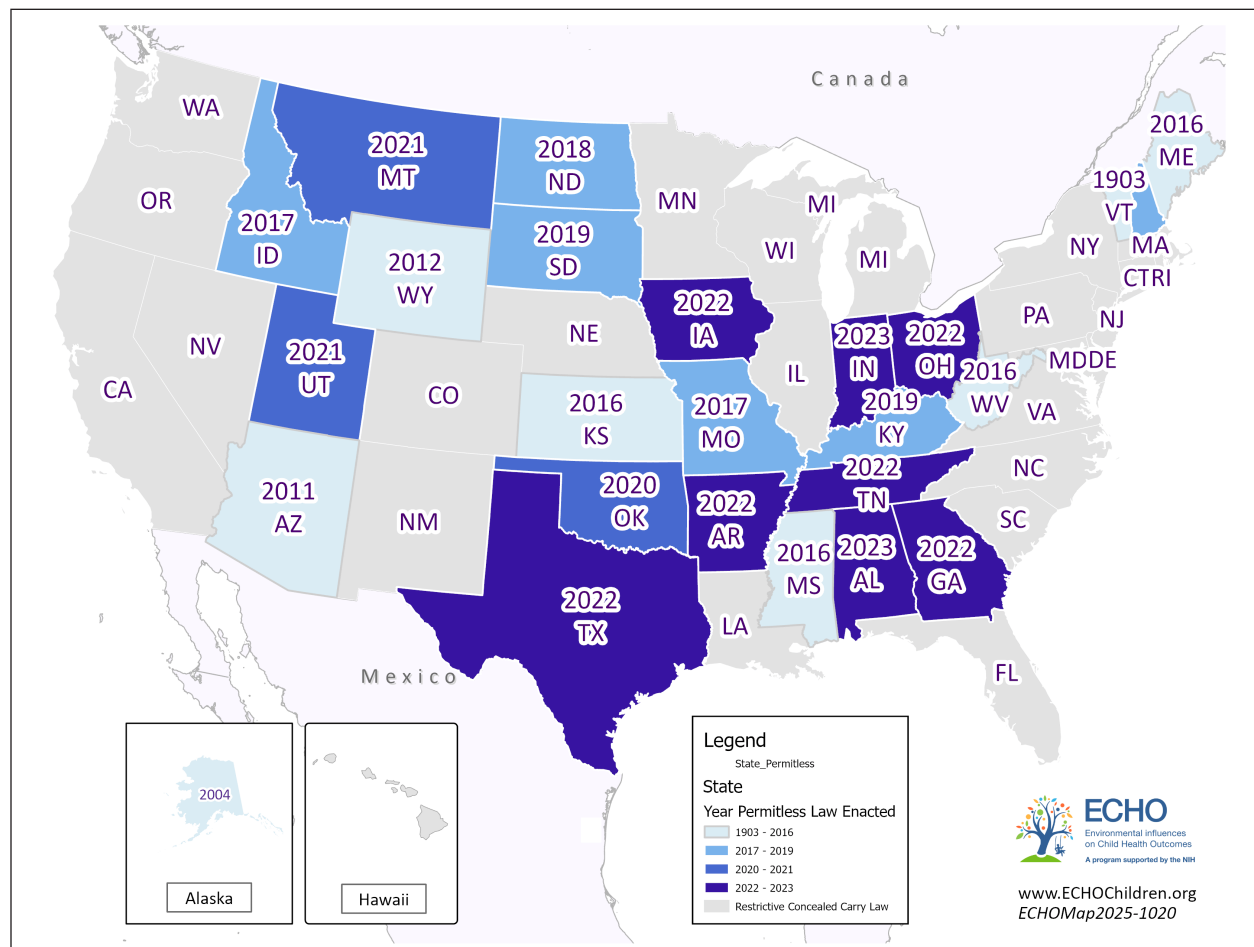
million new gun owners, exposing over 11 million additional individuals to firearms.<sup>2</sup> Since 2020, firearms have been the leading cause of death among US children and adolescents.<sup>3</sup> Beyond the individual mortality and injury associated with gun violence, spillover effects are incurred by communities. Exposure to gun violence contributes to poorer overall community health, with communities experiencing high levels of poverty, unemployment, and other disadvantages being particularly at risk.<sup>4</sup> Several studies have shown associations between community gun violence and adverse child mental

and physical health outcomes.<sup>5</sup> For example, among Black, White, and Hispanic high school students in the United States, witnessing community violence was associated with increased odds of carrying a firearm, substance use, and suicide risk.<sup>6</sup> Moreover, a recent study from the Environmental influences on Child Health Outcomes (ECHO) Cohort showed that the odds of very good to excellent general health were 20% lower among children living in census tracts with high gun violence.<sup>7</sup>

In addition to the rising rates of gun ownership in the United States, firearm laws have loosened considerably over the past 20 years. For the majority of US history, most states required gun carriers to apply for a permit, undergo background checks, obtain a license, or receive training to obtain and carry a concealed gun legally.<sup>8</sup> However, the number of states with permitless concealed carry laws

has risen sharply since 2010, when only two states had such laws in place; by the end of 2023 (Figure 1), half of states had enacted such laws, and currently, most states (29 in total) have done so. These laws allow concealed firearms to be carried without any permitting or licensure from law enforcement or other government officials and are often linked with the removal of requirements for firearm training, placing gun owners and those around them at increased risk. A 2024 study found that states that had adopted permitless concealed carry laws and discontinued live firearm training protocols experienced an increase of 32% in gun assaults, the equivalent of 21 gun assaults per 100,000 people.<sup>9</sup> Furthermore, states that had abandoned the legal prohibition of gun permits to individuals convicted of a violent misdemeanor had an 8.5% increase in gun assaults compared to before the prohibition

FIGURE 1. Years when states enacted permitless concealed carry laws between 1903 and 2023



was dropped.<sup>10</sup> Another study found that after the legalization of carrying a concealed firearm without a permit in West Virginia, homicides and suicides increased by 48% and 22%, respectively.<sup>11</sup> Conversely, lower firearm mortality rates have been observed in states with more gun ownership restrictions: restrictive policies on gun ownership were associated with substantial reductions in gun-related mortality between 1991 and 2016.<sup>12</sup>

Permitless concealed carry laws lower barriers for legally carrying firearms in public. In some states, these laws allow younger adults (18–20 years old), individuals without gun safety training, and those who have not passed background checks to carry concealed guns in public.<sup>13</sup> A higher rate of gun ownership among younger adults and those not receiving a background check or training may lead to a higher rate of youth exposure to guns and gun violence.<sup>14</sup> This, in turn, may increase fear and stress. Exposure to gun violence is associated with posttraumatic stress symptoms among children and with increases in children's acute mental health symptoms.<sup>15</sup> Higher levels of gun violence in communities stymie educational attainment and well-being: among third graders in Syracuse, New York, higher rates of neighborhood gun violence were associated with higher rates of failure on New York State's standardized tests.<sup>16</sup> Among 15-year-olds from 20 large US cities, community exposure to gun homicide was associated with lower aspirations of high school graduation.<sup>17</sup> Studies have shown mixed results on the association between exposure to gun violence and internalizing and externalizing behaviors; to our knowledge, there have been no studies examining the effects of increased *visibility of guns* on child mental health outcomes.<sup>18</sup> It is plausible that increased exposure to guns themselves will result in poorer child health as well as manifestations of increased internalizing and externalizing behavior and reported stress.

As framed by the United Nations High Commissioner for Human Rights, gun violence is not only a public health crisis but an infringement of children's rights to "health, education ... and the right to participate in the cultural life of the community."<sup>19</sup> Scholars have called out gun availability

and ineffective gun control policies and regulations as key factors in the epidemic of firearm violence observed in the United States compared with other high-income countries.<sup>20</sup> Understanding the effects of firearm-related policies on child health and well-being is critical to addressing gun violence as a public health and human rights crisis.

Given this context, our study aimed to evaluate the impact of permitless concealed carry laws on child and adolescent health. To our knowledge, there have been no studies examining associations between permissive handgun policies and individual-level child health outcomes. We sought to fill this gap using data from the nationwide ECHO Cohort. We hypothesized that permitless concealed carry laws would be associated with lower general health status, higher internalizing (e.g., anxiety, social withdrawal) and externalizing (e.g., aggression, defiance) behavior scores, and higher stress scores among children.

## Methods

### *Study design and participants*

The present study leveraged data from 11,325 children participating in the ECHO Cohort, a longitudinal study of children's health and well-being in the United States.<sup>21</sup> Participants in our sample were enrolled in 55 cohort sites and lived in all 50 states (Figure 2), with data collection conducted from 2003 to 2023. The ECHO Institutional Review Board or corresponding local institutional review board approved the study procedures, and written informed consent for participation was obtained. The research was performed in accordance with the Declaration of Helsinki.

This analysis included ECHO children with (1) at least one report of the general health item from the Patient-Reported Outcomes Measurement Information System (PROMIS®) Global Health Scale, (2) a reported residential address six months prior to the PROMIS® Global Health measurement, (3) data on corresponding state- and year-specific status of permitless concealed carry law (this information was unavailable for Washington, D.C., and Puerto Rico; n = 81 participants excluded), and (4)

non-missing geospatial covariates (n = 25 participants excluded) (Figure 3).<sup>22</sup>

### Concealed carry exposure

Based on exposure to permitless concealed carry six months prior to outcome assessment, participants were categorized as either 1 (permits not required in state of residence) or 0 (permits required).<sup>23</sup> State-level permitless concealed carry information was obtained by researchers with the Center for Gun Violence Solutions for all 50 states from 1990 to 2023.<sup>24</sup>

### Outcomes

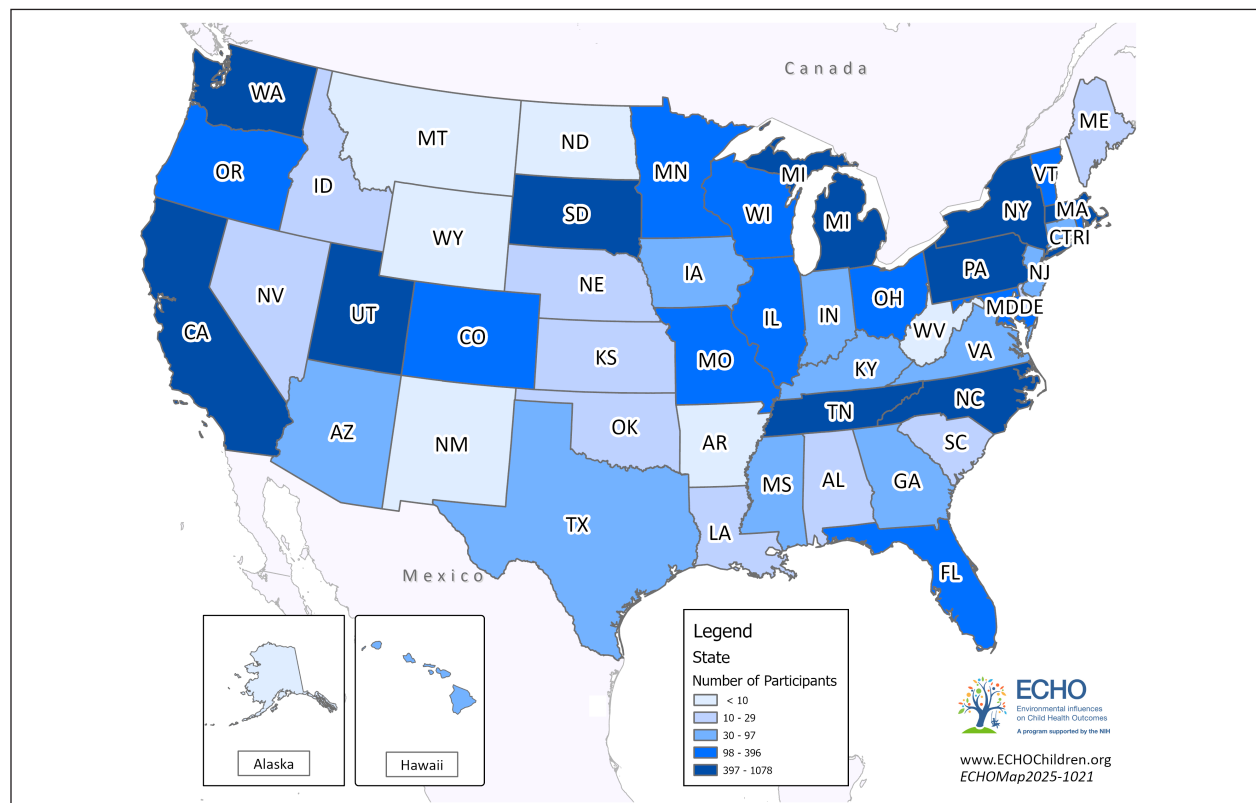
**Child general health.** The primary outcome of interest was child general health: "In general, would you say your (child's) health is: Excellent, Very Good, Good, Fair, or Poor."<sup>25</sup> Responses were dichotomized as (1) excellent/very good and (0) poor/fair/good.<sup>26</sup> Child general health was reported by caregivers for children aged 1–7 years and self-re-

ported by children aged 8–21 years.

**Child behavior.** Child internalizing and externalizing behavior was assessed using caregiver reports on the Child Behavior Checklist for Ages 1.5–5 and the Child Behavior Checklist for Ages 6–18, which are commonly used measures of emotional and behavioral functioning.<sup>27</sup> For this analysis, the internalizing (anxious, depressed, withdrawn, and somatic complaints) and externalizing (rule-breaking and aggressive behavior) broadband scale T scores were used, where higher T scores represent more problems. The two Child Behavior Checklist (CBCL) T scores, which were normed to a mean of 50 and a standard deviation (SD) of 10, were scaled for analysis to represent a 1-SD change for ease of interpretation.

**Child psychological stress.** Children's stress was measured using T scores (mean 50, SD 10) calculated from responses on the pediatric and

FIGURE 2. Geographic distribution of participants by state



parent-proxy versions of the PROMIS® Psychological Stress Experiences (PPSE) form for ages 5–17 years.<sup>28</sup> The PPSE assesses a child's thoughts and feelings of themselves and the world through questions relating to overwhelm, lack of control, and stress, with higher scores representing more stress. For the analysis, the PPSE T score was scaled by 10, the population-normed standard deviation.

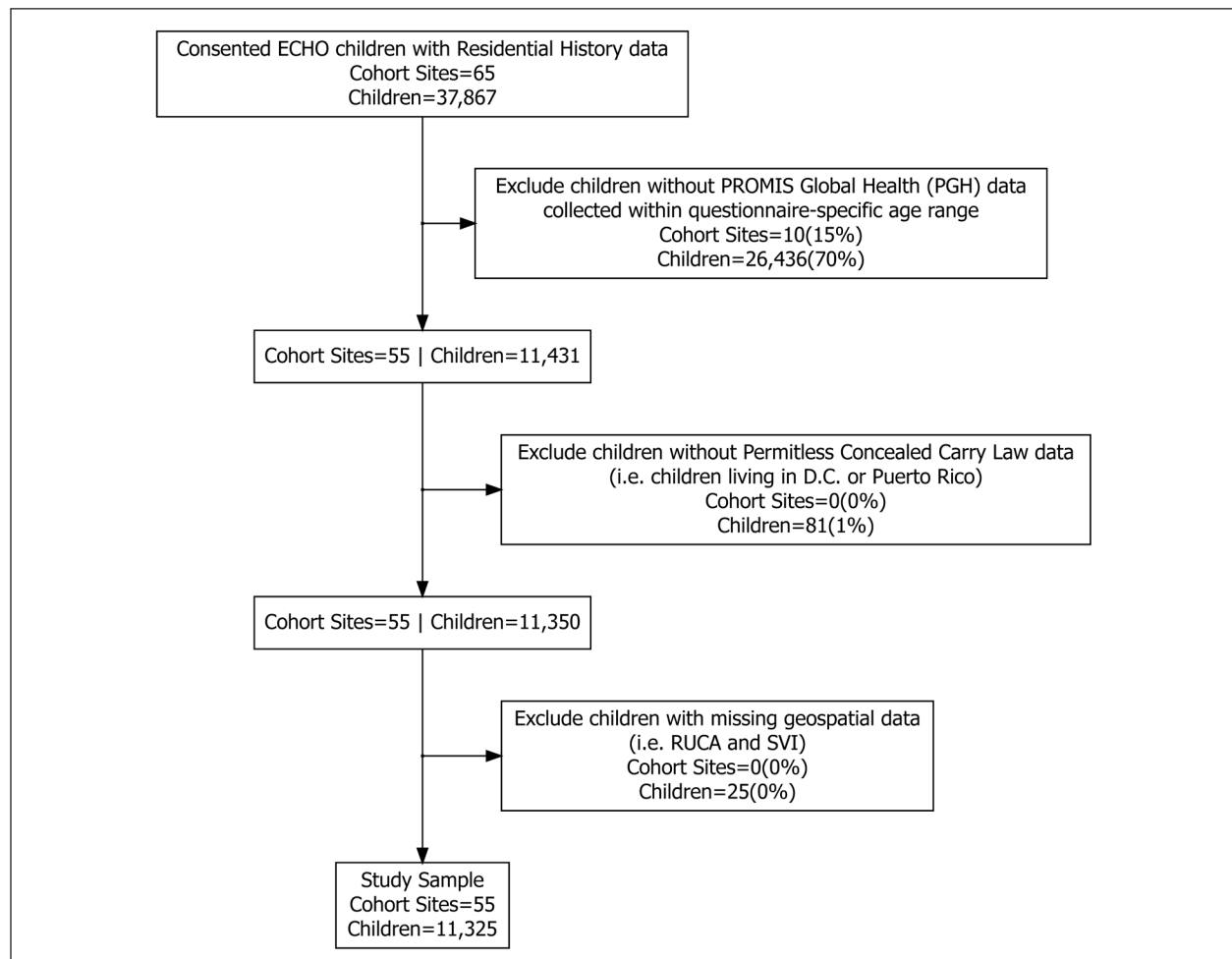
**Timing of outcomes and exposure.** The first recorded observation was selected for analysis if multiple assessments were available. To allow for potential effects of the exposure to occur, six-month lags between the status of the permitless concealed carry law and the date of collection of each outcome

were implemented.

### Covariates

**Individual measures.** We included the following individual-level covariates: child sex (male or female), caregiver-identified child race (American Indian or Alaska Native, Asian, Black, Native Hawaiian or other Pacific Islander, White, other race, or multiple races) and ethnicity (Hispanic or non-Hispanic), age at outcome assessment, maternal education (less than high school degree, high school degree or equivalent, some college but no degree, or bachelor's degree and above), household income (less than \$30,000, \$30,000–\$49,999, \$50,000–\$74,999, \$75,000–\$99,999, \$100,000–\$199,999, or \$200,000

FIGURE 3. Flowchart of participant inclusion



Abbreviations: RUCA = rural-urban commuting area; SVI = Social Vulnerability Index

or more), and cohort site type (sites with participants drawn from the general population, sites that recruited infants in neonatal intensive care units, sites enriched for autism spectrum disorder, or sites enriched for asthma). In addition, COVID-19 pandemic timing indicators were created (outcome collected on or after March 13, 2020, versus before March 13, 2020).

**Geospatial measures.** States that enact permitless concealed carry laws are likely to differ on other factors that may influence child health; therefore, we adjusted for a robust set of area-level characteristics. We included census tract-level measures of rurality using the US Department of Agriculture's rural-urban commuting area codes and socioeconomic status (SES) using the Centers for Disease Control and Prevention/Agency for Toxic Substances and Disease Registry Social Vulnerability Index SES theme (derived from tract-level estimates of poverty, unemployment, burden of housing cost, education, and insurance).<sup>29</sup> We included state-level household firearm ownership estimated by RAND; state-level expansion of the Earned Income Tax Credit law (yes or no) as a proxy for state-level policies supporting families; and American Community Survey five-year estimates of median household income, population density, and total population 25 years or older with a bachelor's degree and above.<sup>30</sup> All geospatial measures were linked to the tract or state of the child at the time of the exposure.

### *Statistical analysis*

Missing data on household income (8.3%), maternal education (2.4%), child race (1.4%), and ethnicity (<1%) were imputed using multiple imputation by chained equations from the "mice" R package.<sup>31</sup> Results were pooled after 25 imputations, with a maximum of 10 iterations. Imputation models included our variables of interest and used family as a cluster variable to impute missing income and education, which were the same within a maternal family.

To explore the association of permitless concealed carry laws and child general health status, we employed logistic regression. Similarly, to ex-

plore the association of permitless concealed carry laws and child behavior and stress, we employed linear regressions. Covariates were selected based on prior literature, and all models were adjusted for corresponding state and year of permitless concealed carry law exposure status, COVID-19 pandemic indicator, child sex, child race and ethnicity, maternal education, household income, cohort site type, rural/urban status and socioeconomic vulnerability (Social Vulnerability Index SES), state-level Earned Income Tax Credit status, estimated firearm ownership, state median household income, population density, and population with bachelor's degree or higher.<sup>32</sup> To explore potential variation in associations across cohort sites, we performed leave-one-out analyses. All analyses were run using R version 4.4.0, and an alpha-level of 0.05 was used.

### Results

Our study population was 50.6% male and represented a diverse sample of children across race (1.5% American Indian or Alaska Native, 1.7% Asian, 17.9% Black, <1.0% Native Hawaiian or other Pacific Islander, 66.2% White, 1.7% other races, and 9.4% multiple races) and ethnicity (12.7% Hispanic) (Table 1). The majority of children had college-educated mothers (53.9% with a bachelor's degree and above). Slightly less than a third (29.0%) reported household income of less than \$50,000, whereas over a third (39.0%) reported household income of \$100,000 or more. The mean age at general health assessment was 9.7 years (SD = 4.3 years), with age ranging from 1 to 21 years, and 22.9% of the sample reported low general health; the majority (71.9%) of the sample had data collected during and after the COVID-19 pandemic. One-fifth (20.9%) of the sample lived in states that allowed permitless concealed carry of a handgun (mean year 2020, years ranging from 2005 to 2023). Most participants had CBCL data (58.1%,  $n = 6585$ ), with a mean internalizing T score of 46.7 (SD = 10.7) and externalizing T score of 46.3 (SD = 10.4). Slightly under three-quarters of the sample (72.7%,  $n = 8238$ ) had PPSE data, with a mean PPSE T score of 52.1 (SD = 9.4). Three-quarters

of the sample lived in metropolitan areas (84.6%) and had low vulnerability, with a mean Social Vulnerability Index SES score of 0.40 (SD = 0.30). Half of the sample (50.0%) lived in states with Earned Income Tax Credit laws. The average state-level gun ownership rate per household was 0.30 firearms (SD = 0.10). Overall, the states in which participants lived had a median household income of US\$69,671 (SD = US\$12,157) and a mean population density of 266.3 people per square mile (SD = 286.4). Additional characteristics of the subset of the study population with CBCL or PPSE outcome data are presented in Supplementary Table 1 (available from the authors).

Permitless concealed carry laws were significantly associated with caregiver and self-reported child general health and psychological stress after adjusting for individual- and area-level covariates. Children exposed to permitless concealed carry laws had 25% lower odds of excellent/very good child health (adjusted odds ratio = 0.75, 95% confidence interval (CI): [0.60, 0.95]) (Table 2). Additionally, children exposed to permitless concealed carry laws had psychological stress scores 0.21 standard deviations higher ( $\beta = 0.21$ , 95% CI: [0.10, 0.31]). Permitless concealed carry laws were not statistically significantly associated with internalizing ( $\beta = 0.07$ , 95% CI: [-0.10, 0.23]) or externalizing ( $\beta = 0.05$ , 95% CI: [-0.10, 0.21]) scores. Analyses leaving out individual cohorts one at a time indicated that the results were robust to the influence of individual cohort sites, as CIs overlapped and the associations found were consistent in direction and magnitude (Supplementary Figures 1 and 2, available from the authors).

## Discussion

Independent of area- and individual-level demographic and social characteristics, permitless concealed carry laws are associated with lower child general health status and higher levels of stress in children in a national cohort of US children. To our knowledge, this is the first large-scale examination of associations between state-level concealed carry laws and individual-level child health outcomes. We found that children living in states with per-

mitless concealed carry laws were 25% less likely to report excellent or very good general health status. This finding was comparable to the effect size found in a similar study that explored the association of community-level gun violence with the same outcome, which found that individuals living in census tracts with high gun violence were 20% less likely to endorse excellent or very good general health status.<sup>33</sup> Our study also found that children living in states with permitless concealed carry laws scored 2.1 points higher on psychological stress than children living in states without these laws, which is a modest yet meaningful difference for a widespread community exposure.<sup>34</sup>

These findings highlight that *all* US children are at risk of being negatively affected by exposure to guns, and not just at risk of firearm-associated violence. In 2017, it was estimated that US civilians owned a total of 393.3 million firearms.<sup>35</sup> During the COVID-19 pandemic, an additional 7.5 million US adults became first-time gun owners, which in turn exposed an additional 5 million children to guns.<sup>36</sup> The US Bureau of Alcohol, Tobacco, Firearms and Explosives' National Firearms Act Division processed 1.9 million firearm applications in 2019 and 3.6 million in 2023.<sup>37</sup> Additionally, in 2023, it was estimated that 32% of US adults owned a gun (up from 22% in 2015) and that 42% lived in a house with a gun, and in 2019, it was estimated that 6 million US adults carried loaded handguns in public daily.<sup>38</sup> Gun ownership in the United States is continuing to rise, and combined with the increasing visibility of guns through permitless carry laws, this increases children's gun exposure and poses a risk that could be mitigated through policy intervention.

The direct risks of these trends are clear. Firearms are the leading cause of death among children in the United States.<sup>39</sup> Recent US reports show that 79% of all homicides are by firearms and that an average of seven children aged 1–17 die each day by a firearm.<sup>40</sup> Notably, the suicide rate among adolescents and young adults (10–24 years) increased from 2007 to 2021, and homicide rates increased from 2014 to 2021.<sup>41</sup> In addition, state-level permitless concealed carry laws are associated with higher rates of homicide, suicide, and gun assaults,

TABLE 1. Participant and community demographic information by binary categorization of child general health outcome

Variables	Poor/Fair/Good General Health Status n = 2,589 (22.9%)	Excellent/Very Good General Health Status n = 8,736 (77.1%)	Overall N = 11,325
<i>Child characteristics</i>			
<b>Child sex</b>			
Male	1,264 (48.8%)	4,466 (51.1%)	5,730 (50.6%)
Female	1,325 (51.2%)	4,270 (48.9%)	5,595 (49.4%)
<b>Child race</b>			
American Indian or Alaska Native	32 (1.2%)	138 (1.6%)	170 (1.5%)
Asian	47 (1.8%)	146 (1.7%)	193 (1.7%)
Black	706 (27.3%)	1,324 (15.2%)	2,030 (17.9%)
Native Hawaiian or other Pacific Islander	5 (<1.0%)	14 (<1.0%)	19 (<1.0%)
White	1,424 (55.0%)	6,068 (69.5%)	7,492 (66.2%)
Other race	54 (2.1%)	140 (1.6%)	194 (1.7%)
Multiple races	261 (10.1%)	804 (9.2%)	1,065 (9.4%)
Missing	60 (2.3%)	102 (1.2%)	162 (1.4%)
<b>Child ethnicity</b>			
Non-Hispanic	2,173 (83.9%)	7,708 (88.2%)	9,881 (87.2%)
Hispanic	414 (16.0%)	1,019 (11.7%)	1,433 (12.7%)
Missing	<5 (<1.0%)	9 (<1.0%)	11 (<1.0%)
<b>Cohort site type</b>			
General population	1,921 (74.2%)	7,112 (81.4%)	9,033 (79.8%)
Neonatal intensive care units	297 (11.5%)	850 (9.7%)	1,147 (10.1%)
Autism spectrum disorder-enriched	127 (4.9%)	315 (3.6%)	442 (3.9%)
Asthma-enriched	244 (9.4%)	459 (5.3%)	703 (6.2%)
<i>Maternal characteristics</i>			
<b>Maternal highest education</b>			
Less than high school degree	176 (6.8%)	352 (4.0%)	528 (4.7%)
High school degree, General Educational Development, or equivalent	403 (15.6%)	990 (11.3%)	1,393 (12.3%)
Some college but no degree	788 (30.4%)	2,236 (25.6%)	3,024 (26.7%)
Bachelor's degree and above	1,158 (44.7%)	4,950 (56.7%)	6,108 (53.9%)
Missing	64 (2.5%)	208 (2.4%)	272 (2.4%)
<b>Household income</b>			
Less than US\$30,000	630 (24.3%)	1,349 (15.4%)	1,979 (17.5%)
US\$30,000–US \$49,999	394 (15.2%)	910 (10.4%)	1,304 (11.5%)
US\$50,000–US\$74,999	379 (14.6%)	1,001 (11.5%)	1,380 (12.2%)
US\$75,000–US\$99,999	246 (9.5%)	1,057 (12.1%)	1,303 (11.5%)
US\$100,000– US\$199,999	547 (21.1%)	2,459 (28.1%)	3,006 (26.5%)
US\$200,000 or more	216 (8.3%)	1,202 (13.8%)	1,418 (12.5%)
Missing	177 (6.8%)	758 (8.7%)	935 (8.3%)

Abbreviations: IQR = interquartile range; SD = standard deviation

TABLE 1. *Continued*

Variables	Poor/Fair/Good General Health Status n = 2,589 (22.9%)	Excellent/Very Good General Health Status n = 8,736 (77.1%)	Overall N = 11,325
<i>Community characteristics</i>			
<b>Rural-urban commuting area</b>			
1 Metropolitan core (most urban)	2,009 (77.6%)	6,538 (74.8%)	8,547 (75.5%)
2 Metropolitan high commuting	223 (8.6%)	726 (8.3%)	949 (8.4%)
3 Metropolitan low commuting	19 (<1.0%)	70 (<1.0%)	89 (<1.0%)
4 Micropolitan core	122 (4.7%)	376 (4.3%)	498 (4.4%)
5 Micropolitan high commuting	62 (2.4%)	348 (4%)	410 (3.6%)
6 Micropolitan low commuting	15 (<1.0%)	44 (<1.0%)	59 (<1.0%)
7 Small-town core	62 (2.4%)	184 (2.1%)	246 (2.2%)
8 Small-town high commuting	12 (<1.0%)	41 (<1.0%)	53 (<1.0%)
9 Small-town low commuting	7 (<1.0%)	15 (<1.0%)	22 (<1.0%)
10 Rural area (most rural)	58 (2.2%)	394 (4.5%)	452 (4.0%)
<b>Social Vulnerability Index socioeconomic status</b>			
Mean (SD)	0.5 (0.3)	0.4 (0.3)	0.4 (0.3)
Missing	0 (0%)	0 (0%)	0 (0%)
<b>Household gun ownership</b>			
Mean (SD)	0.3 (0.1)	0.4 (0.1)	0.3 (0.1)
Missing	0 (0.0%)	0 (0.0%)	0 (0.0%)
<b>Earned Income Tax Credit law status</b>			
No	1,266 (48.9%)	4,394 (50.3%)	5,660 (50%)
Yes	1,323 (51.1%)	4,342 (49.7%)	5,665 (50%)
<b>Median household income in US\$</b>			
Mean (SD)	70,141 (12,612)	69,532 (12,016)	69,671 (12,157)
Missing	0 (0.0%)	0 (0.0%)	0 (0.0%)
<b>Population density (people per square mile)</b>			
Mean (SD)	277.9 (276.4)	262.8 (289.3)	266.3 (286.4)
Missing	0 (0.0%)	0 (0.0%)	0 (0.0%)
<b>Population 25+ years with bachelor's degree or higher</b>			
Mean (SD)	2,389,020 (2,182,359)	2,013,029 (2,111,933)	2,098,984 (2,133,991)
Missing	0 (0.0%)	0 (0.0%)	0 (0.0%)
<i>Law exposure</i>			
<b>Permitless concealed carry law status</b>			
No	2,160 (83.4%)	6,796 (77.8%)	8,956 (79.1%)
Yes	429 (16.6%)	1,940 (22.2%)	2,369 (20.9%)
<b>Year of permitless concealed carry law status</b>			
Mean (SD)	2020.1 (2.2)	2019.4 (3.6)	2019.6 (3.3)
Median [min, max]	2020 [2005, 2023]	2020 [2005, 2023]	2020 [2005, 2023]
Missing	0 (0.0%)	0 (0.0%)	0 (0.0%)

Abbreviations: IQR = interquartile range; SD = standard deviation

TABLE 1. *Continued*

Variables	Poor/Fair/Good General Health Status n = 2,589 (22.9%)	Excellent/Very Good General Health Status n = 8,736 (77.1%)	Overall N = 11,325
<i>Outcomes</i>			
<b>General health status score</b>			
Mean (SD)	2.8 (0.5)	4.5 (0.5)	4.1 (0.9)
Median (IQR)	3.0 (3.0, 3.0)	5.0 (4.0, 5.0)	4.0 (4.0, 5.0)
Missing	0 (0.0%)	0 (0.0%)	0 (0.0%)
<b>Child age at general health status</b>			
Mean (SD)	11.8 (4.2)	9.1 (4.2)	9.7 (4.3)
Median (IQR)	11.3 (8.5, 15.5)	7.8 (5.9, 11.4)	8.7 (6.1, 12.1)
Missing	0 (0.0%)	0 (0.0%)	0 (0.0%)
<b>General health status collected during COVID-19 pandemic</b>			
No	665 (25.7%)	2,516 (28.8%)	3,181 (28.1%)
Yes	1,924 (74.3%)	6,220 (71.2%)	8,144 (71.9%)
<b>Internalizing behavior T score</b>			
Mean (SD)	48.9 (11.2)	45.8 (10.3)	46.7 (10.7)
Median (IQR)	48.0 (41.0, 57.0)	45.0 (37.0, 53.0)	45.0 (39.0, 54.0)
Missing	836 (32.3%)	3,904 (44.7%)	4,740 (41.9%)
<b>Externalizing behavior T score</b>			
Mean (SD)	48.0 (10.9)	45.7 (10.2)	46.3 (10.4)
Median (IQR)	47.0 (40.0, 55.0)	44.0 (39.0, 52.0)	46.0 (39.0, 54.0)
Missing	836 (32.3%)	3,904 (44.7%)	4,740 (41.9%)
<b>Child age at internalizing/externalizing behavior T scores</b>			
Mean (SD)	7.9 (5.7)	6.5 (4.6)	6.9 (5.0)
Median (IQR)	6.1 (3.0, 13.5)	5.2 (2.5, 9.0)	5.4 (2.6, 9.2)
Missing	836 (32.3%)	3,904 (44.7%)	4,740 (41.9%)
<b>Internalizing/externalizing behavior collected during COVID-19 pandemic</b>			
No	1,072 (41.4%)	2,730 (31.2%)	3,802 (33.6%)
Yes	681 (26.3%)	2,102 (24.1%)	2,783 (24.6%)
Missing	836 (32.3%)	3,904 (44.7%)	4,740 (41.9%)
<b>Psychological stress T score</b>			
Mean (SD)	55.1 (9.9)	51.2 (9.1)	52.1 (9.4)
Median (IQR)	56.1 (47.6, 62.0)	50.7 (39.6, 58.1)	52.5 (45.7, 58.5)
Missing	694 (26.8%)	2,393 (27.4%)	3,087 (27.3%)

Abbreviations: IQR = interquartile range; SD = standard deviation

TABLE 1. *Continued*

Variables	Poor/Fair/Good General Health Status n = 2,589 (22.9%)	Excellent/Very Good General Health Status n = 8,736 (77.1%)	Overall N = 11,325
<i>Outcomes</i>			
<b>Child age at psychological stress T score</b>			
Mean (SD)	11.1 (3.3)	9.6 (3.7)	10.0 (3.7)
Median (IQR)	10.8 (8.6, 14.1)	8.8 (6.6, 11.7)	9.1 (7.0, 12.0)
Missing	694 (26.8%)	2,393 (27.4%)	3,087 (27.3%)
<b>Psychological stress measured during COVID-19 pandemic</b>			
No	646 (25%)	2,108 (24.1%)	2,754 (24.3%)
Yes	1,249 (48.2%)	4,235 (48.5%)	5,484 (48.4%)
Missing	694 (26.8%)	2,393 (27.4%)	3,087 (27.3%)

Abbreviations: IQR = interquartile range; SD = standard deviation

and in general, gun death rates tend to be higher in states with weaker gun laws.<sup>42</sup> Moreover, the nation is trending toward more permissive gun laws, illustrated by an additional six states enacting permitless concealed carry laws since 2023 and 15 states since 2020.<sup>43</sup>

The indirect risks of firearms for US children are also substantial. Community gun violence has been linked to an array of mental and physical health outcomes, including increased anxiety, depression, posttraumatic stress, increased substance use, poorer test scores, and a worse outlook on the future.<sup>44</sup> Though gun violence varies geographically and is concentrated in certain areas, gun exposure is widespread across the nation. Our findings suggest that this exposure comes with risk to US children: living in a state with permissive gun laws was associated with poorer overall health and increased stress.

Promoting the health and well-being of children is fundamentally intertwined with protecting their rights; gun violence remains a public health crisis that not only violates the rights of victims but also has spillover effects on society as a whole.<sup>45</sup> While acknowledging the tension between protecting individual liberties and promoting societal safety, experts generally agree that restrictive gun laws are essential both to protect citizens from direct harm and to promote their rights to participate in all aspects of life.<sup>46</sup> The United Nations Conven-

tion on the Rights of the Child—adopted in 1989, ratified by nearly every nation, and signed by the United States—establishes international standards for the protection of children. The treaty declares that states are responsible for ensuring children's rights to safety, development, and well-being.<sup>47</sup> Specifically, article 19 requires states to “take all appropriate legislative, administrative, social, and educational measures to protect children from physical or mental violence, injury, abuse, neglect, maltreatment, and exploitation.”<sup>48</sup> To meet this standard, governments are obligated to enact comprehensive laws that protect children from threats, which includes protection from gun violence. Previous evidence has linked permissive concealed carry laws to homicide, suicide, gun assaults, and gun deaths; our findings further suggest that permitless concealed carry laws represent one type of modifiable legislation that worsens child health and well-being.<sup>49</sup> In accordance with the Convention on the Rights of the Child, governments have a human rights duty to enact and enforce reasonable firearm regulations to protect children from harm. Permissive gun laws should therefore be viewed not only as a public health concern but also as a children's health and children's rights issue.

### Limitations

This study has several limitations that should in-

form future research. First, although we had data from every state from the past two decades, we implemented a cross-sectional analysis since we did not have sufficient data to examine individuals' health scores before and after changes in state laws. As a result, quasi-experimental and longitudinal methods that leverage specific thresholds to evaluate individuals on either side of the threshold were not feasible. We believe that such studies should be performed in the future. Second, we combined child self-reports and caregiver reports of child general health and stress to maximize the sample size. Parental and child reports of psychological constructs are not highly correlated, and combining the two may introduce measurement error. However, several published studies have combined child self-reports and caregiver reports.<sup>50</sup> Third, caregiver reports of preschool behaviors on the CBCL in diverse samples can be subject to measurement bias, and 31.2% of our sample had this measure, though the associations found were null.<sup>51</sup> Thus, due to our reliance on caregiver and self-reported measurement and measurement bias, more in-depth assessments for general health, behavioral health, and stress are needed. Last, we found that exposure to permitless concealed carry laws was associated with general health and stress but not behavior. In our sample, only 9.1% of children with

CBCL data were exposed to such laws, compared to 20.9% and 18.9% with the general health and stress outcomes, respectively. It is possible that we were unable to detect an association with behavior due to the sample size. However, there may also be differences in how behavior manifests in children and how children feel. Therefore, future research that explores biological mechanisms is warranted.

## Strengths

Despite these limitations, our study has many strengths, including the utilization of prospectively collected, individual-level caregiver reports and self-reports of child health in a large, geographically diverse sample representing all 50 US states. To account for unobserved differences between states that may lead to spurious associations, we included state-level effects in our models and adjusted for a robust set of state-level covariates, consistent with other studies of state-level gun policies. Due to the rich child outcome data collected in the ECHO Cohort, we were able to examine a range of health outcomes, including an overall measure of physical and mental health, behavioral outcomes, and psychological stress. Moreover, our study is one of the first to evaluate state-level gun policies on individual health outcomes, broadening our understanding

TABLE 2. Multivariable associations of permitless concealed carry laws with child general health, internalizing behavior, externalizing behavior, and psychological stress

Outcome	Sample size	Permitless estimate	
		Odds ratio* [95% CI]	p-value
General health status (excellent/very good versus poor/fair/good)	11,325	0.75 [0.60, 0.95]	0.017
		Beta coefficient† [95% CI]	p-value
Internalizing behaviors (scaled by 10)	6,586	0.07 [-0.10, 0.23]	0.429
Externalizing behaviors (scaled by 10)	6,586	0.05 [-0.10, 0.21]	0.513
Psychological stress (scaled by 10)	8,238	0.21 [0.10, 0.31]	<0.001

Abbreviations: CI = confidence interval; SD = standard deviation

\* Estimate is an adjusted odds ratio of children exposed to permitless concealed carry laws from a logistic regression model reflecting odds being in excellent/very good health.

† Estimates are beta coefficients of children exposed to permitless concealed carry laws from linear regression models reflecting an SD change in the corresponding child health outcome (internalizing behaviors, externalizing behaviors, or psychological stress).

Note: All models are adjusted for state and year of permitless concealed carry law exposure status, outcome-specific COVID-19 indicator, child sex, child race, child ethnicity, maternal education, household income, cohort type, tract-level rural/urban status, tract-level socioeconomic status, state-level Earned Income Tax Credit status, state-level estimated firearm ownership, state-level median household income, state-level population density, and state-level population with a bachelor's degree or higher.

of how children are negatively impacted by gun regulation.

## Conclusion

Guns and gun violence are pervasive in the United States and represent a significant threat to public health. Using data from a national study of children's health and well-being, we found that state-level permitless concealed carry laws were associated with worse general health and increased stress among children living in states with such laws. Together with findings from other studies, our results suggest that enacting more restrictive concealed carry laws is one pathway to securing children's rights to "health, education ... and the right to participate in the cultural life of the community."<sup>52</sup> Following the international standard established by the Convention on the Rights of the Child, the United States has an obligation to utilize legislative avenues to promote child health, safety, and well-being.

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## Data availability statement

Select de-identified data from the ECHO Program are available through the NICHD Data and Specimen Hub (<https://dash.nichd.nih.gov/>). Information on study data not available on DASH, such as some Indigenous datasets, can be found on the ECHO study DASH web page (<https://dash.nichd.nih.gov/explore/study?type=study&search=echo>).

## Ethics approval

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## References

1. World Population Review, "Gun Ownership by Country 2025," <https://worldpopulationreview.com/country-rankings/gun-ownership-by-country>; National Center for Health Statistics, "National Vital Statistics System, Mortality 2018–2023," Centers for Disease Control and Prevention, <http://wonder.cdc.gov/ucd-icd10-expanded.html>; S. Conroy, "Firearms and Violent Crime in Canada, 2023," Statistics Canada, <https://www150.statcan.gc.ca/n1/daily-quotidien/250225/dq250225a-eng.htm>.
2. M. Miller, W. Zhang, and D. Azrael, "Firearm Purchasing During the COVID-19 Pandemic: Results from the 2021 National Firearms Survey," *Annals of Internal Medicine* 175/2 (2022).
3. S. Villarreal, R. Kim, E. Wagner, et al., *Gun Violence in the United States 2022: Examining the Burden Among Children and Teens* (Center for Gun Violence Solutions, Johns Hopkins Bloomberg School of Public Health, 2024); R. Kim, E. Wagner, P. Nestadt, et al., *Gun Violence in the United States 2023: Examining the Gun Suicide Epidemic* (Center for Gun Violence Solutions and Center for Suicide Prevention, Johns Hopkins Bloomberg School of Public Health, 2025).
4. D. C. Semenza, R. Stansfield, I. A. Silver, and B. Savage, "Reciprocal Neighborhood Dynamics in Gun Violence Exposure, Community Health, and Concentrated Disadvantage in One Hundred US Cities," *Journal of Urban Health* 100/6 (2023); K. J. Mitchell, V. Banyard, B. G. Taylor, et al., "Prevalence of Exposure to Someone Else's Firearm Violence, Threats, and Risky Behavior Among a National Sample of Young People in the United States," *Frontiers in Public Health* 13 (2025).
5. C. R. Harper, J. Li, K. Sheats, M. F. Hertz, et al., "Witnessing Community Violence, Gun Carrying, and Associations with Substance Use and Suicide Risk Among High School Students—Youth Risk Behavior Survey, United States, 2021," *Morbidity and Mortality Weekly Report* 72/1 (2023); H. A. Turner, K. J. Mitchell, L. M. Jones, et al., "Gun Violence Exposure and Posttraumatic Symptoms Among Children and Youth," *Journal of Traumatic Stress* 32/6 (2019); A. Vasan, H. K. Mitchell, J. A. Fein, et al., "Association of Neighborhood Gun Violence with Mental Health-Related Pediatric Emergency Department Utilization," *JAMA Pediatrics* 175/12 (2021).
6. Harper et al. (see note 5).
7. N. Somayaji, E. A. Knapp, M. L. Churchill, et al., "Associations Between Neighborhood-Level Gun Violence and Child General Health Status: An ECHO Cohort Analysis,"

*Injury* 56/11 (2025).

8. Center for Gun Violence Solutions, Johns Hopkins Bloomberg School of Public Health, "Questions and Answers: Public Carry of Firearms, Permitless Carry and Stand Your Ground Laws" (March 18, 2025), <https://publichealth.jhu.edu/center-for-gun-violence-solutions/2025/questions-and-answers-public-carry-of-firearms-permitless-carry-and-stand-your-ground-laws>.

9. M. L. Doucette, C. Crifasi, A. D. McCourt, et al., "Deregulation of Public Civilian Gun Carrying and Violent Crimes: A Longitudinal Analysis 1981–2019," *Criminology and Public Policy* 23/4 (2024).

10. Ibid.

11. E. W. Lundstrom, J. K. Pence, and G. S. Smith, "Impact of a Permitless Concealed Firearm Carry Law in West Virginia, 1999–2015 and 2016–2020," *American Journal of Public Health* 113/11 (2023).

12. P. Sharkey and M. Kang, "The Era of Progress on Gun Mortality: State Gun Regulations and Gun Deaths from 1991 to 2016," *Epidemiology* 34/6 (2023).

13. Everytown Research & Policy, "Permitless Carry: Carrying a Concealed Gun in Public with No Permit and No Training," Everytown for Gun Safety Support Fund (February 20, 2020), <https://everytownresearch.org/report/permitless-carry-carrying-a-concealed-gun-in-public-with-no-permit-and-no-training/>.

14. B. G. Taylor, K. J. Mitchell, H. A. Turner, et al., "Prevalence of Gun Carrying and Gun Violence Victimization and Perpetration Among a Nationally Representative Sample of U.S. Youth and Young Adults," *AJPM Focus* 4/1 (2025).

15. Turner et al. (see note 5); Vasan et al. (see note 5).

16. Turner et al. (see note 5); D. Bergen-Cico, S. D. Lane, R. H. Keefe, et al., "Community Gun Violence as a Social Determinant of Elementary School Achievement," *Social Work in Public Health* 33/7–8 (2018).

17. A. Bruns, A. J. Aubel, X. Zhang, et al., "Community Exposure to Gun Homicide and Adolescents' Educational Aspirations," *Journal of Adolescence* 96/5 (2024).

18. C. Leibbrand, H. Hill, A. Rowhani-Rahbar, and F. Rivara, "Invisible Wounds: Community Exposure to Gun Homicides and Adolescents' Mental Health and Behavioral Outcomes," *SSM – Population Health* 12 (2020); A. M. Gard, J. Brooks-Gunn, S. S. McLanahan, et al., "Deadly Gun Violence, Neighborhood Collective Efficacy, and Adolescent Neurobehavioral Outcomes," *PNAS Nexus* 1/3 (2022); X. Zhang, A. J. Aubel, A. Bruns, et al., "Heterogeneous Effects of Environmental Exposure to Gun Violence on Adolescent Problem Behavior," *Journal of Interpersonal Violence* 41/9–10 (2025).

19. Human Rights Council, Human Rights and the Regulation of Civilian Acquisition, Possession and Use of Firearms, UN Doc. A/HRC/32/21 (2016).

20. "Gun Violence in the USA: Children's Right to Health," *Lancet* 399/10341 (2022).

21. E. A. Knapp, A. M. Kress, C. B. Parker, et al., "The Environmental Influences on Child Health Outcomes (ECHO)-Wide Cohort," *American Journal of Epidemiology* 192/8 (2023).

22. R. D. Hays, J. B. Bjorner, D. A. Revicki, et al., "Development of Physical and Mental Health Summary Scores from the Patient-Reported Outcomes Measurement Information System (PROMIS) Global Items," *Quality of Life Research* 18/7 (2009); C. B. Forrest, C. A. Tucker, U. Ravens-Sieberer, et al., "Concurrent Validity of the PROMIS Pediatric Global Health Measure," *Quality of Life Research* 25/3 (2016); C. B. Forrest, K. B. Bevans, R. Pratiwadi, et al., "Development of the PROMIS Pediatric Global Health (PGH-7) Measure," *Quality of Life Research* 23/4 (2014).

23. Doucette et al. (see note 9); Center for Gun Violence Solutions, Johns Hopkins Bloomberg School of Public Health, "Regulation of Public Carry," <https://publichealth.jhu.edu/sites/default/files/2025-04/regulation-of-public-carry-factsheet.pdf>.

24. Doucette et al. (see note 9).

25. Hays et al. (2009, see note 22); Forrest et al. (2016, see note 22); Forrest et al. (2014, see note 22).

26. R. D. Hays, K. L. Spritzer, W. W. Thompson, and D. Cella, "U.S. General Population Estimate for 'Excellent' to 'Poor' Self-Rated Health Item," *Journal of General Internal Medicine* 30/10 (2015).

27. T. M. Achenbach and L.A. Rescorla, *Manual for the ASEBA School-Age Forms and Profiles: Child Behavior Checklist for Ages 6–18, Teacher's Report Form, Youth Self-Report: An Integrated System of Multi-Informant Assessment* (Achenbach System of Empirically Based Assessment, 2001); T. M. Achenbach and L.A. Rescorla, *Manual for the ASEBA Preschool Forms and Profiles: An Integrated System of Multi-Informant Assessment; Child Behavior Checklist for Ages 1 1/2–5; Language Development Survey; Caregiver-Teacher Report Form* (Achenbach System of Empirically Based Assessment, 2000).

28. K. B. Bevans, W. Gardner, K. Pajer, et al., "Qualitative Development of the PROMIS Pediatric Stress Response Item Banks," *Journal of Pediatric Psychology* 38/2 (2013); K. B. Bevans, W. Gardner, K. A. Pajer, et al., "Psychometric Evaluation of the PROMIS Pediatric Psychological and Physical Stress Experiences Measures," *Journal of Pediatric Psychology* 43/6 (2018).

29. US Department of Agriculture Economic Research Service, "2020 Rural-Urban Commuting Area Codes," <https://www.ers.usda.gov/data-products/rural-urban-commuting-area-codes>; US Centers for Disease Control and Prevention, "CDC/ATSDR Social Vulnerability Index (CDC/ATSDR SVI)," <https://www.ers.usda.gov/data-products/rural-urban-commuting-area-codes/>.

30. T. L. Schell, S. Peterson, B. G. Vegetabile, et al., "State-Level Estimates of Household Firearm Ownership," RAND Corporation (April 22, 2020), <https://www.rand.org/>

- pubs/tools/TL354.html; S. Markowitz, K. A. Komro, M. D. Livingston, et al., "Effects of State-Level Earned Income Tax Credit Laws in the U.S. on Maternal Health Behaviors and Infant Health Outcomes," *Social Science and Medicine* 194 (2017); Institute on Taxation and Economic Policy, "When Did Your State Enact an Earned Income Tax Credit (EITC)?" (April 2, 2025), <https://itep.org/when-did-your-state-enact-an-earned-income-tax-credit-eitc/>; US Census Bureau, "American Community Survey (ACS)," <https://www.census.gov/programs-surveys/acs/news/data-releases.html>.
31. S. van Buuren and K. Groothuis-Oudshoorn, "Mice: Multivariate Imputation by Chained Equations in R," *Journal of Statistical Software* 45 (2011).
32. Somayaji et al. (see note 7); Sharkey and Kang (see note 12).
33. Somayaji et al. (see note 7).
34. C. B. Terwee, J. D. Peipert, R. Chapman, et al., "Minimal Important Change (MIC): A Conceptual Clarification and Systematic Review of MIC Estimates of PROMIS Measures," *Quality of Life Research* 30/10 (2021).
35. World Population Review, "Gun Ownership by Country 2026," <https://worldpopulationreview.com/country-rankings/gun-ownership-by-country>.
36. Miller et al. (see note 2).
37. Bureau of Alcohol, Tobacco, Firearms and Explosives, "Data and Statistics," <https://www.atf.gov/resource-center/data-statistics>.
38. PEW Research Center, "For Most U.S. Gun Owners, Protection Is the Main Reason They Own a Gun" (August 16, 2023), <https://www.pewresearch.org/politics/2023/08/16/for-most-u-s-gun-owners-protection-is-the-main-reason-they-own-a-gun/>; A. Rowhani-Rahbar, A. Gallagher, D. Azrael, and M. Miller. "Trend in Loaded Handgun Carrying Among Adult Handgun Owners in the United States, 2015-2019," *American Journal of Public Health* 112/12 (2022); D. Azrael, L. Hepburn, D. Hemenway, and M. Miller, "The Stock and Flow of U.S. Firearms: Results from the 2015 National Firearms Survey," *RSF: The Russell Sage Foundation Journal of the Social Sciences* 3/5 (2017).
39. Villareal et al. (see note 3); Kim et al. (see note 3).
40. Villareal et al. (see note 3); Kim et al. (see note 3).
41. S. C. Curtin and M. F. Garnett, "Suicide and Homicide Death Rates Among Youth and Young Adults Aged 10-24: United States, 2001-2021," National Center for Health Statistics Data Brief 471 (2023).
42. Kim et al. (see note 3).
43. Doucette et al. (see note 9); Center for Gun Violence Solutions, "Regulation of Public Carry" (see note 23).
44. Vasan et al. (see note 5); Turner et al. (see note 5); Harper et al. (see note 5); Bergen-Cico et al. (see note 16); Bruns et al. (see note 17).
45. Human Rights Council (see note 19); E. Barnert, J. Wright, C. Choi, et al., "Reimagining Children's Rights in the US," *JAMA Pediatrics* 176/12 (2022); M. Yost, K. Fernandez, E. Nelson, et al., "Gun Violence Against Children in the U.S.," *Human Rights Quarterly* 46/4 (2024).
46. R. B. Siegel and J. Blocher, "Why Regulate Guns," *Journal of Law, Medicine and Ethics* 48/4 (2021).
47. Convention on the Rights of the Child, G.A. Res. 44/25 (1989).
48. Ibid.
49. Kim et al. (see note 3).
50. Somayaji et al. (see note 7).
51. S. Zheng, M. Mansolf, M. McGrath, et al., "Measurement Bias in Caregiver-Report of Early Childhood Behavior Problems Across Demographic Factors in an ECHO-Wide Diverse Sample," *JCPP Advances* 4/1 (2023).
52. Human Rights Council (see note 19).



## EDITORIAL

# Accountability, Resistance, and Dissent in Public Health

JOSEPH J. AMON AND CARMEL WILLIAMS

In his 1970 book *Exit, Voice, and Loyalty*, economist Albert Hirschman observed that “under any economic, social, or political system, individuals, business firms, and organizations in general are subject to lapses from efficient, rational, law-abiding, virtuous, or otherwise functional behavior.”<sup>1</sup> He argued that society must be able to “marshal from within itself forces which will make as many of the faltering actors as possible revert to the behavior required for its proper functioning.”<sup>2</sup>

Today, as public health institutions face unprecedented attacks and the very foundations of evidence-based medicine are undermined by political interference, Hirschman’s framework offers critical insights into how public health professionals must respond when their institutions are unable to fulfill their fundamental duty to protect population health.

### *The courage to expose injustice*

The history of public health is marked by individuals who refused to remain silent in the face of institutional wrongdoing. John Snow’s removal of the Broad Street water pump handle in London in 1854 is taught to all public health students as an example of causal analysis and decisive action to end a cholera epidemic. Less often discussed is the fact that politicians ordered the pump handle’s return and that periodic epidemics continued—a perhaps even more important lesson for students, and one reason why schools of public health teach human rights, policy, and advocacy alongside epidemiology and biostatistics.<sup>3</sup>

Unfortunately, the challenges faced by Snow are common among public health whistleblowers, who often face severe and sustained attacks when challenging authorities, whether government or private companies. For example, Dr. Jeffrey Wigand revealed in 1996 that Brown & Williamson, a major tobacco company, had intentionally manipulated its tobacco blend with chemicals such as ammonia to increase the addictive effects of nicotine.<sup>4</sup> His disclosures were instrumental in the case brought by state attorneys

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general against tobacco manufacturers, leading to major regulatory changes and historic financial settlements. But the personal cost was devastating—Wigand faced intimidation, legal threats, and character assassination.

In December 2019, Dr. Li Wenliang, an ophthalmologist, warned colleagues about a new SARS-like virus circulating in Wuhan, China. Rather than receiving support to fully investigate his early warning, Dr. Li was detained and reprimanded by Chinese authorities and forced to sign a statement acknowledging that he had made false statements that disturbed the public order. Dr. Li later contracted COVID-19 while treating patients and died in February 2020. His death became a rallying point for demands for freedom of expression in China, but only after his silencing contributed to delays in the global response that cost countless lives.<sup>5</sup>

Attacks on health researchers who are at odds with powerful interests often follow a predictable pattern that can include allegations of scientific misconduct, media campaigns, and administrative and legal assaults. The consequences for whistleblowers can be severe. Research shows that 84% of whistleblowers experience severe depression or anxiety symptoms, 84% report feelings of isolation or powerlessness, 78% develop distrust of others, 69% experience declining physical health, 66% suffer severe financial decline, and 53% report problems with family relations.<sup>6</sup>

Retaliation tactics can be sophisticated and multifaceted, attacking the scientific integrity of whistleblowers and undermining their reputation and accomplishments. Government persecution of public health professionals—especially in the face of an epidemic outbreak—represents a particularly dangerous threat to the right to health because delay can increase disease spread. Covering up the failures of disease surveillance systems and gaps in protection for vulnerable populations can prevent the implementation of effective strategies. In Ecuador, researchers who raised concerns about the H5N1 influenza outbreak faced disciplinary action.<sup>7</sup> In Brazil, as well as many other countries, Ministry of Health and frontline health workers

during the COVID-19 pandemic faced bullying, harassment, threats, and defamation from their own governments.<sup>8</sup>

In the United States, the scale of government attacks on public health since President Trump has returned to office has been alarming, including the dismantling of the United States Agency for International Development (USAID), the gutting of the National Institute for Occupational Safety and Health, the termination of federal grants, reductions in research funding, bans on gender-affirming care, and the removal of health information from government websites.<sup>9</sup> Trump's appointed public health leaders have embraced conspiracy theories, undermined confidence in scientists and public health research, and criticized universities as elitist institutions, contributing to the fracturing of public trust in biomedical advances and public health accomplishments.<sup>10</sup>

This is a situation different from retaliation against a single whistleblower. It is a political and ideological war against science and against social welfare, and quite clearly an example of what Hirschman characterized as a “lapse” from “rational, law-abiding, virtuous, or otherwise functional behavior.”

So how can the public health and human rights community “marshal from within itself” the forces required to “make as many of the faltering actors as possible revert” to sound science and respect for human rights? How does Hirschman's framework of “exit, voice, loyalty” inform the moment we are in, where loyalty does not mean allegiance to protect rights, where voice is stifled and free speech is threatened, and where exit—and abandoning a mission to advance health and rights—is a difficult, last resort?

### The ethical imperative for dissent

In this moment, when claims are made that vaccines are dangerous, access to sexual and reproductive health is restricted, gender-affirming care is contested, budgets are slashed, environmental regulations are gutted, and trust in public health authorities is diminishing, what does resistance

and dissent look like?

Examples of resistance—or exit—abound. In August 2025, Susan Monarez, director of the Centers for Disease Control and Prevention (CDC), was fired after refusing to follow what her lawyers characterized as unscientific directives from Health and Human Services Secretary Robert F. Kennedy Jr., triggering a wave of high-level resignations, including those of Chief Medical Officer Dr. Debra Houry, Dr. Daniel Jernigan (head of the National Center for Emerging and Zoonotic Infectious Diseases), and Dr. Demetre Daskalakis (head of the National Center for Immunization and Respiratory Diseases).<sup>11</sup> Resignations of top public health leaders represent more than individual career changes—they constitute a hemorrhaging of institutional expertise and leadership at precisely the moment when evidence-based public health guidance is most needed. Each departure, forced or voluntary, removes decades of experience and creates gaps in the systems designed to protect population health.

The impact was felt not only at the top. President Trump's fiscal year 2026 budget proposed a 50% cut in the CDC's funding, slashing nearly five billion dollars. Chronic disease prevention funding was cut, along with US\$12 billion for public health programs to states. Funding for disease surveillance and vaccines for children and uninsured adults were similarly targeted. Resistance has also come from litigation, filed by organizations such as Public Citizen, the American Public Health Association, the AIDS Vaccine Advocacy Coalition, and the Global Health Council. Outcomes have been mixed. While in some cases the courts have acted as a safeguard for the rule of law, the process is slow and often met with government appeals.

Nearly all of USAID's 16,000 employees were laid off. An estimated 280,000 contractors, partners, and local hires worldwide lost their jobs. The Environmental Protection Agency, whose mission is critical to the protection of public health, was also targeted by the Trump administration and forced to roll back climate change and clean air protections. Post-exit, using their voice, there are now over 750 former Environmental Protection Agency staff in the Environmental Protection Network,

volunteering their time and expertise to develop science-based policies to protect the environment and to defend agency staff against harassment and intimidation.<sup>12</sup>

### Using exit, voice, and loyalty to advance human rights

Jonathan Mann, a pioneering voice in public health and human rights, and the first editor of this journal, engaged in all three strategies of *Exit, Voice, and Loyalty* in his work responding to the HIV pandemic. As the director of the Global Program on AIDS at the World Health Organization (WHO), he spoke out in the 1990s about the mishandling of the HIV pandemic by many governments and the decline of public health, ascribing the field's failures to an ongoing "reluctance and inability to work directly on the societal roots of health problems."<sup>13</sup>

After clashing with the WHO Director-General Hiroshi Nakajima, Mann left WHO, and he again used voice to challenge those working within the field of public health, writing that "while expanding enormously its scientific capacity to measure, public health may have lost clarity about why it is measuring, and to what purpose?"<sup>14</sup> In essence, Mann was appealing to the loyalty of public health practitioners and to the power of their tools, but exhorting them to apply those tools to realize the right to health for all.

Time moves on; 30 years later, WHO is also expressing dissent from the current anti-science trend with its choice of this year's theme: "Together for health. Stand with science."<sup>15</sup> The fight now is not just to work on the roots of health problems but to maintain a workforce and resources that can undertake such scientific pursuits. WHO calls on its global voice to fight misinformation and to "rebuild trust in science and public health."<sup>16</sup>

United Nations High Commissioner for Human Rights Volker Türk told the Human Rights Council in February that the response needed at this time requires "calling out violations of international law, regardless of the perpetrators."<sup>17</sup> In stating that the rhetoric of some leaders reveals a belief that they are above the law, including the

United Nations Charter, and in accusing them of spreading disinformation to distract, silence, and marginalize, he used “voice.”

*Health and Human Rights* continues Mann’s legacy, stands with science, and fights the silencing; it offers authors a publishing platform that recognizes the importance of diverse voices advocating for a public health approach that is grounded in human rights and dignity and that is not simply technocratic but transformative.

This issue, June 2026, comes at a time of global anxiety over ongoing conflict, attacks on health facilities, discrimination against minority groups, regression on sexual and reproductive health, infectious disease outbreaks (including a resurgence of measles in the United States and Ebola in Uganda and the Democratic Republic of the Congo), mental health crises, environmental catastrophes and disaster-related illness and injuries, and a widely acknowledged rollback of human rights and support for the institutions upon which accountability mechanisms depend.

The right to health cannot be realized without robust protections for those who expose threats to population health.<sup>18</sup> The papers in this issue highlight the importance of collective action and professional solidarity as the struggle for health rights continues around the globe.

As Hirschman understood, institutions fail. They deviate from their stated purposes, they become captured by interests antithetical to their missions, they sacrifice principle for political expediency. What determines whether these failures lead to institutional decay or renewal is whether there are individuals willing to speak out, to take personal risks to call institutions back to their core purposes, and to demand—whether through exit, voice, or loyalty—that the right to health be assured for all.

## References

1. A. O. Hirschman, *Exit, Voice, and Loyalty: Responses to Decline in Firms, Organizations, and States* (Harvard University Press, 1970).
2. Ibid.

3. G. Davey Smith, “Behind the Broad Street Pump: Aetiology, Epidemiology and Prevention of Cholera in Mid-19th Century Britain,” *International Journal of Epidemiology* 31/5 (2002).

4. J. Wigand, “The Fight to Stub Out Tobacco,” *Bulletin of the World Health Organization* 90/9 (2012).

5. E. Petersen, D. S. Hui, D. H. Hamer, et al., “Li Wenliang, A Face to the Frontline Healthcare Worker. The First Doctor to Notify the Emergence of the SARS-CoV-2, (COVID-19), Outbreak,” *International Journal of Infectious Diseases* 93 (2020).

6. P. G. van der Velden, M. Pecoraro, M. S. Houwerzijl, et al., “Mental Health Problems Among Whistleblowers: A Comparative Study,” *Psychological Reports* 122/2 (2019).

7. E. Ortiz-Prado, J. S. Izquierdo-Condoy, M. A. Vasconez-Gonzalez, et al., “Upholding Academic Freedom: A Call to Protect Freedom of Expression and Science in Ecuador and Beyond,” *Frontiers in Public Health* 11 (2023).

8. J. Paulo Roberto da Silva, P. Porto, M. C. Rocha, and E. R. Tamaki, “Women and Working in Healthcare During the COVID-19 Pandemic in Brazil: Bullying of Colleagues,” *Globalization and Health* 19/1 (2023); M. Razafindrakoto, F. Roubaud, M. R. Castilho, et al., “Investigating the ‘Bolsonaro Effect’ on the Spread of the COVID-19 Pandemic: An Empirical Analysis of Observational Data in Brazil,” *PLOS One* 18/19 (2024).

9. J. J. Amon, “Politicized Science and Attacks on Public Health,” *Health and Human Rights* 27/2 (2025); A. E. Yamin, E. J. Lenge, and G. Gonsalves, “Building a Resistance to US Assaults on Public Health,” *Lancet* 406/10499 (2025).

10. Amon (see note 9).

11. S. Soucheray, “CDC Director Fired After She ‘Refused to Rubber-Stamp’ Kennedy’s Vaccine Directives” Center for Infectious Disease Research & Policy Research and Innovation Office, University of Minnesota (August 29, 2025), <https://www.cidrap.umn.edu/public-health/cdc-director-fired-after-she-refused-rubber-stamp-kennedy-vaccine-directives>.

12. Environmental Protection Network, “Our Work,” <https://www.environmentalprotectionnetwork.org/our-work>.

13. J. M. Mann, “Society and Public Health: Crisis and Rebirth,” *Western Journal of Medicine* 169/2 (1998).

14. J. Mann, “Human Rights and the New Public Health,” *Health and Human Rights* 1/3 (1995), p. 233.

15. World Health Organization, “World Health Day 2026: Together for Health. Stand with Science” (April 7, 2026), <https://www.who.int/news-room/events/detail/2026/04/07/default-calendar/world-health-day-2026-together-for-health-stand-with-science>.

16. Ibid.

17. Office of the United Nations High Commissioner for Human Rights, “High Commissioner Türk Opens the Hu-

man Rights Council: People's Pursuit of Dignity, Equality, and Justice Is Unshakeable" (February 23, 2026), <https://www.ohchr.org/en/statements-and-speeches/2026/02/high-commissioner-turk-opens-human-rights-council-peoples-pursuit>.



## VIEWPOINT

# Trump's War on Clean Air

RICHARD PEARSHOUSE

Air pollution rarely appears on death certificates. With a notable exception from a London coroner's report following the death of a nine-year-old girl in 2013, individual deaths are not typically attributed to air pollution.<sup>1</sup> Yet in the United States, an estimated 100,000 to 200,000 people die prematurely each year because of polluted air.<sup>2</sup> These deaths receive less attention than they merit in large part because air pollution's effects are insidious, cumulative, and difficult to attribute to a single cause.

Air pollution harms lungs—causing lung cancer and exacerbating pneumonia and asthma—but it more frequently kills through cardiovascular pathways, including strokes and heart attacks. It also affects the brain, contributing to cognitive decline, dementia, and even depression. As scientific understanding evolves, the evidence of harm continues to expand. Even at levels below current regulatory thresholds, air pollution has measurable adverse health effects.

The burden of these harms is unevenly distributed. Children, older people, those with preexisting health conditions, and communities that are low income or racial and ethnic minorities are disproportionately exposed and more vulnerable to the effects of polluted air. This unequal distribution contributes to the systemic masking of air pollution as a public health crisis.

If understanding the health impacts of air pollution is inherently challenging, it has become significantly more so during President Trump's second term. The administration has systematically dismantled elements of the regulatory framework designed to protect air quality, weakening multiple pollution standards and reducing the institutional capacity of the federal agency tasked with implementing the Clean Air Act.<sup>3</sup> These moves represent a form of regulatory regression that is increasingly incompatible with the right to the enjoyment of the highest attainable standard of physical and mental health under international human rights law.

As early as 2000, the Committee on Economic, Social and Cultural Rights noted in its General Comment 14 that the right to health includes “the prevention and reduction of the population's exposure to harmful substances ... and harmful chemicals or other detrimental environmental conditions that directly

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or indirectly impact upon human health.”<sup>4</sup>

The Environmental Protection Agency (EPA)’s recent rollbacks are both intricately technical and profoundly consequential. In 2024, the EPA strengthened the primary National Ambient Air Quality Standards (NAAQS) for fine particulate matter (PM<sub>2.5</sub>), lowering the allowable annual concentration from 12 to 9 micrograms per cubic meter.<sup>5</sup> The agency’s scientific modeling estimated that the new standard could prevent up to 4,500 early deaths, 800,000 cases of asthma symptoms, and 290,000 lost workdays annually by 2032.<sup>6</sup>

However, in November 2025, the EPA took the unprecedented step of asking the United States Court of Appeals for the District of Columbia Circuit to vacate the revised standard. In justifying its reversal, the EPA’s press office stated that the rule would cost Americans “hundreds of millions, if not billions of dollars” if fully implemented.<sup>7</sup>

It is unlikely the EPA has the statutory authority to consider implementation costs when setting NAAQS. The US Supreme Court has previously ruled the EPA must set NAAQS based exclusively on what is necessary to protect human health.<sup>8</sup> But the move flagged a deeper methodological shift.

Other rules under the Clean Air Act do permit the EPA to undertake a cost-benefit analysis of their implementation. In January 2026, the EPA finalized a rule limiting nitrogen oxide emissions from gas turbines and industrial sources.<sup>9</sup> While the rule quantified emissions reductions, it departed from long-standing practice by declining to monetize the health benefits associated with those reductions.<sup>10</sup> In effect, the agency’s cost-benefit analysis considered the compliance costs to industry while excluding the economic value of avoided deaths, reduced hospitalizations, and improved public health. The Environmental Protection Network—an association of former EPA career staff—has described this as “zeroing out lives saved,” a phrase that succinctly captures the cooking of regulatory books.<sup>11</sup>

By eliminating the monetization of health benefits, the EPA is structurally excluding the value of human life and health from regulatory decision-making. This can be clearly seen in the

EPA’s decision in February 2026 to rescind a recent strengthening of federal emissions standards for mercury and other toxic pollutants.<sup>12</sup> In 2024, the EPA estimated that stronger rules would generate US\$260 million in health benefits—decreased cardiac and pulmonary risks, avoided mortality, avoided health care costs, and economic benefits associated with fewer missed work and school days—alongside US\$130 million in climate-related benefits between 2028 and 2037.<sup>13</sup>

But these benefits were effectively erased from the regulatory calculus when the EPA neither quantified nor monetized the health impacts associated with increased emissions of particulate matter and ozone.<sup>14</sup> This represents a clear example of how methodological changes can produce outcomes that systematically undervalue public health.

Behind the details are real and foreseeable human consequences. A child with asthma in California’s San Joaquin Valley may experience more frequent attacks and missed school days. A construction worker in Pittsburgh may develop chronic obstructive pulmonary disease after prolonged exposure to particulate pollution. An older adult in Fairbanks may suffer a fatal cardiac event during winter inversions that trap pollution close to the ground.

The US government’s moves stand in stark tension with a growing body of international human rights law recognizing the right to health, and its interdependence with other human rights, when it comes to air pollution. In March 2026, the United Nations Special Rapporteur on the right to a healthy environment called on states to “enact and regularly update air quality standards and progressively strengthen and avoid regressions, based on best available science, including World Health Organization guidelines and considering particularly vulnerable populations.”<sup>15</sup>

The United States is doing the opposite. World Health Organization guidelines are considerably more stringent than EPA thresholds. For example, the World Health Organization recommends an annual average PM<sub>2.5</sub> limit of 5 micrograms per cubic meter.<sup>16</sup> The move from 9 (micrograms per cubic meter) to 12 is a move in the wrong direction.

This weakening of pollution thresholds represents a form of regulatory retrogression incompatible with the right to health.

General Comment 14 makes clear that retrogressive measures are not permissible except where the state can show that they are fully justified by reference to the totality of rights in the International Covenant on Economic, Social and Cultural Rights and that the state has carefully considered all alternatives.<sup>17</sup> The US has signed but not ratified the covenant.<sup>18</sup> Though it is not formally bound by its provisions, the United States, as a signatory, has an obligation to refrain from taking steps that undermine their “object and purpose.”<sup>19</sup>

Although the United States has historically resisted a right to health in US law, clean air is increasingly understood as interdependent with other human rights. For example, a recent report of the Special Rapporteur on the right to a healthy environment notes that the impacts of air pollution “undermine the rights to life, health, a healthy environment and an adequate standard of living, and to equality and non-discrimination.”<sup>20</sup>

Comparative human rights jurisprudence reinforces this position. In *Inhabitants of La Oroya v. Peru*, the Inter-American Court of Human Rights found that Peru violated numerous rights when failing to control air, water, and soil pollution from a metallurgical facility in the city of La Oroya.<sup>21</sup> The court not only relied on the right to health but derived the obligation to control pollution from a broader set of rights, including the right to life and the right to a healthy environment. The court found that it was sufficient for the plaintiffs to show that exposure to pollution created a significant health risk, without having to prove causation of a specific health condition or disease.<sup>22</sup>

Recent jurisprudence from the European Court of Human Rights is also instructive. In *Canavacciuolo and Others v. Italy*, the European Court of Human Rights held that Italy’s failure to prevent and respond to widespread toxic waste pollution in Campania exposed residents to a real and immediate risk to life, thereby violating the obligation to protect the right to life.<sup>23</sup> As in *La Oroya*, the court found a violation of the right to life on the basis of

exposure to toxic pollution rather than evidence of specific health impacts.<sup>24</sup>

The Trump administration’s deregulation of air quality regulations demonstrates how technical regulatory changes can have profound consequences for human health. As international human rights law increasingly recognizes a right to clean air, these policy shifts place the United States at odds with emerging global standards. The right to health and its interdependence with other human rights provides a critical framework for challenging these changes and re-centering environmental governance on its fundamental purpose: the protection of human life.

## References

1. C. Dyer, “Air Pollution from Road Traffic Contributed to Girl’s Death from Asthma, Coroner Concludes,” *BMJ* 371/4902 (2020).
2. S. K. Thakrar, S. Balasubramanian, P. J. Adams, et al., “Reducing Mortality from Air Pollution in the United States by Targeting Specific Emission Sources,” *Environmental Science and Technology Letters* 7/9 (2020).
3. D. J. Fiorino, “The Trump Administration and Environmental Policy, One Year In,” *Policy Quarterly* 22/1 (2026).
4. Committee on Economic, Social and Cultural Rights, General Comment No. 14, UN Doc. E/C.12/2000/4 (2000), para. 15.
5. Environmental Protection Agency, *Final Rule to Strengthen the National Air Quality Health Standard for Particulate Matter Fact Sheet* (2024), <https://www.epa.gov/system/files/documents/2024-02/pm-naaqs-overview.pdf>.
6. *Ibid.*
7. R. Frazin, “EPA Asks Court to Overturn Biden-Era Limits on Deadly Soot Pollution,” *The Hill* (Nov 25, 2025), <https://thehill.com/policy/energy-environment/5622557-soot-fine-particulate-matter-epa-trump-zel-din-biden/>.
8. *Whitman v. American Trucking Ass’n, Inc.*, 531 U.S. 457 (2001).
9. Environmental Protection Agency, *New Source Performance Standards Review for Stationary Combustion Turbines and Stationary Gas Turbines* (2026), <https://www.federalregister.gov/documents/2026/01/15/2026-00677/new-source-performance-standards-review-for-stationary-combustion-turbines-and-stationary-gas>.
10. *Ibid.*, sec. V(E).
11. Environmental Protection Network, *Safer Not Sicker: The EPA Must Put Our Health First* (2026) <https://safenot-sicker.org/>.

12. Environmental Protection Agency, *National Emissions Standards for Hazardous Air Pollutants: Coal- and Oil-Fired Electric Utility Steam Generating Units: Final Repeal* (2026), <https://www.federalregister.gov/documents/2026/02/24/2026-03638/national-emission-standards-for-hazardous-air-pollutants-coal--and-oil-fired-electric-utility-steam>.

13. Environmental Protection Agency, *Regulatory Impact Analysis for Final National Emission Standards for Hazardous Air Pollutants: Coal- and Oil-Fired Electric Utility Steam Generating Units Review of the Residual Risk and Technology Review* (2024), <https://www.epa.gov/system/files/documents/2024-04/2024-mats-rtr-final-ria-final.pdf>.

14. S. Hart-Curran, “Final Rule Rescinding 2024 MATS Rule and Reinstating 2012 Standards,” Harvard University, <https://eelp.law.harvard.edu/wp-content/uploads/2026/03/MATS-Final.pdf>.

15. Human Rights Council, *Priority Actions Towards Breathing Clean Air, Protecting Public Health, and Ensuring a Healthy Environment: Report of the Special Rapporteur on the Human Right to a Clean, Healthy and Sustainable Environment*, UN Doc. A/HRC/61/47 (2026), para. 86.

16. World Health Organization, *WHO Global Air Quality Guidelines* (2021).

17. Committee on Economic, Social and Cultural Rights (see note 4), para. 32.

18. International Covenant on Economic, Social and Cultural Rights, G.A. Res. 2200A (XXI) (1966).

19. Vienna Convention on the Law of Treaties, 1155 UNTS 331 (1969), art. 18(a).

20. Human Rights Council (see note 15), para. 6.

21. *Inhabitants of La Oroya v. Peru*, Inter-American Court of Human Rights, judgment of November 27, 2023.

22. *Ibid.*, para. 204.

23. *Cannavacciuolo v. Italy*, European Court of Human Rights, judgment of April 30, 2025.

24. *Ibid.*, para. 390.

## VIEWPOINT

# Disaster Epidemiology: Human Rights and the US Immigration and Customs Enforcement Siege of Minneapolis

JOSEPH J. AMON

Before its leadership and staff were gutted, the US Centers for Disease Control and Prevention provided technical assistance and disaster epidemiology training to state and local public health professionals.<sup>1</sup> The field of public health rightly understood that its tools, including surveillance systems to detect emerging threats, risk assessment and vulnerability mapping to identify at-risk and vulnerable populations, and outbreak investigation to quickly identify causes and address risk, could be applied wherever disasters—natural or human-made—emerged.

Public health practitioners, guided by the adage that an ounce of prevention is worth a pound of cure, also developed strategies for the prevention and mitigation of disasters. They routinely designed models to simulate how quickly a disease could spread through crowded evacuation shelters and to estimate medical supply needs.

Core epidemiological principles—defining populations at risk, measuring health outcomes systematically, identifying causal relationships, and evaluating interventions—provide the scientific foundation for evidence-based disaster management. These methods transform chaotic emergency situations into structured problems that can be analyzed and addressed systematically, ultimately saving lives and reducing suffering.

The same approaches need to be applied currently in Minneapolis, Minnesota, amid the ongoing tsunami of violence caused by Immigration and Customs Enforcement (ICE) targeting immigrants, minoritized American citizens, and protesters exercising fundamental human rights to speech and assembly.

Following a disaster epidemiology approach, public health practitioners should respond to the

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ICE-instigated epidemic of violence in Minneapolis by working to build resilient systems, address urgent needs, protect human rights, and ensure accountability.

### Preparedness: Building resilient systems

Effective disaster preparedness requires integrated early warning systems coupled with comprehensive public education. Of course, ICE officials understand this as well and act to evade such efforts, moving into cities with little to no warning. Cities, especially those where a majority of citizens did not vote for the current president, need to engage communities, develop plans, and create early warning systems.<sup>2</sup>

One lesson from previous disasters, however, is that while coordinated efforts and alerts can save lives, they may be insufficient. Communities must understand warning signals and know evacuation routes. Studies following the 2004 Indian Ocean tsunami found that populations with traditional knowledge of ocean behavior and those who had participated in tsunami drills experienced significantly lower mortality rates.<sup>3</sup> In other words, be prepared and do not underestimate the cruelty.

Health care infrastructure resilience constitutes another critical preparedness element. Hospitals and clinics in cities targeted by ICE must be prepared for mass casualties, including kinetic projectile impact injuries (e.g., from rubber bullets, beanbags, and pepper balls), chemical agent exposures (e.g., tear gas and pepper spray), and physical and blunt force trauma (e.g., baton injuries), as well as long-term and psychological effects (e.g., vision loss, cognitive impairment from brain injuries, and psychological trauma). Research on the policing of protest crowds has found that a significant percentage of injuries from projectiles are severe, with many affecting the head and neck.<sup>4</sup>

In Minneapolis, ICE officials have shot civilians with impunity, failed to provide first aid, and interfered with those who try to provide lifesaving care.<sup>5</sup> They have followed this with lies about the risk posed and defamatory statements about victims, which have been repeated by the White House.

For those afraid to leave their homes, preparedness should include stocking critical medicines at home and finding ways to refill prescriptions and food stocks. Telemedicine alternatives should be made available, as should online education alternatives for children afraid to travel to and from school.<sup>6</sup>

### Addressing urgent health needs, protecting human rights, and ensuring accountability

The acute phase following an ICE siege in a community requires a coordinated emergency medical response, addressing, in particular, mental health needs. But it also requires efforts beyond disaster epidemiology's traditional view. It requires rebuilding communities shattered by violence but held together by inspiring solidarity. It must also reinforce human rights protections and the rule of law and find mechanisms of accountability.

While research has found that psychological first aid programs and community-based mental health interventions can reduce anxiety and help prevent progression to posttraumatic stress disorder and depression following a disaster, accountability and justice must also be addressed.<sup>7</sup>

The siege of Minneapolis violates numerous US constitutional and international human rights protections. For example, the Universal Declaration of Human Rights and the International Covenant on Civil and Political Rights (ICCPR) protect the freedom of peaceful assembly, including the right to organize and participate in peaceful protests.<sup>8</sup> The ICCPR also guarantees freedom of expression (article 19), which covers protest speech and demonstration. Restrictions on these rights must be lawful, necessary, and proportionate to legitimate aims.

The US Constitution, in its Fifth and Fourteenth Amendments, guarantees that no person shall be deprived of life, liberty, or property without due process of law.<sup>9</sup> The use of force must be "objectively reasonable."<sup>10</sup> It is important to note that due process applies to all persons, regardless of immigration status, and includes a right to notice of charges and a hearing before deportation, a right to

present evidence, a right to counsel, and protection against arbitrary detention.

Article 9 of the ICCPR similarly protects against arbitrary arrest and detention, requiring a legal basis for any detention, the prompt notification of charges, the right to challenge detention before a court, and the humane treatment of detainees.

The United Nations Basic Principles on the Use of Force and Firearms by Law Enforcement Officials provide that force should be used only when strictly necessary; lethal force should be used only when strictly unavoidable to protect life; force must be proportional to the threat; and officials must identify themselves and give clear warning before using force.<sup>11</sup> All of these principles have been violated in Minnesota.

## Conclusion

In addition to disaster epidemiology, public health professionals have recognized, researched, and published articles on violence as a public health crisis.<sup>12</sup> The siege on Minneapolis, the public health impacts, the human rights violations, and the inhumanity must end. Accountability through courts, as well as community forums that create accountability from below, must ensure that what has happened is accurately reported and prevented from occurring again, and that justice prevails.<sup>13</sup>

## References

- Centers for Disease Control and Prevention, "Public Health Surveillance During a Disaster" (April 5, 2024), <https://www.cdc.gov/disaster-epidemiology-and-response/php/disaster/surveillance.html>.
- Axios, "Trump Orders ICE to Step Up Deportation Efforts in Democrat-Run Cities" (June 16, 2025), <https://www.axios.com/2025/06/16/trump-ice-democrat-cities-immigration-deport>.
- P. Mikulecký, A. Punčochářová, F. Babič, et al., "Dealing with Risks Associated with Tsunamis Using Indigenous Knowledge Approaches," *International Journal of Disaster Risk Reduction* 86 (2023).
- C. Pearl, S. Torbati, and J. M. Geiderman, "Kinetic Projectile Injuries Treated During Civil Protests in Los Angeles: A Case Series," *Clinical Practice and Cases in Emergency Medicine* 5/4 (2021).
- S. Heffernan and T. Meagher, "How ICE and Border Patrol Keep Injuring and Killing People," The Marshall Project (January 26, 2026), <https://www.themarshallproject.org/2026/01/26/ice-minneapolis-shooting-alex-pretti>.
- L. Romero, "Judge Blocks Removal of 5-Year-Old Detained by ICE in Minnesota," *ABC News* (January 27, 2026), <https://abcnews.go.com/US/judge-blocks-removal-5-year-detained-ice-minnesota/story?id=129614901>.
- L. Wang, I. Norman, V. Edleston, et al., "The Effectiveness and Implementation of Psychological First Aid as a Therapeutic Intervention After Trauma: An Integrative Review," *Trauma, Violence, and Abuse* 25/4 (2024).
- Universal Declaration of Human Rights, G.A. Res. 217A (III) (1948), art. 20; International Covenant on Civil and Political Rights, G.A. Res. 2200A (XXI) (1966), art. 21.
- Constitution of the United States, amendments V, XIV.
- Graham v. Connor*, 490 U.S. 386 (1989).
- United Nations Office of the High Commissioner for Human Rights, Basic Principles on the Use of Force and Firearms by Law Enforcement Officials (1990), <https://www.ohchr.org/en/instruments-mechanisms/instruments/basic-principles-use-force-and-firearms-law-enforcement>.
- American Public Health Association, "Violence Is a Public Health Issue: Public Health Is Essential to Understanding and Treating Violence in the US" (November 12, 2018), <https://www.apha.org/policy-and-advocacy/public-health-policy-briefs/policy-database/2019/01/28/violence-is-a-public-health-issue>.
- P. Hunt and A. Kapilashrami, "Exploring Accountability for Health Rights," *Health and Human Rights* 27/2 (2025).



## VIEWPOINT

# Health Data Protection and Governance Under the Kenya–US Health Agreement

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On December 4, 2025, Kenya and the United States signed a health cooperation framework aimed at “guiding collaboration to eliminate HIV, malaria, TB, and other emerging infectious diseases; strengthen Kenya’s health system toward self-reliance; and advance US interests abroad, including strengthening the US–Kenya partnership.”<sup>1</sup> This was the first bilateral agreement signed as part of the Trump administration’s Make America Healthy Again campaign.<sup>2</sup> While the Kenya–US agreement is framed as beneficial to both governments in detecting, preventing, and responding to emerging and existing infectious disease threats, the extensive data sharing obligations raise fundamental human rights questions on data protection, privacy, consent, accountability, and state responsibility with regard to the realization of the right to health.

These serious concerns about data sharing led to the High Court of Kenya issuing conservatory orders suspending implementation of the agreement pending the hearing and determination of the case challenging it.<sup>3</sup> Underlying these concerns are fears that gaps in confidentiality, informed consent, and accountability in the use of health data may discourage individuals from seeking care, particularly for stigmatized conditions such as HIV and tuberculosis, and may therefore disproportionately harm the most marginalized.

Data sharing, especially around surveillance, always raises concerns that health data could be used to discriminate against marginalized groups and exclude them from having access to health care.<sup>4</sup> These anxieties were amplified in the COVID-19 pandemic, when digital health data were used to promote discriminatory processes against migrants, LGBTQ populations, and homeless people.<sup>5</sup> Digital health data also risk being securitized in a way that exceeds public health objectives. During the COVID-19 pandemic, the governments of Israel, Kenya, Mexico, and Turkey, among others, reportedly used COVID-19 data to

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analyze private communications under the guise of contact tracing.<sup>6</sup>

The increased role of private actors in the collection, storage, and secondary use of big data also leads to fears around transparency, accountability, and long-term harms to vulnerable groups. Once data move into private ownership, they can be merged with other datasets for commercial purposes. It is then extremely difficult to create accountability mechanisms for misuse, especially in cases of future health harms such as insurance denials based on non-transparent risk assessments generated through large artificial intelligence health datasets.<sup>7</sup>

### Data sharing implications of the Kenya–US agreement

Under the framework, Kenya will provide aggregated and system-level data from national digital health platforms and share programmatic and outcome data for US-supported health programs in Kenya.<sup>8</sup>

This agreement enables the large-scale collection, processing, and cross-border transfer of health data, raising questions about necessity, proportionality, and accountability under Kenya's constitutional and international human rights obligations.

It contains several provisions that, on their face, seek to address data protection concerns. These include commitments that data provision will comply with Kenyan law, that Kenya shall not provide individual-level or personally identifiable information “to the maximum extent practical,” that the United States shall use the data solely for purposes consistent with the metrics or activities under the agreement, that the US government shall take all reasonable measures to protect the confidentiality of information shared, and that Kenya retains sole ownership of the data and all intellectual property rights.<sup>9</sup> The agreement also states that Kenyan law prevails where there is disagreement and requires notification of data breaches involving personally identifiable information.<sup>10</sup> However, the presence of formal safeguards does not, on its own, guarantee

effective protection, particularly where enforcement, oversight, and remedies remain uncertain.

Although these clauses appear to align with domestic legal frameworks, including the Data Protection Act of 2019 and the Digital Health Act of 2023, closer scrutiny exposes substantial gaps that give rise to serious data protection concerns.

### Risk of sharing personal identifiable health information

In Kenya, health data are classified as sensitive personal information that must be processed lawfully, fairly, and transparently; collected for specific and legitimate purposes; limited to what is necessary; kept accurate and up to date; retained only for as long as necessary; and protected from unauthorized transfer outside Kenya unless adequate safeguards or the data subject's consent are in place.<sup>11</sup>

The Kenya–US agreement aims to limit data sharing to aggregate-level data, which aligns with the data minimization principle under the Data Protection Act. However, the framework appears to permit broad access to Kenyan health data by the United States despite the increasing risks of re-identification, especially around genomic information and longitudinal surveillance data.

The agreement limits US use of the data to the purposes specified under the cooperation framework and expressly prohibits any use beyond those purposes, consistent with the principle of purpose limitation under the Data Protection Act. However, the mechanisms for enforcing these restrictions remain unclear. It is not evident whether Kenya has effective measures in place to verify how the United States will utilize the health data collected. Furthermore, the scope of permitted access—encompassing activities such as surveillance, analytics, reporting, and emergency response—is so broad that monitoring or verifying specific uses may be impracticable. In effect, compliance appears to rely largely on mutual trust and goodwill between the parties, raising concerns as to whether this provides sufficient protection against prohibited use.

Such risks are not abstract. Where individuals

fear that their health data may be repurposed for surveillance, profiling, or punitive state action, they may avoid testing, treatment, or engagement with public health programs. This undermines core elements of the right to health, including the accessibility and acceptability of health care services, particularly for already marginalized populations.

There are also concerns about function creep in the use of accessed health data. Disease-specific surveillance systems—particularly those relating to HIV, tuberculosis, and other stigmatized conditions—carry heightened risks of discrimination and social harm, including profiling, targeting, and further exclusion of affected populations. Considering the United States’ recent positions on human rights, gender identity, and diversity, it is unclear what safeguards will be in place to ensure that such data access does not exacerbate stigma, criminalization, or structural vulnerabilities. Additionally, there is a need for clear safeguards to establish explicit firewalls between health data systems and their use for law enforcement, immigration control, and employment-related purposes.

### Data ownership without control

The Digital Health Act designates health data as a strategic national asset and underscores the obligation to safeguard its privacy, confidentiality, and security in information sharing and use. While the Kenya–US agreement affirms that Kenya retains sole ownership of the data and all associated intellectual property rights in the covered data systems, the agreement appears to cede significant control over the data to the United States, potentially leaving Kenya without effective mechanisms to exercise or enforce those ownership rights. This raises concerns regarding Kenya’s ability to prevent misuse, ensure timely deletion, or regulate the incorporation of the data into secondary datasets, beyond the agreed scope and duration.

In this context, data ownership without effective control risks becoming symbolic rather than substantive, weakening Kenya’s ability to exercise health data sovereignty.

### Conclusion

We recommend that the Office of the Data Protection Commissioner, which is the primary authority for regulating data in Kenya, play a central role in scrutiny and approval of these data sharing agreements so that it can ensure data minimization and confidentiality and so that safeguards against re-identification in aggregate form are maintained. This will involve scaling up the resources of this vital service and ensuring greater collaboration with the Ministry of Health.

Second, civil society has an important role to play in bringing together marginalized communities to participate, in enabling independent audits of compliance, and in ensuring and scrutinizing ongoing public reporting of how public health data are used and safeguarded. This may require clearer approval mechanisms for cross-border health data transfers, independent audits of compliance, and public reporting on how shared data are used and safeguarded.

Given the recognition of health data as a public good, there have been strong calls for a right to health approach to data sharing that prioritizes equitable rather than extractive practices; emphasizes the collective responsibilities of the state and private actors involved in the collection, storage, and processing of data; and ensures that all data sharing processes—including those established through bilateral agreements such as this one—uphold due process and strengthen participation and inclusion safeguards, particularly for marginalized and discriminated groups.

### References

1. Government of the Republic of Kenya and Government of the United States of America, Cooperation Framework Between the Government of the Republic of Kenya and the Government of the United States of America on Health (2025), para. 1.
2. S. Lewis, “U.S. Signs Pact With Kenya Under ‘America First’ Global Health Plan,” Reuters (December 4, 2025), <https://www.reuters.com/business/healthcare-pharmaceuticals/us-signs-pact-with-kenya-under-america-first-global-health-plan-2025-12-04/>.
3. G. Mosoku, “Court Suspends U.S.–Kenya Health Data

Sharing Deal,” *The Star* (December 11, 2025), <https://www.the-star.co.ke/news/2025-12-11-court-suspends-us-kenya-health-data-sharing-deal>.

4. S. Sekalala, S. Dagrón, L. Forman, and B. M. Meier, “Analyzing the Human Rights Impact of Increased Digital Public Health Surveillance During the COVID-19 Crisis,” *Health and Human Rights* 22/2 (2020).

5. *Ibid.*

6. Privacy International, “Knesset Committee Denies Extension of Police Access to Mobile Phone Location Data” (May 6, 2020), <https://privacyinternational.org/examples/3770/knesset-committee-denies-extension-police-access-mobile-phone-location-data>; Privacy International, “Kenya Tracks Mobile Phones for Quarantine Enforcement” (April 9, 2020), <https://privacyinternational.org/examples/3662/kenya-tracks-mobile-phones-quarantine-enforcement>; Privacy International, “Mexican Telcos Grant Government Access to Cell Phone Antennas” (March 31, 2020), <https://privacyinternational.org/examples/3691/mexican-telcos-grant-government-access-cell-phone-antennas>; “Turkey to Use Mobile Data to Track Isolation,” *Hürriyet Daily News* (April 9, 2020), <https://www.hurriyetaidailynews.com/turkey-to-use-mobile-data-to-track-isolation-153698>.

7. Sekalala et al. (see note 4).

8. Government of the Republic of Kenya and Government of the United States of America, Cooperation Framework (see note 1).

9. Government of the Republic of Kenya and Government of the United States of America, Data Sharing Agreement Between the Government of the Republic of Kenya and the Government of the United States of America (2025), arts. 2(a), 3(a), 3(b), 3(d).

10. *Ibid.*, arts. 3(b), 5(f).

11. Kenya Government, Data Protection Act (2019), sec. 25.

## VIEWPOINT

# Prescribing Death: Israel's Regional War on Health

MIRA YOUNES, SAMIRAH JARRAR, SAHAR SAEIDNIA, MALAK MAKKI, AND NIZAR HARIRI

On March 13, 2026, amid Israeli preparations for a ground invasion of southern Lebanon, an airstrike killed two paramedics at a health facility in Al Sowana (Marjayoun District). That same night, Israeli bombardments destroyed the primary health care center in Burj Qalawiya (Bint Jbeil District), one of the few still operating in the area. Nearly all staff present in the center (12 doctors, paramedics, and nurses) were killed in the strikes.<sup>1</sup>

On March 14, 2026, an official statement by the Israeli army spokesperson declared that Israel “will act in accordance with international law against Hezbollah’s military activity using these facilities and ambulances,” although independent investigations have consistently refuted claims about Hezbollah using health care infrastructure for military purposes.<sup>2</sup>

This declaration has provoked only limited international condemnation and mobilization—even as witnesses reported that Israeli special forces, wearing Lebanese military uniforms, used ambulances resembling those of Hezbollah’s Islamic Health Organization to carry out a deadly raid on Nabi Chit in the Bekaa Valley on March 6–7, 2026.<sup>3</sup>

During the brief period from March 2 to April 14, 2026, alone, the World Health Organization has verified the killing of 88 health workers in Lebanon in Israeli attacks.<sup>4</sup>

These systematic killings are part of a broader pattern of repeated and routinized attacks on health care institutions and personnel, as documented in Gaza since October 2023, paired with a recurring justificatory framework.<sup>5</sup> Recent conflict-monitoring data show that the weaponization of health care, in violation of international humanitarian law, has reached unprecedented levels globally, with attacks on hospitals, ambulances, and health workers becoming a habitual feature of contemporary warfare.<sup>6</sup> However, Israel

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has presented these attacks as compatible with international law, under the pretext that enemy combatants were embedded within medical facilities, a narrative designed to manufacture public consent for destroying health care systems.<sup>7</sup>

The recurrence of these attacks, which have been woven into a predictable routine both in this context and globally, combined with the surrounding propaganda, has gone hand in hand with a progressive erosion of public outrage.<sup>8</sup> This shift is visible in Lebanon's public response to attacks on health care. While the destruction of Al-Ahli Hospital in Gaza prompted a national day of mourning in Lebanon on October 18, 2023, the destruction of the Burj Qalawiya health care center in March 2026 has elicited only minimal public response.<sup>9</sup>

According to a report by the Safeguarding Health in Conflict Coalition, more than 470 health workers were reported arrested or detained across 15 countries and territories in 2024, with over 55% of those arrests attributed to the Israeli military in the occupied Palestinian territory.<sup>10</sup> The report also found that Lebanon recorded the highest number of health workers killed that year—"at least 408, accounting for nearly 50% of all reported health worker killings in 2024."<sup>11</sup> Separate reporting has documented the arbitrary detention, torture, ill treatment, and deaths in custody of Palestinian health workers held by Israeli authorities.<sup>12</sup>

Israel's assertion of its power to prescribe death not only to health care and rescue personnel but to all who rely on them represents just one facet of what scholars have described as an expansion of the Israeli military's war plan, from the "Dahiya Doctrine" to a "Gaza Doctrine."<sup>13</sup>

What requires emphasis, however, is the cumulative nature of attacks on health care and rescue infrastructure over time. Such attacks are part of a broader historical process of colonial destruction directed not only at people but also at the material and institutional conditions of collective survival.

Recent scholarship has situated the systematic targeting and degradation of Palestinian health care within a longer colonial history. Layth Malhis conceptualizes this as "de-healthification"—the dismantling of health systems as a condition for

colonial rule—tracing this process from the British Mandate to the present.<sup>14</sup> Malhis's analysis includes the 1982 Israeli invasion of Lebanon, during which medical infrastructure was massively bombarded under the pretext of its use by the Palestine Liberation Organization.<sup>15</sup> This framework bridges earlier foundational studies that, rather than focusing solely on direct attacks, examined the administrative and economic policies of structural dependency that impeded the development of a robust Palestinian health system.<sup>16</sup> Yara Asi interprets this de-development as part of a broader strategy of dispossession.<sup>17</sup> Constraints on patient and physician mobility, restrictions on medications and medical equipment importation, budgetary limitations, infrastructure destruction, and territorial fragmentation exemplify the everyday systemic violence and control imposed on the Palestinian population and their health care.<sup>18</sup>

In both Lebanon and Palestine, the intensification of attacks must be understood within a long-term process of colonial destruction, in which war accelerates the erosion of the very capacity of communities to project themselves into the future. It also targets those who bear witness to the violence—health workers, rescue personnel, journalists, and gravediggers alike.

However, health has also historically been central to strategies of Palestinian resistance and national liberation. Since 2023, health care workers have established collectives around the world, either to volunteer in Gaza directly or to lobby their colleagues, unions, and governments to support the Palestinian struggle.<sup>19</sup> Against the backdrop of what Joelle Abi-Rached and colleagues describe as "healthocide" in Gaza, Ghassan Abu Sitta foregrounds the response of doctors, nurses, and medics who continued to provide care under siege.<sup>20</sup> He points to those who, after being blockaded in al-Shifa Hospital for ten days without food or water, immediately sought to join another hospital upon their release. For Abu Sitta, this reflects the way health care in Gaza has become inseparable from a broader struggle to sustain life under conditions of siege, destruction, and attempted erasure.<sup>21</sup>

This perspective also extends to all rescue

workers across Palestine and Lebanon, most of whom are unpaid volunteers. Confronted with colonial necropolitics, their work is, quite literally, an insistence on providing burials for the dead and a determined effort to sustain life and protect their people and their “landscapes of togetherness.”<sup>22</sup> It is precisely because this work carries such profound political significance that those who perform it are punished by colonial powers. Killing these volunteers inflicts, for the same reason, a deep wound upon their communities.

Against the normalization of this war on health, we assert and defend this political understanding of rescue and health care work in a colonial context as an act of stubborn persistence. We call for its support and amplification through speaking out, international solidarity, and a collective commitment from the health research community to ensure that the lives and labor of those who sustain health under deadly conditions are neither ignored nor erased.

## References

1. “WHO Chief Tedros Says 12 Dead in Strike on Primary Healthcare Center in Lebanon,” Reuters (March 14, 2026), <https://www.reuters.com/world/middle-east/who-chief-tedros-says-12-dead-strike-primary-healthcare-center-lebanon-2026-03-14/>.
2. “Medical Staff Among 23 Killed in Israeli Strikes, Lebanese Health Ministry Says,” *Haaretz* (March 14, 2026), [https://www.proquest.com/newspapers/medical-staff-among-23-killed-israeli-strikes/docview/3313569283/se-2; Amnesty International, “Lebanon: Israeli Attacks on Health Care Providers Must Be Investigated as War Crimes” \(March 5, 2025\), https://www.amnesty.org/en/documents/mde18/9062/2025/en/](https://www.proquest.com/newspapers/medical-staff-among-23-killed-israeli-strikes/docview/3313569283/se-2; Amnesty International, “Lebanon: Israeli Attacks on Health Care Providers Must Be Investigated as War Crimes” (March 5, 2025), https://www.amnesty.org/en/documents/mde18/9062/2025/en/).
3. “Dozens Killed as Israeli Special Forces Raid Lebanese Village in Search of 40-Year-Old Remains,” BBC (March 7, 2026), <https://www.bbc.com/news/articles/cy8l2p2l3voo>.
4. World Health Organization, “Lebanon Health Emergency : Situation Update #19” (April 14, 2026), <https://www.emro.who.int/images/stories/lebanon/Lebanon-Emergency-Sitrep-19-2026.pdf>.
5. World Health Organization, *Attacks on Health Care in the Gaza Strip* (October 2, 2025), [https://www.emro.who.int/images/stories/palestine/Attacks\\_on\\_Health\\_Oct\\_2023\\_2\\_Oct\\_2025\\_1.pdf](https://www.emro.who.int/images/stories/palestine/Attacks_on_Health_Oct_2023_2_Oct_2025_1.pdf).
6. Safeguarding Health in Conflict Coalition, *Epidemic of Violence: Violence Against Health Care in Conflict 2024* (April 1, 2025).
7. S. Devi, “The Erosion of Medical Neutrality,” *Lancet* 406 (2025).
8. L. Rubenstein, R. J. Haar, and J. J. Amon, “Attacks on Healthcare in War Are Being Steadily Normalized—We Need to End Impunity,” *BMJ* 390 (2025).
9. A. Mahfouz, “A National Day of Mourning, 5 Hezbollah Fighters Killed, Countries Urge Citizens to Leave Lebanon,” *L’Orient Today* (October 18, 2023), <https://today.lorientlejour.com/article/1353616/a-national-day-of-mourning-5-hezbollah-fighters-killed-countries-urges>.
10. Safeguarding Health in Conflict Coalition (see note 6), p. 12.
11. *Ibid.*, p. 10.
12. S. El-Solh, “Torture and Health Worker Complicity in Israeli Detention Sites,” *BMJ* 391 (2025).
13. T. Abou-Hodeib, “The Gaza Doctrine: Israel’s New Levels of Brutality in Gaza Defines Its Warfare in Lebanon,” Polis Project (October 16, 2024), <https://thepolisproject.com/read/gaza-doctrine-israel-lebanon-invasion/>; L. Deeb, M. Mikdashi, T. Nalbantian, et al., “A Primer on Lebanon-History, Palestine and Resistance to Israeli Violence,” Middle East Research and Information Project (January 29, 2025), <https://www.merip.org/a-primer-on-lebanon-history-palestine-and-resistance-to-israeli-violence-2/>.
14. L. Malhis, “The Systematic Targeting of Health Care in Palestine: From the British Mandate to the Siege of Gaza,” Institute for Palestine Studies Policy Paper (2026), <https://www.palestine-studies.org/en/node/1658477>.
15. *Ibid.*
16. R. Giacaman, *Health Conditions and Services in the West Bank and Gaza Strip* (United Nations Conference on Trade and Development, 1994). See also M. Barghouti and R. Giacaman, “The Emergence of an Infrastructure of Resistance: The Case of Health,” in J. Nassar and R. Heacock (eds), *Intifada: Palestine at the Crossroads* (Praeger, 1990).
17. Y. M. Asi, “Palestinian Dependence on External Health Services: De-Development as a Tool of Dispossession,” *Middle East Law and Governance* 14/3 (2022).
18. *Ibid.*; L. Wick, “Building the Infrastructure, Modeling the Nation: The Case of Birth in Palestine,” *Culture, Medicine, and Psychiatry* 32/3 (2008).
19. L. Hanbali, “Reimagining Liberation Through the Popular Committees,” *Al-Shabaka* (February 16, 2022), <https://al-shabaka.org/briefs/reimagining-liberation-through-the-popular-committees/>; L. Hanbali, “The Destruction of the Health Sector in the Gaza Strip,” Institute for Palestine Studies Policy Paper (2024), <https://www.palestine-studies.org/en/node/1655249>.
20. J. M. Abi-Rached, A. I. Sharara, M. P. Nasrallah, et al., “Healthicide and Medical Neutrality: A Call for Action and Reflection,” *BMJ Global Health* 10 (2025).
21. S. Allaw, “Ghassan Abu Sitta: The Healing Hero of Gaza,” *Legal Agenda* (December 13, 2023), <https://english.>

[legal-agenda.com/ghassan-abu-sitta-the-healing-hero-of-gaza/](https://legal-agenda.com/ghassan-abu-sitta-the-healing-hero-of-gaza/).

22. N. Shalhoub-Kevorkian, "Criminality in Spaces of Death," *British Journal of Criminology* 54 (2014); D. G. Atallah and Y. M. Abu-Jamei, "Rethinking Trauma Against a Genocidal World: Palestinian Healing Is a Sound of Our Victory," *Journal of Palestine Studies* 54 (2025).

## VIEWPOINT

# The Frame That Kills: Post-Abortion Care, Colonial Penal Law, and the Right to Health

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On April 24, 2026, the Kenyan Court of Appeal at Malindi reinstated criminal proceedings against a girl who had been arrested at age 17 for receiving post-abortion care for an incomplete abortion and against the clinical officer who had treated her.<sup>1</sup> The judgment in *Kenya Christian Professionals' Forum v. PAK* will be read as a setback for abortion rights in Kenya, and in that frame, it is a setback. But the frame is the problem.<sup>2</sup> *PAK* is not, on its facts, an abortion case. It is a post-abortion care case prosecuted under abortion statutes, and in this viewpoint, we argue that the court of appeal's central failure was to allow the slippage between these two categories to govern the proceedings. Recognizing this slippage as the mechanism of harm reframes both the doctrinal failure and the violation of the right to health that the judgment entails.

The right to health imposes obligations on the state.<sup>3</sup> General Comment 2 on Article 14 of the Maputo Protocol issued by the African Commission on Human and Peoples' Rights establishes that women must not be arrested, charged, or prosecuted for seeking abortion services or post-abortion care, that they must incur no legal sanctions for benefiting from such services, and that states must train and sensitize law practitioners, judges, magistrates, and police officers to give effect to this protection.<sup>4</sup> Kenya has ratified article 14(1) of the Maputo Protocol without reservation, and the threshold obligation is operative in domestic law through article 2(6) of the Constitution.<sup>5</sup> The obligation is engaged the moment a patient is arrested for receiving post-abortion care or a provider is charged for offering it, regardless of whether the prosecution

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eventually succeeds. Conviction is not the harm. Prosecution is.

The mechanism by which this threshold obligation is violated requires careful naming. Sections 158, 159, and 160 of the Kenyan Penal Code, under which the petitioners were charged, are direct descendants of the English Offences Against the Person Act 1861, transplanted into colonial Kenya through the 1930 Penal Code.<sup>6</sup> They remain similar to the 1861 act, with the Kenyan provisions more expansive than the English original in their scope of criminal liability. They were drafted more than 160 years ago, in a clinical environment that did not recognize post-abortion care as a category.<sup>7</sup> Post-abortion care—the management of complications regardless of whether the abortion was spontaneous or induced—emerged as a distinct clinical practice only in the late 20th century and was subsequently recognized by the World Health Organization as essential emergency obstetric care.<sup>8</sup> The Kenyan Ministry of Health adopted post-abortion care as official policy in 2012, and in 2013 directed that it be made an integral part of free maternity services.<sup>9</sup>

Sections 158, 159, and 160 of the Penal Code predate this entire architecture and contain no recognition of the distinction between procuring an abortion and treating its complications. The colonial provisions cannot, in their text, reach post-abortion care. Sections 158 and 160 require proof that the accused administered drugs or supplied instruments with the intent to procure miscarriage.<sup>10</sup> Section 159 requires the woman to have acted with the intent to procure her own miscarriage.<sup>11</sup> The *mens rea* is temporally located at the moment of action upon a continuing pregnancy. A clinician treating a woman after the miscarriage has already commenced or completed has not administered drugs to procure a miscarriage. The miscarriage has occurred. The intervention is directed at its consequences. Intent cannot operate retrospectively upon what has already happened.

The PAK charges nonetheless alleged the procurement of abortion against evidence that uniformly described post-abortion care. The petitioner's affidavit, the clinical officer's affidavit, and

the uncontroverted specialist evidence of Professor Joseph Karanja, an obstetrician who reviewed her medical records, all described an incomplete abortion presenting with bleeding, severe pain, and dizziness, managed clinically after the patient's arrival. The investigating officer's contrary assertion that no post-abortion care had been provided rested on no medical foundation.<sup>12</sup> The charges alleged conduct that the elements of the offenses could not reach. The proper response was threshold dismissal under the established Kenyan doctrine that prosecutions disclosing no offense constitute abuse of process, articulated in *Meme v. Republic* and *Commissioner of Police v. Kenya Commercial Bank*.<sup>13</sup> The court of appeal instead treated the case as a forum dispute about whether constitutional petitions are the proper vehicle for challenging prosecutions, accepting as given precisely what was at issue: that the conduct alleged matched the elements of the offenses charged. It did not.

### The frame slippage has a chilling effect

This is the frame slippage. A prosecution alleges abortion. Evidence describes post-abortion care. The court accepts the abortion frame, reinstates the prosecution, and treats the distinction between the two as a factual matter for trial rather than a legal matter for the threshold. The reinstatement is not neutral. It is itself the harm that the threshold obligation prohibits. By the time of acquittal—if acquittal comes—the patient has been arrested from a hospital bed, subjected to forced examination, detained for a month in juvenile remand, and put through years of criminal process. The clinician has been arrested at the workplace, had patient records seized, faced months in custody, and watched their professional reputation collapse. Other clinicians watch and learn. The systematic review evidence establishes that providers anticipate criminal justice procedures resulting from their clinical practice and that criminalization produces a chilling effect on health care provision, with negative implications for the rights to life, health, and privacy of women seeking care.<sup>14</sup>

The cost of this chilling is denominated in

deaths. Up to 14% of pregnancies in Kenya end in unsafe abortion, resulting in approximately 2,600 deaths annually, with severe complications most common among women aged 10 to 19 and a case fatality rate approximately nine times the rate in developed regions.<sup>15</sup> A 2024 study found that only 46% of primary-level facilities in Kenya had staff trained on post-abortion care, and only 16.6% had functional operating theaters or manual vacuum aspiration rooms.<sup>16</sup> The young, rural, economically marginalized women who bear this mortality share the petitioner's demographic profile. The legal architecture that the *PAK* judgment sustains shapes the clinical environment in which they live or die.

The right to health framework offers a remedy that does not require expanding the contested constitutional jurisprudence on abortion.<sup>17</sup> Courts can be asked to enforce, at the threshold of criminal proceedings, the distinction between abortion and post-abortion care that the clinical literature treats as foundational, that the colonial drafting of the Penal Code could not have anticipated, and that General Comment 2 requires states to maintain.<sup>18</sup> The argument asks courts to apply ordinary criminal law principles—the requirement that the conduct alleged match the elements of the offense charged—in light of uncontested clinical categories and uncontested human rights obligations.<sup>19</sup> It does not require courts to recognize abortion as a freestanding right; it requires only that they read criminal statutes faithfully.

*PAK* makes the requirement visible. The criminal law of Kenya does not, in its text, criminalize post-abortion care. We contend that the court of appeal, by allowing the frame slippage to pass unchallenged, permitted the criminal process to operate against post-abortion care in practice. The right to health framework demands that this gap between law and practice be closed. How long it remains open is now a question for every court that follows.

## References

1. “Kenyan Appeal Court Overturns Ruling That Affirmed the Right to Abortion,” *Africanews* (April 24, 2026), <https://www.africanews.com/2026/04/26/kenya-court-over->

[turns-landmark-abortion-rights-ruling/](#).

2. *Attorney General & Another v. PAK & Another*, Court of Appeal of Kenya at Malindi, Civil Appeal No. E030 of 2022, judgment of Kairu, Ngenye Macharia and Laibuta JJA, April 24, 2026.

3. Committee on Economic, Social and Cultural Rights, General Comment No. 14, UN Doc. E/C.12/2000/4 (2000); Committee on Economic, Social and Cultural Rights, General Comment No. 22, UN Doc E/C.12/GC/22 (2016).

4. African Commission on Human and Peoples' Rights, General Comment No. 2 on Article 14 of the Maputo Protocol (2014), para. 49; Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa (Maputo Protocol), OAU Doc. CAB/LEG/66.6 (2003), art. 14(1).

5. Constitution of Kenya (2010), art. 2(6).

6. Penal Code, ch. 63, secs. 158–160; derived from Offences Against the Person Act 1861 (UK), secs. 58–59. See also N. Akinyi, W. Saoyo, and T. Griffith, “Kenya’s Abortion Law Reform: A Tale of Hope and Despair,” in C. Ngwenya, E. Durojaye, S. Nabaneh, and N. Murungi (eds), *Abortion Law Reform in Africa: A Reproductive Health and Rights Perspective* (Pretoria University Law Press, 2025), [https://www.pulp.up.ac.za/images/edocman/edited-collections/abortion\\_law\\_reform/Chapter%206.pdf](https://www.pulp.up.ac.za/images/edocman/edited-collections/abortion_law_reform/Chapter%206.pdf).

7. World Health Organization, *Abortion Care Guideline* (2022).

8. *Ibid.*

9. Ministry of Medical Services, *Standards and Guidelines for Reducing Morbidity and Mortality from Unsafe Abortion in Kenya* (2012).

10. Penal Code (see note 6).

11. *Ibid.*

12. *Attorney General & Another v. PAK & Another* (see note 2), paras. 3–17.

13. [2004] KEHC 2623 (KLR); [2013] KECA 182 (KLR).

14. F. de Londras, A. Cleeve, M. I. Rodriguez, et al., “The Impact of Criminalisation on Abortion-Related Outcomes: A Synthesis of Legal and Health Evidence,” *BMJ Global Health* 7/12 (2022).

15. African Population and Health Research Center, “Unintended Pregnancies, Unsafe Abortion and Maternal Mortality in Kenya” (November 16, 2023), <https://aphrc.org/publication/unintended-pregnancies-unsafe-abortion-and-maternal-mortality-in-kenya-2/>. See also G. Obhai, “Social and Structural Determinants of Unsafe Abortion in Kibera, Kenya: Implications for Young Women’s Reproductive Health Policy,” *Open Journal of Preventive Medicine* 15/4 (2025).

16. W. Muga, K. Juma, S. Athero, et al., “Barriers to Post-Abortion Care Service Provision: A Cross-Sectional Analysis in Burkina Faso, Kenya and Nigeria,” *PLOS Global Public Health* 4/3 (2024).

17. ICJ Kenya, *Right to Health Bench Book: Select Deci-*

*sions, Issues and Themes* (2023), <https://reproductiverights.org/wp-content/uploads/2024/10/Right-to-Health-Bench-Book.pdf>.

18. World Health Organization (see note 7).
19. Criminal Procedure Code (1930), sec. 134.

## VIEWPOINT

# A Decade of Failure: Attacks on Health Care Ten Years After Resolution 2286

JOSEPH J. AMON AND ROHINI J. HAAR

In May 2026, the Safeguarding Health in Conflict Coalition (SHCC) and Insecurity Insight issued their 2025 annual report on attacks on health care in conflict, entitled *Care in the Crosshairs: Violence Against Health Care in Conflict*.<sup>1</sup> The report marks an important milestone: 10 years since the unanimous adoption of United Nations Security Council Resolution 2286, which condemned violence against health facilities, patients, and health workers and demanded improved reporting, investigation, and accountability for perpetrators. A key finding of the report is that in the past decade, the resolution had little impact on the behavior of perpetrators, with 2,546 incidents of violence against or obstruction of health care documented across 33 countries and territories in 2025. Health facilities were damaged or destroyed on at least 790 occasions; 455 health workers were killed; 218 were kidnapped; and 263 were arrested. State forces were responsible for more than half of the attacks, but nonstate armed actors, including organized criminal groups, were also implicated.

The incidents documented—killings, kidnappings, and arrests of health workers; destruction of hospitals; and targeting of ambulances—occurred in 33 countries, including Palestine, Ukraine, Sudan, Myanmar, and the Democratic Republic of the Congo. In Gaza alone, 432 incidents were recorded, with at least 128 health workers killed and health facilities damaged or destroyed at least 97 times. Children’s hospitals, field hospitals, clinics, and medical storage sites were damaged by aircraft and drone strikes, artillery shelling, missiles, tank fire, and gunfire. In Sudan, children’s, field, women’s, and teaching hospitals, as well as health centers and laboratories, were damaged or destroyed on at least 40 occasions.

While intentionally targeting health workers and facilities can violate international humanitarian law, it is clear that systematically destroying health systems also undermines, if not makes impossible, government efforts to realize the right to health and improve underlying determinants of health (including access to clean water, sanitation, and food).<sup>2</sup>

How did we get here? What must be done to protect health workers and facilities?

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## The expansion of drone warfare and explosive weapons

Two years ago, SHCC's report on attacks occurring in 2023 noted that drones were increasingly being used to target first responders and health facilities.<sup>3</sup> The report documented drone attacks in nine countries: Burkina Faso, Ethiopia, Lebanon, Myanmar, the Occupied Palestinian Territory, Sudan, Syria, Ukraine, and Yemen. In 2024, the number of drone-delivered explosives that impacted health care services nearly quadrupled. One hundred forty-eight health facilities were damaged, killing at least 59 health workers.<sup>4</sup> In 2025, the use of drone-delivered explosives impacting health care increased even more, with 410 incidents recorded.<sup>5</sup> Incidents were reported in 12 countries, with new incidents of drone use documented in the Democratic Republic of the Congo, Iran, and Yemen.

In Ukraine, incidents where hospitals—including maternity and children's facilities—were damaged or destroyed by drones rose by 116%, from 137 in 2024 to 296 in 2025, with peaks between June and September corresponding to major military offensives. In Sudan, drone attacks rose by 700%, with over 75% linked to the Rapid Support Forces, particularly in the states of North Darfur and North Kordofan.

In Gaza, access to health care was affected by the Israel Defense Forces' use of explosive-laden robots—devices capable of causing extensive destruction—which were deployed near health facilities in Gaza City and Jabalia refugee camp in northern Gaza. The Israel Defense Forces also increased the use of gun drones (unmanned aerial vehicles specifically equipped with kinetic firearms) near health facilities and ambulances.

### Health workers arrested and detained

In 2025, health workers also faced an alarming escalation in arrests or detentions. More than 260 health workers were arrested or detained across 17 countries and territories. The circumstances of these detentions were often brutal: Many health workers were beaten or tortured in custody, and

at least seven died at the hands of their captors in Ethiopia, Gaza, Sudan, and Syria.

Health workers were arrested during violent hospital raids, seized at home or while en route to provide care, and swept up in mass civilian detention campaigns. In Ethiopia, over 26% of all health worker arrests occurred during coordinated crackdowns by the Ethiopian National Defense Force amid nationwide protests over pay, working conditions, and governance in the health sector, illustrating how health workers become targets during political upheaval.

In Sudan, both parties to the conflict detained health staff on allegations that they supported opposing forces, subjecting many of them to beatings, threats, and sexual abuse. Syria witnessed similar patterns, with interim government forces arresting health workers during hospital raids and at checkpoints. In Myanmar, arrests continued based on accusations of treating or having links to opposition forces. In Haiti, kidnappings surged in gang-controlled areas of Port-au-Prince.

### Addressing attacks on health

Despite clear prohibitions in international humanitarian law, violence against health care has become a disturbing feature of modern conflict. Laws meant to protect health care are disregarded, undermined, and impunity for perpetrators remains the norm.

Some have suggested approaching attacks on health care as a public health problem—documenting the scale and scope, identifying those most vulnerable, and developing preventive interventions.<sup>6</sup> These important efforts must be coupled with strengthening respect for international humanitarian law and ending impunity.

The 2025 SHCC report includes several recommendations addressed to United Nations (UN) member states, the UN Secretary-General, and the International Criminal Court. Specifically, the report calls for:

- UN member states to establish a new global alliance to protect health care during conflict, composed of a “coalition of the willing” that

would coordinate diplomatic pressure and action against attacks.

- the UN Secretary-General and member states to forcefully reject interpretations of international humanitarian law that undermine the protection of health care, including claims of broad license to attack hospitals based on misinterpretations of the law.
- the International Criminal Court to prioritize investigations and prosecutions of war crimes involving attacks on health care in all situations under its jurisdiction.

## Conclusion

Attacks on health facilities, personnel, and transport have profound impacts on the right to health broadly. The destruction of health facilities and the killing of health workers interrupt the ability of communities to access care and prevention services for days, months, and even years, jeopardizing realization of the highest attainable standard of physical and mental health. International human rights law obligates states to respect, protect, and ensure the right to health for all, including in conflict settings.

In 2025, millions of people lost access to health care as a result of attacks on health and the international community's inability to translate Resolution 2286 from noble intent to effective protection. A decade of little progress demands urgent, coordinated action. Change—and the protection of health care in conflict—remains possible, but only if states, international institutions, and civil society act expeditiously to demand accountability and end impunity for attacks on the wounded, the sick, and those who care for them.

## Acknowledgments

We would like to acknowledge the efforts of all SHCC members and health workers in conflict settings worldwide for their dedication to protecting workers, patients, and facilities.

## References

1. Safeguarding Health in Conflict Coalition and Insecurity Insight, *Care in the Crosshairs: Violence Against Health Care in Conflict 2025* (2026).
2. J. J. Amon and L. Rubenstein, "Drone Attacks on Health in 2023: International Humanitarian Law and the Right to Health," *Health and Human Rights* 26/1 (2024); L. Rubenstein, R. J. Haar, and J. J. Amon, "Attacks on Healthcare in War Are Being Steadily Normalized—We Need to End Impunity," *British Medical Journal* 390 (2025); M. A. Mamun, "How Can the Protection of Medical Personnel and Facilities Under International Humanitarian Law Be Strengthened?," *Medicine, Conflict and Survival* 40/3 (2024).
3. Safeguarding Health in Conflict Coalition and Insecurity Insight, *Critical Condition: Violence Against Health Care in Conflict 2023* (2024).
4. Safeguarding Health in Conflict Coalition and Insecurity Insight, *Epidemic of Violence: Violence Against Health Care in Conflict 2024* (2025).
5. Safeguarding Health in Conflict Coalition and Insecurity Insight (2026, see note 1).
6. K. H. Footer and L. S. Rubenstein, "A Human Rights Approach to Health Care in Conflict," *International Review of the Red Cross* 95/889 (2013).



# Women's Rights and Gender Equality: A Global Index to Monitor Government Action

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## Abstract

Globally, gender inequality is deepening, with nearly 40% of countries experiencing regression between 2019 and 2022 and significant backlash against women's rights in 2025. The Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) provides a legally binding framework for accountability, yet the potential of the Committee on the Elimination of Discrimination Against Women—the body that monitors state compliance with CEDAW—is constrained by the absence of systematic monitoring tools. This paper introduces the CEDAW Index, an artificial intelligence-supported digital dashboard designed to strengthen accountability by consolidating state reports,

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civil society shadow reports, and committee concluding observations. The current pilot focuses on recommendations regarding gender-based violence, with a framework designed to be extended across the full scope of CEDAW. We describe how the CEDAW Index assigns implementation status to each recommendation; tracks variables such as region, income group, and humanitarian crisis context; and integrates civil society perspectives to counterbalance government reporting. Pilot analyses of the most recent CEDAW reviews from 117 countries between 1997 and 2020 informed the dashboard's design and identified 423 laws that governments implemented or amended in response to law-related recommendations, representing 46% of such recommendations made by the committee during those reviews. We examine challenges associated with government opacity, artificial intelligence, and oversimplification, while arguing that the index offers a novel pathway to enhance transparency, amplify advocacy, and reinforce women's rights implementation globally.

## Introduction

Globally, gender inequality not only persists but is deepening. Examples from both the Global North and South, including restrictions on abortion care in the United States and a law permitting girl children to be married in Iraq, demonstrate some of the ways that women and girls' autonomy and rights are being eroded around the world. Advancing gender equality enhances the health, stability, and prosperity of all nations. Yet as we approach the 2030 deadline for the Sustainable Development Goals, not a single indicator under Goal 5 (gender equality) has been fully achieved.<sup>1</sup> Further, between 2019 and 2022, nearly 40% of countries, home to over 1.1 billion women and girls, experienced either stagnation or regression in advancing gender equality.<sup>2</sup>

One of the most pervasive manifestations of gender inequality is gender-based violence (GBV), which represents a major and well-documented public health concern. An estimated 736 million women—almost one in three globally—have been subjected to physical or sexual intimate partner violence, non-partner sexual violence, or both at least

once in their life.<sup>3</sup> In 2022, almost 50,000 women and girls worldwide were killed by their intimate partners or other family members—an average of more than five women or girls every hour.<sup>4</sup>

GBV has profound and long-term impacts on women's health. Women at risk of violence face a disproportionate burden of ill health, including depression and suicidal ideation and a twofold risk of being diagnosed with cervical cancer.<sup>5</sup> They often have poor access to life-saving, quality services that provide health and psychosocial support, particularly in low-resource settings.<sup>6</sup> These impacts extend beyond health, shaping women's ability to participate fully in social and economic life.<sup>7</sup>

The year 2025 marked the 30th anniversary of the seminal global blueprint for advancing women's rights, the Beijing Declaration and Platform for Action, adopted by 189 countries at the Fourth World Conference on Women. Three decades on, however, progress has been uneven and fragile. The anniversary is a milestone but also a reminder that despite rhetorical commitments, governments have fallen short of delivering the systemic reforms needed to secure women's rights in practice. The urgency of developing tools that can support advocates and

policy makers in advancing timebound and effective government action has become increasingly clear. International women's rights scholars and advocates have called for the more strategic use of global institutions, including the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW), to enhance the accountability of United Nations (UN) member states with regard to women's rights.<sup>8</sup> Civil society advocates have argued that such institutions have the leverage and mechanisms needed to hold UN member states accountable.<sup>9</sup>

For over four decades, the Committee on the Elimination of Discrimination Against Women (CEDAW Committee) has monitored state compliance with obligations set out in the convention, issuing legally binding recommendations to 189 ratifying countries through a four-yearly periodic review process, as well as through individual communications and inquiry procedures. Grounded in a treaty that spans all areas of social, economic, and political life, the committee's work addresses issues across health, education, justice, labor, and beyond. GBV is not confined to a single provision of the convention and is addressed across multiple articles, including those relating to health, equality before the law, and nondiscrimination, and elaborated through the committee's general recommendations, which provide authoritative guidance on how states should interpret and implement their obligations in practice. As a result, recommendations and corresponding government actions relating to GBV are often diverse, spanning legal reform, service provision, data collection, and institutional change. This cross-sectoral approach has driven major legal and policy reforms in contexts as diverse as Paraguay, Mauritius, the Netherlands, Uzbekistan, and Mexico, including legal and institutional changes to address GBV.<sup>10</sup> However, many recommendations remain unimplemented, unacknowledged, or insufficiently resourced, limiting their impact and visibility over time.

At the same time, the CEDAW Committee's work is under increasing strain. Some sessions in 2025 were canceled due to funding shortages across the UN treaty body system. In a period of upheaval

for the UN, strengthening tools that can extend and complement the committee's monitoring function has never been more critical.

To respond to this gap, we are developing the CEDAW Index, a digital dashboard supported by artificial intelligence (AI) that is designed to strengthen accountability by consolidating state reports, civil society organization shadow reports, and CEDAW Committee concluding observations (hereafter recommendations). While these materials are publicly available, they are dispersed across multiple platforms and formats, making them difficult to access and compare over time. Our index goes beyond aggregation by applying a structured analytical framework to assess the nature and extent of government action in response to recommendations.

Using a combination of AI-assisted methods and expert review, the index identifies reported actions, categorizes them, and assigns an implementation status. The current pilot focuses on GBV-related recommendations. However, the framework underpinning the CEDAW Index is designed to assess implementation across the full scope of women's rights obligations.

By translating legal obligations into transparent, comparable data, the index offers advocates, researchers, and policy makers a shared evidence base to assess progress, identify barriers, and sustain pressure for reform. Over time, it aims to reduce the analytical burden on under-resourced institutions and enable a more coordinated response across civil society, research, and policy domains.

This paper explores the rationale for the tool, the methodological processes behind data capture, the interpretation of outputs, and the tool's intended application and impact.

## The need for coordinated data and tools in CEDAW monitoring

While the CEDAW Committee provides a comprehensive framework for advancing international women's rights, no tool currently exists to systematically track the implementation of the committee's

recommendations across the 189 state parties to the convention. Periodic state reports differ widely in scope, structure, and specificity, reflecting national diversity but making cross-country comparison challenging. The result is fragmented, descriptive data that can obscure whether commitments translate into action.

In this context, implementation is often difficult to evaluate. In some cases, states may take steps that are ineffective, poorly designed, or misaligned with the needs and experiences of the women they are intended to assist.<sup>11</sup> Without effective scrutiny, government inaction or superficial reforms can go unchecked and unchallenged.

Compounding the absence of a systematic monitoring tool, the CEDAW Committee relies heavily on the contributions of often under-resourced civil society organizations to provide shadow reports that serve as a critical “reality check” on state party compliance.<sup>12</sup> These reports often highlight discrepancies between government claims and lived experiences, bringing to light persistent barriers to implementation, including policy failures that undermine access and equity. For example, our research on state responses to committee recommendations identified common challenges, including ongoing government inaction, gender-discriminatory legal provisions, and the chronic underfunding of health and social support systems.<sup>13</sup>

A further limitation lies in the disconnect between different knowledge communities, including public health researchers and human rights advocates. Public health and development researchers generate extensive evidence on violence against women, service delivery, and intervention effectiveness, while human rights advocates focus on legal accountability and state compliance.<sup>14</sup> These domains are often only partially integrated. Researchers may not engage directly with human rights frameworks, while human rights advocates may have limited access to comparative or evaluative evidence on what interventions are effective. This fragmentation reduces opportunities to link evidence with accountability.

Several tools already exist to rank or categorize

government action as it relates to CEDAW. For example, the Gender Legislative Index ranks and scores legislation against CEDAW’s international standards on women’s rights in four countries.<sup>15</sup> The Danish Human Rights Institute’s SDG–Human Rights Data Explorer links CEDAW Committee recommendations to the Sustainable Development Goals.<sup>16</sup> The UN Women Global Database on Violence Against Women and Girls serves as a descriptive repository of national laws, policies, and services, including some CEDAW data.<sup>17</sup> However, none of these tools systematically tracks the implementation or outcomes of CEDAW Committee recommendations. This led us to begin development of the CEDAW Index.

To address this gap, we undertook a pilot analysis of CEDAW reviews from 117 countries between 1997 and 2020. This analysis identified 423 laws that governments reported implementing or amending, including 85 concerning GBV, the rights of refugees and migrants, and protections for LGBTQIA+ individuals.<sup>18</sup> While these reforms cannot be attributed solely to CEDAW Committee recommendations, they reflect areas where domestic legal change aligns with issues raised through the CEDAW review process.

These findings challenge some common assumptions. Implementation patterns were broadly similar across World Bank income groups (low-, lower-middle-, upper-middle-, and high-income countries). Governments facing resource constraints or humanitarian crises took meaningful steps, although implementation remained lower in crisis-affected countries, where 34% of recommendations were implemented compared with 53% in non-crisis settings. At the same time, the presence of legal change does not necessarily indicate effective implementation or improved outcomes for women. Many reforms are under-resourced or unevenly enforced, limiting their impact in practice.

By systematically structuring and analyzing these data, the CEDAW Index highlights both the potential and limitations of existing accountability processes. It demonstrates how more coordinated monitoring can reveal patterns of response across contexts, while underscoring the need to interpret

legal and policy change alongside evidence on implementation and lived experience.

### The CEDAW Index: A new framework for monitoring implementation

The CEDAW Index will offer a systematic approach to tracking and analyzing the CEDAW Committee's recommendations, government actions, and responses from civil society organizations. Findings will be visualized through a digital dashboard that consolidates recommendations from periodic reviews, categorizing them by nature, scope, and extent of implementation, while distilling key insights from local, regional, and global contexts.

Here, the key unit of analysis is individual CEDAW recommendations. The term "index" is used to denote a systematic framework for organizing and analyzing implementation data across multiple dimensions, rather than a composite indicator that aggregates performance into a single score.

The CEDAW Index has been designed for human rights advocates, researchers, and policy makers, as well as the CEDAW Committee itself. It offers a unique opportunity to monitor government actions on women's rights by providing robust data and insights. The index will provide advocates with the opportunity to communicate effectively, craft evidence-based arguments, and contribute to mobilizing grassroots movements. We believe that these insights will be instrumental in strengthening women's rights advocacy, shaping global accountability processes, and driving systemic change. At the same time, it is important to note that the index tracks reported state actions and patterns of response; it does not, on its own, measure the effectiveness of those actions or their impact on women's lived experiences. Rather, it provides a foundation that can be complemented by qualitative insights and outcome-focused research.

#### *Primary data sources*

The index will draw from three key data sources: periodic reports submitted to the CEDAW Committee by governments (state reports), shadow

reports submitted by civil society organizations, and the concluding observations issued after review by the committee. All reports are publicly accessible through the UN Treaty Body Database, hosted by the Office of the United Nations High Commissioner for Human Rights.<sup>19</sup>

To analyze implementation, the index links recommendations issued in a given review cycle with information reported in subsequent state and civil society submissions (each country's most recent report). State reports often describe legislative, policy, or programmatic developments since the previous review, while shadow reports provide additional context, including critiques of implementation gaps. By aligning these sources across reporting cycles, the index identifies instances where governments report legal or policy changes in areas addressed by prior recommendations. This approach allows for systematic analysis of how reported actions correspond to issues raised through the CEDAW review process.

#### *Participatory development*

The development of the CEDAW Index followed an iterative, participatory design process involving researchers, data scientists, and civil society organizations to ensure both methodological rigor and utility for end users. In March 2024, two virtual workshops were held to test the dashboard's design. The first, hosted by the George Institute for Global Health, focused on the needs of researchers; the second, co-hosted by the George Institute for Global Health and International Women's Rights Action Watch Asia Pacific, engaged civil society organizations from South Africa, Kenya, India, and Indonesia to explore how the index could strengthen advocacy and accountability.

Across both workshops, participants emphasized methods transparency, noting that the tool's credibility depends on open access to data protocols, clear inclusion criteria, and acknowledgment of limitations. This led to the inclusion of a dedicated methods section within the dashboard, providing users with access to data sources, methodology, and the rationale underpinning each classification. This includes brief model-generated

justifications alongside human analyst explanatory notes. Each data point links back to its original UN report, ensuring traceability and building trust in the findings.

Accuracy and reliability were prioritized. Researchers recommended robust quality control systems for all AI-assisted processes. The index will therefore use a human-in-the-loop workflow, whereby machine learning supports, but does not replace, expert review. All AI-generated outputs are reviewed by human experts prior to inclusion, with particular attention given to cases where the classification of government actions in relation to a recommendation is not straightforward.

Participants also underscored the need for responsiveness to end users, recommending continuous engagement through usability testing and feedback channels. Collaboration with civil society organizations was viewed as essential by both researchers and civil society organizations for expanding coverage, particularly to spotlight populations and forms of violence underrepresented in human rights monitoring. The index's data model will therefore accommodate perspectives from both government and civil society reports, and civil society organizations can highlight implementation barriers and local context.

Civil society partners highlighted the importance of going beyond implementation to measure the impact and effectiveness of the index. This feedback informed the plan to integrate case studies and qualitative insights from civil society organizations and researchers, positioning the index not only as an accountability tool but as a learning platform on what drives and hinders reform.

### *Key features of the CEDAW Index dashboard*

Building on the design principles developed through the participatory design process, the index will provide both summary and raw data for each CEDAW Committee recommendation and corresponding government action. Raw data consist of excerpts from state and civil society reports, which are often lengthy and heterogeneous in format. These are complemented by concise summaries that synthesize relevant information while preserv-

ing key details, enabling users to quickly interpret findings while retaining access to source material. Each data point is linked to its original periodic report via a direct hyperlink, allowing users to review the information in the context of the full country submission where needed.

Each recommendation is assigned an implementation status based on predefined criteria:

- Fully implemented: The action meets all elements of the recommendation.
- Partially implemented: Only some aspects are addressed.
- Inadequate response: The action taken diverges from or falls short of what was recommended.
- Unacknowledged: The recommendation is not mentioned or acted upon.

Recommendations and corresponding actions will be tracked across multiple variables, including country and region, World Bank income group, humanitarian crisis status, form of GBV, and affected population groups.

Technologies such as AI offer fresh opportunities to strengthen women's movements by making information and solutions more accessible. Over the last two years, the annual United Nations Commission on the Status of Women has convened global stakeholders to assess progress on gender equality through the lens of innovation, technology, and digital education. UN Women and other groups have recognized AI's vast potential to transform how employment, public services, and education benefit women and girls. At the same time, they have highlighted the risks of AI, including its relatively unregulated nature, rapid pace of advancement, and inequities in access to the technology and opportunities to shape it. UN Women has noted that the gender digital divide—where, for example, only 20% of people in low-income countries have internet access—creates a data gap that contributes to gender bias in AI. Who develops AI systems, and what assumptions or biases are embedded within them, can either perpetuate or reduce gender inequalities. These biases manifest

in multiple ways, including discriminatory hiring algorithms, stereotyping in digital assistants, and exclusion of women's health data from training datasets. Yet insufficient attention has been paid to how these biases can be addressed, as well as how we can harness the transformative potential of AI for women's rights.

Analyses for the CEDAW Index will be undertaken by health, policy, and human rights experts, supported by AI and large language models (LLMs). The analysis draws on the team's grounding in global health research, particularly in areas such as GBV, while applying a framework that spans the full scope of CEDAW obligations.

To assess how well LLMs perform across different tasks in the CEDAW reporting process, proof-of-concept workflow (Figure 1) comprises three components. First, using human-extracted CEDAW recommendations, an LLM, prompted using structured instructions developed and validated by a team of data scientists (SZ and UA) is used to assign an implementation status. Second, based on the same inputs, the LLM is used to generate metadata tags by classifying recommendations and government actions by theme, facilitating systematic monitoring and comparative analysis. Third, using human-extracted recommendations paired with the original state reports, the LLM is used to extract relevant government actions for inclusion in the database.

Preliminary analyses led by SZ evaluated recent, well-performing open-source LLMs (LLaMA 3 and LLaMA 3.1 series) at the time, and the best-performing configurations were selected for each task. As an initial feasibility assessment, the analysis was conducted using data from five countries ( $n = 36$ ) to enable a focused and controlled evaluation prior to scaling up the approach. All periodic reports used in this analysis are publicly available through the Office of the United Nations High Commissioner for Human Rights database in English (as well as other official UN languages), and no additional translation was required for this study. Given the limited sample size, a formal train-test split was not performed, as the objective was to assess feasibility and to examine whether the tasks

could be effectively addressed under optimized prompting conditions.

Model performance for the first two tasks was assessed using overall accuracy. The model (Llama-3.1-70B-Instruct with 4-bit quantization) achieved high accuracy on the first task, correctly identifying implementation status in about 91.67% of cases. Meanwhile, the model (Llama3-8B-instruct) exhibited robust performance on the second task, accurately categorizing recommendations across 15 themes, such as forms of violence and population subgroups (e.g., women within lower socioeconomic communities or lower socioeconomic status), with an overall accuracy of 82.93%. While accuracy varied for categories with few data points, these results establish a baseline for future analyses.

For the third task, two context-engineering approaches to providing context to the LLM were explored. In a long-context approach, the full document is provided as input, allowing access to complete contextual information, although performance may be affected for longer or more complex documents. In a retrieval-augmented generation (RAG) approach, documents are segmented into smaller text units and encoded using an embedding model (float/e5-mistral-7b-instruct), and semantic similarity is used to retrieve the most relevant segments, which are then provided as context to the LLM. This approach focuses the LLM on the most relevant portions of the text.

The performance of the third task was assessed using both an automated similarity measure (measured as the average cosine similarity between the model outputs and reference text, where values closer to 1 indicate higher similarity) and human validation. The long-context approach achieved higher cosine similarity than the RAG approach (0.69 vs. 0.63), whereas human validation scores were higher for the RAG approach (63% vs. 60%), indicating improved relevance and completeness. Across both approaches, the model (Llama-3.1-8B-Instruct) consistently achieved the strongest performance. Human validation was conducted by a data scientist (SZ) and a global health lawyer (JS), with agreement reached through consensus based on the proportion of extracted actions judged to be

correct by both reviewers.

Additional analyses were conducted for the third task. First, we assessed whether our solution introduced bias in the model's ability to distinguish between cases where governments had acted and those where no action was taken. No statistically significant difference was observed between the two cases ( $p > 0.05$ , twoproportion Ztest), suggesting that the method performs comparably across both scenarios without favoring one over the other. Second, we assessed generalizability by applying the approach to an independent held-out external dataset ( $n = 19$ ) from additional countries. When applied to new country reports, accuracy declined, with long-context and RAG approaches achieving approximately 0.41 and 0.39 (cosine similarity), and 35% and 42% (human validation), respectively, reflecting the diversity of reporting formats and the limited size of the development dataset. These results should be interpreted cautiously. The evaluation applies a strict binary criterion, where partially correct or semantically similar outputs may be classified as incorrect, making the metric inherently conservative. Notably, in several instances the model identified relevant government actions not captured in manual review, suggesting its value as a complementary analytical tool.

During the development of the dataset that will support the CEDAW Index, we recorded explanatory notes for each committee recommendation, documenting the reasoning behind the assigned implementation status.

The explanatory notes provide an implementation assessment—a structured reasoning process that documents how each recommendation's implementation status is determined. It ensures transparency, consistency, and traceability in the analyst's judgment.

As discussed earlier, each CEDAW Committee recommendation from cycle 1 is compared against the government's cycle 2 report to assess what actions were taken. Analysts first identify the corresponding state actions and then evaluate the extent of implementation, classifying it as fully implemented, partially implemented, inadequate response, or unacknowledged.

The explanatory notes record the reasoning behind each classification, drawing on key interpretive dimensions that guide analysts in determining implementation quality and completeness, including action specificity, timelines (when and over what period government action occurred), legal or institutional status (whether the measure is binding, adopted, and operational), and resourcing (evidence of budget allocation or implementation capacity).

Analysts use these dimensions to explain why a particular implementation status was assigned, especially in ambiguous cases where state reporting is vague or incomplete. This reasoning is documented within the index dataset as a transparent "audit trail," enabling others to understand the interpretive logic behind each assessment by connecting textual evidence, contextual understanding, and expert judgment to produce a reproducible implementation status.

These analyses allowed us to demonstrate, for example, how broad policy commitments without targeted measures were classified as only partially implemented, or how the absence of any state response was recorded as unacknowledged. By systematically applying this method across countries, our analysis highlighted where governments had taken meaningful action, where they had failed or declined to act, and where responses were inadequate. It also revealed recurring gaps in implementation, such as vague or generalized measures that did not address the specific focus of a recommendation, while situating these findings within wider global trends. Table 1 provides illustrative assessments of government responses to CEDAW recommendations, including the implementation status assigned in each case.

Findings of the analyses will be presented on the dashboard through data visualizations that enhance accessibility for advocates, researchers, and decision-makers, enabling them to easily identify patterns and trends. These visualizations also aim to foster collaboration between researchers and civil society organizations, facilitating the generation of empirical research findings that support advocacy efforts, while providing valuable real-world

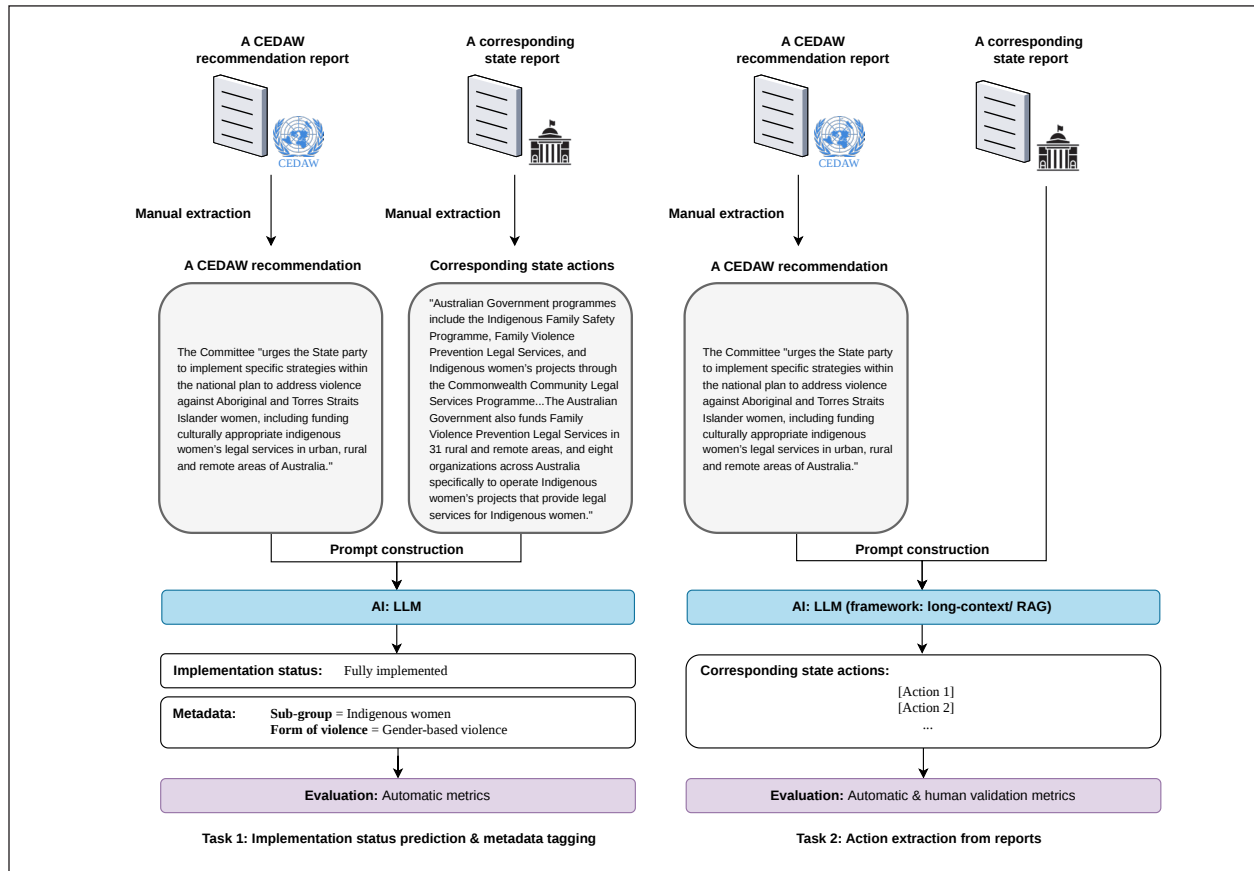
insights into implementation challenges.

By mapping implementation across countries, the index will reveal common enablers and barriers—political, fiscal, cultural, and otherwise—that impact governments’ abilities to fulfill their CEDAW obligations. For instance, prior analyses using pilot data distinguished between instances where governments required additional time to introduce GBV legislation and those where they refused to implement it. Those analyses showed that Haiti had drafted a framework law criminalizing marital rape, which was awaiting inclusion in the next legislative agenda, while Uruguay had presented similar legislation to the House of Representatives. Conversely, the governments of the Democratic Republic of Congo, Malaysia, and Sri Lanka defended their existing legislative frameworks, which lacked specific provisions criminalizing domestic violence and marital rape.<sup>20</sup>

Where available, civil society insights into government actions will accompany each of the index’s published recommendations and actions, capturing nuances related to the quality, scale, resources, and reasons for implementation failures that may not be reflected in official government reporting. This dual perspective offers a more comprehensive view of the implementation process and highlights persistent barriers to effective action. Table 2 illustrates the value of this dual perspective, showing how civil society reporting can provide detail that is absent from state reports.

Additionally, the CEDAW Index will feature case studies that illustrate real-world examples of both successes and challenges in implementation. Informed by data from civil society organizations and empirical research findings, these case studies will provide detailed insights into the impact of policies, programs, and laws, enabling the index

FIGURE 1. Workflow of CEDAW Index large language models



to be used to identify successfully implemented legislative and policy models (as reported by governments) that can be replicated or scaled in other jurisdictions. It is hoped that over time, showcasing the ongoing effectiveness and acceptability of interventions years after their introduction can help ensure that implementation is treated not as a final goal but rather as an ongoing process requiring evaluation and refinement.

As an example, following its 2007 review of Brazil, the CEDAW Committee recommended the systematic monitoring of the Maria da Penha Law on domestic violence. While the Brazilian gov-

ernment highlighted at its subsequent review that the law had led to over 300,000 prosecutions and 100,000 judgments, civil society organizations have highlighted that its benefits remain concentrated largely in urban areas. This uneven implementation raises concerns in relation to article 14 of CEDAW, which obliges states to ensure that rural women enjoy equal access to legal protections and services. The ongoing CEDAW review process will allow for continued refinement of legal and policy models over time.<sup>21</sup>

Ultimately, at a systems level, the CEDAW Index could enhance the review process in several

TABLE 1. Illustrative assessments of government responses to CEDAW recommendations

Example 1	
Summary recommendation by CEDAW Committee	Government response
Develop strategies to prevent domestic violence-induced homelessness and support women affected by domestic and family violence. (Australia, 2010)	“In 2013, the Tasmanian Women’s Plan 2013–2018 was launched. It focuses on six priority areas: economic security and financial independence; education and training; health and wellbeing; housing and homelessness; leadership and community participation; and safety and justice.” “The Australian Government provides states and territories with approximately AUD \$1.3 billion annually under the NAHA [National Affordable Housing Agreement], including approximately AUD \$250 million to address homelessness.”
<b>Implementation status:</b> Partial	
<b>Explanatory notes:</b> While references are made to funding allocations and broad policy commitments related to homelessness, there is no evidence of specific strategies targeting homelessness caused by domestic violence. Moreover, the information provided does not address the impact or effectiveness of any initiatives, leaving the committee without assurance that women affected by domestic violence—and their children—are receiving appropriate, ongoing accommodation and integrated support.	
Example 2	
Summary recommendation by CEDAW Committee	Government response
Widen the definition of rape in India’s Penal Code and remove the exception for marital rape. Consult widely with women’s groups in the process of reform. (India, 2007)	No state action taken
<b>Implementation status:</b> Unacknowledged	
<b>Explanatory notes:</b> There is no reference to the intervention requested by the committee in the state party report.	
Example 3	
Summary recommendation by CEDAW Committee	Government response
Establish support services to meet the health and psychosocial needs of victims of female genital mutilation. (Kenya, 2011)	“A National Domestic Toll Free Short Code was allocated to Health-care Assistance Kenya by Communication Authority of Kenya and launched on 21st February 2013. The Toll-free helpline 1195 enhances support for survivors of rape, defilement, FGM [female genital mutilation] and physical assault.”
<b>Implementation status:</b> Partial	
<b>Explanatory notes:</b> While the government’s introduction of the toll-free helpline aligns with the committee’s imprecise recommendation to “establish support services,” there is no indication in the state’s response about how this helpline “meets health and psychosocial needs.” Additionally, it is a generalized helpline, not one tailored to the needs of victim-survivors of female genital mutilation. While the committee’s recommendation was imprecise, “support services” connotes a broader, more direct provision of care that potentially includes the health care workforce.	

ways: (1) by providing historical data on previous periodic reports submitted by state parties, highlighting areas where recommendations were made but not implemented; (2) by providing implementation insights to inform constructive dialogue and the design of new recommendations; and (3) by providing research and information regarding best-practice interventions that can be used by the CEDAW Committee and civil society organizations in the follow-up process at the national level.

### Challenges associated with the CEDAW Index

Despite its potential, the CEDAW Index faces several challenges. First, governments largely control the narrative surrounding their human rights records and have been known to engage in practices that may obscure the reality of their actions, particularly when there are perceived political consequences to human rights failures.<sup>22</sup> Where governments are not forthcoming about their implementation of recommendations, this can hinder the index’s ability to present an accurate picture

of global progress in addressing GBV. Here, the voice of civil society is essential: Shadow reports, advocacy, and independent monitoring can counterbalance state narratives and provide a reality check that strengthens the accuracy and legitimacy of the index.

Another major hurdle is the involvement of AI. While AI can enhance efficiency, automating data extraction and enabling large-scale comparative analysis, it also carries inherent limitations. Effective use demands human oversight, rigorous data curation, and a commitment to ensuring data quality, completeness, and objectivity in model training. AI may be constrained in addressing the complex and context-dependent nature of women’s rights, since local gender norms, religious beliefs, and political power structures shape implementation in ways that AI models may not adequately capture. Moreover, the “black-box” nature of deep learning models can hinder transparency in decision-making. To mitigate these risks, the index combines machine learning with expert human assessment: Models are trained only on approved datasets and are required to produce a replicable

TABLE 2. Comparison of government and civil society reporting to the CEDAW Committee

Example 1	
Summary recommendation by CEDAW Committee	Government response
Adopt, implement, and adequately fund the National Action Plan to Reduce Violence against Women and Their Children, incorporating an independent monitoring mechanism. (Australia, 2010)	“All governments in Australia are currently implementing the National Plan to Reduce Violence against Women and their Children 2010–2022 ... These efforts complement a \$100 million women’s safety package.”
<b>Civil society organization response:</b> “There is no specific budget allocation for the implementation of the Australian NAP [National Action Plan]. It is assumed that planning for, and implementation and monitoring and evaluation of NAP responsibilities will take place within existing resources ... The 1st Australian NAP lacks a robust monitoring and evaluation framework to assess progress, achievements and impacts. The descriptive nature of indicators only allows for a recounting of actions undertaken under each of the five strategies.” (Women, Peace and Security)	
Example 2	
Summary recommendation by CEDAW Committee	Government response
Widen the definition of rape in India’s Penal Code and remove the exception for marital rape. Consult widely with women’s groups in the process of reform.	No state action taken
<b>Civil society organization response:</b> “The Indian Penal Code continues to retain a rape exception when committed by a man on a wife who is over 15 years of age. Only rape committed within a marriage when the spouses are living separately can be punished, and then with a lower sentence than that given to rape outside a marriage. Courts in India have used the exception provided in Section 375 to acquit men accused of committing marital rape. In May 2014, a ‘fast-track’ court in Delhi designated to hear cases of sexual assault against women relied on this exception to rule that sexual intercourse between a legally wedded husband and wife ‘even if forcible, is not rape.’” (Amnesty International)	

reasoning pathway (explanatory notes) that is reviewed by human experts before findings are finalized. In this way, AI augments rather than replaces human judgment.

A further challenge is that while visualizing human rights data can support international collaboration and shared understanding, it also has drawbacks. Applying a status to complex women's rights issues may oversimplify social phenomena and obscure rich contextual factors that are needed for a comprehensive analysis.<sup>23</sup> For example, countries making significant legislative reforms may appear to have higher implementation rates simply because they have more ground to cover, while countries with already higher levels of gender equality may register fewer new reforms—a phenomenon often described as “the last mile.”<sup>24</sup> To avoid the impression of a ranking exercise, the index does not assign comparative “scores.” Instead, it classifies implementation status and provides contextualized analyses that situate country actions within their specific political, legal, and social contexts. While the current dataset is cross-sectional, future iterations of the index may incorporate historical data to track change over time.

As an illustration, our pilot report using cross-sectional data in the Asia-Pacific region showed that Afghanistan—a context in which women have been prohibited from speaking in public, and more recently praying aloud in front of other women—had fully implemented 63% and partially implemented 21% of the CEDAW Committee's recommendations.<sup>25</sup> These results were higher than those recorded for Australia and New Zealand, underscoring that the index measures willingness and capacity to respond to the committee's recommendations, rather than overall progress in achieving gender equality. To provide a more nuanced picture beyond the limited scope of the four-year review cycle, forthcoming country case studies will integrate historical data to identify patterns of progress and regression. By incorporating these perspectives, we hope to contribute to more constructive and transparent dialogue between the CEDAW Committee and government representatives.

Another challenge lies in the ongoing push for

sex-based frameworks within women's rights advocacy and UN processes. These frameworks, while presented as protective, often intentionally exclude trans, non-binary, and gender-non-conforming people from effective protections. For the index, resisting this narrowing of rights is essential: The tool is designed to reflect the diverse ways violence manifests across relational dynamics, geopolitical privilege, and economic disparities, and to avoid perpetuating epistemic violence.

A final challenge in leveraging the index to drive change is the persistent issue of government inaction. Despite CEDAW imposing legal obligations on state parties, the CEDAW Committee lacks the ability to compel states to address repeated implementation failures.<sup>26</sup> While the index cannot enforce compliance, it can expose gaps, mobilize civil society, and equip advocates with the data needed to push for meaningful reform. By amplifying the work of the committee and civil society organizations, and by combining data transparency with independent voices, the index aims to strengthen accountability through visibility and evidence.

## Conclusion

The fight for gender equality is at a crossroads. Despite the significant strides made over recent decades, stagnation and backsliding on women's rights remains a formidable challenge. While mechanisms such as the CEDAW review process provide a framework for accountability, the lack of systematic and accessible monitoring continues to hinder efforts to hold governments to account.

The CEDAW Index described here aims to address these challenges by providing a comprehensive, systematic approach to tracking and analyzing the CEDAW Committee's recommendations, related government actions, and civil society reporting. In its pilot form, this tool offers a unique opportunity to evaluate how well states are meeting their CEDAW obligations relating to GBV. Despite the challenges outlined above, the index offers a pathway to strengthening transparency and accountability in international women's rights

implementation.

While the CEDAW review process may often represent a tipping point—spurring governments to act only after extended periods of advocacy—it remains one of the strongest global mechanisms available to leverage international legal obligations for women’s rights. Our review of laws implemented following CEDAW reviews demonstrated that 47% of law-related recommendations were implemented in low-income countries, 48% in lower-middle and upper-middle-income countries, and 53% in high-income countries.<sup>27</sup> Additionally, we found that 14 countries had implemented or amended laws after initially failing to acknowledge the CEDAW Committee’s recommendations during their reviews. For example, in Nepal, penalties for marital rape were increased from up to six months to five years, while Angola updated its Penal Code to criminalize female genital mutilation. Bolivia legalized abortion in cases of rape, and Lesotho introduced a bill addressing domestic violence. These examples highlight that while the process of women’s rights implementation is often non-linear and drawn out, the strategic actions of advocates and women’s movements continue to play a critical role in getting GBV reforms and essential programs and services over the line.<sup>28</sup>

Ultimately, the development of tools such as the CEDAW Index, coupled with sustained advocacy efforts, offer a powerful pathway to enhancing the transparency, accountability, and impact of government actions on women’s rights. By providing robust, data-driven insights, fostering collaboration across sectors, and ensuring that diverse voices—particularly those of civil society—are amplified in the process, we can move closer to realizing the global commitment to gender equality and advancing the rights of women and girls everywhere.

## References

1. UN Women, *Progress on the Sustainable Development Goals: The Gender Snapshot 2024* (2024).
2. Equal Measures 2030, “2024 SDG Gender Index,” <https://equalmeasures2030.org/2024-sdg-gender-index/>.
3. World Health Organization, *Global Status Report on*

*Alcohol and Health 2018* (2018).

4. United Nations Office on Drugs and Crime and UN Women, *Gender-Related Killings of Women and Girls (Femicide/Feminicide): Global Estimates of Female Partner/Family-Related Homicides in 2022* (2023).

5. World Health Organization (2021), *Violence Against Women Prevalence Estimates, 2018: Global, Regional, and National Prevalence Estimates for Intimate Partner Violence Against Women and Global and Regional Prevalence Estimates for Non-Partner Sexual Violence Against Women* (2021).

6. United Nations Population Fund, *State of the World Population 2020: Against My Will—Defying the Practices That Harm Women and Girls and Undermine Equality* (2020).

7. World Bank, *Violence Against Women and Girls Resource Guide* (2015).

8. J. Klugman, *Gender Based Violence and the Law* (2017).

9. International Women’s Rights Action Watch Asia Pacific, *Annual Report 2023* (2024).

10. J. Shanthosh, *Redressing the Balance: Using Human Rights Law to Improve Health for Women Everywhere* (George Institute for Global Health, 2023).

11. M. L. Satterthwaite and A. Rosga, “Measuring Human Rights: UN Indicators in Critical Perspective,” in K. Davis et al. (eds), *Governance by Indicators: Global Power Through Quantification and Rankings* (Oxford University Press, 2013).

12. M. A. Freeman, “The Committee on the Elimination of Discrimination Against Women and the Role of Civil Society in Implementing International Women’s Human Rights Norms,” *New England Journal of International and Comparative Law* 16/1 (2010).

13. Shanthosh (see note 10).

14. R. Vijayarasa, “Quantifying CEDAW: Concrete Tools for Enhancing Accountability for Women’s Rights,” *Harvard Human Rights Journal* 34 (2021).

15. Gender Law Index, “Gender Legislative Index,” <https://www.genderlawindex.org/>.

16. Danish Institute for Human Rights, “SDG–Human Rights Data Explorer,” <https://sdgdata.humanrights.dk/en>.

17. UN Women, “Global Database on Violence Against Women,” <https://data.unwomen.org/global-database-on-violence-against-women>.

18. Shanthosh (see note 10).

19. J. Shanthosh, K. Muvva, M. Woodward, et al., “Assessing the Reach, Scope and Outcomes of Government Action on Women’s Health and Human Rights: A Protocol for the Development of an International Women’s Rights Dataset,” *International Journal of Qualitative Methods* 21 (2022).

20. Shanthosh et al. (see note 10).

21. Ibid.

22. H. Charlesworth and E. Larking (eds), *Human Rights and the Universal Periodic Review: Rituals and Ritualism*

(Cambridge University Press, 2015).

23. S. E. Merry, *The Seductions of Quantification: Measuring Human Rights, Gender Violence, and Sex Trafficking* (University of Chicago Press, 2016).

24. P. Alston (ed), *The Complexity of Human Rights: From Vernacularization to Quantification* (Bloomsbury Publishing, 2024).

25. OECD, *Is the Last Mile the Longest? Economic Gains from Gender Equality in Nordic Countries* (2018).

26. J. Shanthosh, *Launching the CEDAW Implementation Map on Women's Health: Progress on the Journey Towards Health and Human Rights for All Women* (George Institute for Global Health, 2021).

27. Shanthosh et al. (see note 10).

28. S. E. Merry, "Transnational Human Rights and Local Activism: Mapping the Middle," *American Anthropologist* 108/1 (2006).

# Well-Being Under Structural Constraints of Political Instability in the Israeli-Occupied West Bank: A Cross-Sectional Study

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## Abstract

The well-being of Palestinians living under prolonged Israeli occupation is deeply conditioned by the structures of deprivation and control that shape daily life. Using data from 3,000 adults residing in refugee camps and surrounding urban areas of the West Bank, this study examines how deprivation, political violence, and human rights violations relate to well-being as measured by the World Health Organization-Five Well-Being Index. Nearly three-quarters of respondents (73.8%) reported poor well-being. Material deprivation showed the strongest association with well-being: Those reporting low or moderate deprivation had 1.7- and 2.4-fold higher odds of poor well-being, respectively. Household exposure to political violence was associated with higher odds of poor well-being with an odds ratio (OR) of 1.35, while human rights violations by the Israeli military and the Palestinian Authority was associated with higher odds of poor well-being with an OR of 1.51 and 1.72, respectively. An interaction between locality and displacement revealed that stable camp residents had lower odds of poor well-being, while those displaced from camps had the highest risk. These findings show that in the West Bank of the Israeli-occupied Palestinian territory, well-being reflects the social geography of inequality, where displacement, deprivation, and ongoing political violence transform daily existence into a struggle for security and dignity, rendering the right to health inseparable from the right to live freely and safely.

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## Introduction

The well-being of populations living under chronic political instability is profoundly shaped by the structural constraints in which they live.<sup>1</sup> In the Israeli-occupied Palestinian territory (oPt), decades of Israeli military occupation have fragmented land and services, breaking the country into disconnected pieces and creating overlapping political, economic, and social constraints that define the daily lives of Palestinians. Restrictions on movement, widespread unemployment, land confiscation, and unequal control over resources have produced a system of structural constraints that extends far beyond direct violence and violations.<sup>2</sup> These constraints interact to inhibit people's opportunities and systematically undermine their physical and mental health.<sup>3</sup>

Within this context, human rights violations are widespread. Here, human rights refer to standards that define how persons should be treated.<sup>4</sup> In contexts of military occupation and armed conflict, the primary focus of the human rights discourse is on the relationship between the state and individuals, including how state agents observe or violate human rights under conditions of military occupation and, in the case of armed conflict, how protections are expressed in international humanitarian law.<sup>5</sup> Under the prolonged Israeli military occupation of the Palestinian territory, such violations have become embedded within the social, economic, and institutional fabric of daily life, producing what can be described as structural constraints on well-being.<sup>6</sup> Human rights violations in the oPt are various and are manifested through restrictions on movement, economic marginalization, spatial segregation, and unequal access to resources—conditions that constrain life opportunities and systematically undermine well-being.<sup>7</sup>

Published research related to the oPt has also largely prioritized exposure to political violence and its effect on health and well-being.<sup>8</sup> Although the political conditions that Palestinians endure under Israeli occupation and colonization are particularly harsh—affecting all aspects of life and generally undermining both well-being and physical health—exposure to political violence is not

the only form of harm to which Palestinians, and others worldwide, are subjected. Evidence shows that violence from family and community members, over and above the violence perpetrated by the Israeli military and the Palestinian Authority, is also important and contributes to the suffering that Palestinians experience throughout their lives.<sup>9</sup> This suffering produces what we call the invisible wounds inside a person, which can negatively influence health and well-being and need to be considered when examining the effects of violation, regardless of the perpetrator.<sup>10</sup>

Deprivation is another key dimension of harm in this context, encompassing the material, economic, social, and political restrictions that shape daily life under prolonged political instability. In the oPt, deprivation is not limited to poverty or lack of resources but also includes restricted movement, limited access to services, political fragmentation, and constraints on freedom and dignity.<sup>11</sup>

These personal and collective experiences of deprivation and violence reinforce cycles of vulnerability and limit opportunities for recovery and well-being.<sup>12</sup> In this sense, deprivation itself can be understood as a chronic violation of the rights to health, security, and dignity, linking inequalities directly to human rights violations.

This study builds on a research trajectory that we at the Institute of Community and Public Health at Birzeit University have pursued over the past several years. Our work has sought to understand how political instability, exposure to political violence, and deprivation interact with human rights violations to shape health and well-being among Palestinians living under occupation. This broader approach situates well-being as a reflection of structural constraints, including deprivation, gendered power relations, and prolonged political instability.

This study forms part of a broader research project that investigates the well-being of adults living in the West Bank of the oPt and the factors associated with their well-being, as assessed through participant reports using the World Health Organization-Five Well-Being Index (WHO-5). The study also examines the relationship between

these well-being reports and human rights violations by four categories of potential perpetrators, using a locally developed and validated instrument that understands human rights violations in an ecological and locally grounded way and captures violations across family, community, governing authority, and military occupation levels. In addition, the study assesses exposure to political violence, deprivation, and other demographic and socio-economic characteristics and how they are linked to well-being. In doing so, the study illuminates how persistent human rights violations, deprivation, and political instability together shape the well-being of Palestinians living under one of the world's most enduring military occupations.

## Methods

This is a cross-sectional study conducted between June 15 and July 31, 2025, in Palestinian refugee camps and surrounding urban areas in the north, center, and south of the Israeli-occupied West Bank. We used the World Health Organization's framework on the social determinants of health to guide our understanding of how political, economic, social, and material conditions shape well-being.<sup>13</sup> We also drew on the socio-ecological framework to conceptualize the multilayered nature of human rights violations and to organize the measured variables across personal, household, community and locality, and broader contextual levels. This framework is rooted in Urie Bronfenbrenner's ecological systems theory from the 1970s and was later adapted to the health sciences in the 1980s; it conceptualizes health as shaped by interacting influences across multiple levels, including intra-personal, interpersonal, institutional, community, and policy levels.<sup>14</sup>

We examined human rights violations across different social and political levels, including violations attributed to family, community, the Palestinian Authority, and the Israeli military occupation.<sup>15</sup> personal-level variables included age, sex, marital status, number of children, education, employment status, and chronic disease. Household-level variables included household exposure

to political violence and material deprivation. Community- and locality-level variables included governorate, locality, refugee status, displacement, and community-level human rights violations. Broader contextual variables included human rights violations by the Palestinian Authority and the Israeli military occupation, sociopolitical deprivation, and Oslo area classification. The study did not aim to measure all levels of the socio-ecological framework exhaustively, such as personal behaviors or policy-level variables; rather, we used the framework to support a layered interpretation of exposure and to organize the variables measured in this survey.

### *Target population and sample*

The study population included Palestinian men and women aged 18 years or older who lived in one of six areas across the northern, central, and southern regions of the West Bank. These areas included three Palestinian refugee camps and their surrounding urban areas. In the north, we selected the Jenin refugee camp and the surrounding urban area of Jenin City. In the center, we selected the al-Am'ari refugee camp for its proximity to the twin cities of Ramallah and al-Bireh. In the south, we selected al-Dheisheh refugee camp and the surrounding urban area of Bethlehem city.

The sample size was calculated separately for each of the six strata using a simple random sampling formula, based on the estimated prevalence of poor well-being from a 2022 study, a 95% confidence level, and a 5% margin of error.<sup>16</sup> The initial minimum required sample size across the strata was 2,244 participants (see Table 1). To account for the clustered sampling design, we increased this by 20%, resulting in a minimum required sample of approximately 2,693 participants. We therefore targeted 3,000 participants, with approximately 500 participants sampled from each stratum.

### *Data collection*

Within each stratum in the central and southern regions and the urban regions in the north, we selected clusters using systematic random sampling based on Palestinian Central Bureau of Statistics

enumeration units. We then systematically selected households within each cluster and selected one participant per household using the Kish table. In the Jenin refugee camp, household selection differed due to large-scale displacement following the 2023 war on Gaza and the subsequent escalation of Israeli military violence in the West Bank. Data collection relied on displacement lists obtained from the camp's popular committee, as approximately 75% of camp residents were displaced at the time of the study. Sampling within and outside the camp was conducted proportionally to cluster size to achieve the target sample size for each stratum. Data were collected by trained fieldworkers using electronic tablets and the Kobo Toolbox platform.

### Study instrument

We assessed well-being using the validated Arabic version of WHO-5. Item scores were summed, transformed to a 0–100 scale, and then dichotomized into poor versus good well-being using a cut-off score of 50.<sup>17</sup> Human rights violations were measured using locally developed instruments, including a general human rights violations scale and four perpetrator-specific subscales. In this analysis, human rights violations refer to reported violations across four perpetrator levels—family, community, Palestinian Authority, and Israeli military occupation—capturing exposure across different social and political contexts. Each scale included up to 15 items reflecting violations relevant to the specific context or ecological level. Scale scores represented the number of reported violations and were recoded into binary variables, with 0 indicating no reported

violations and 1 indicating the presence of at least one violation.<sup>18</sup>

We also used a scale measuring exposure to political violence, which captures personal and household exposure to political violence, as well as exposure through witnessing political violence. For each reported exposure, participants were asked to identify the perpetrator, with response options including the Palestinian Authority, the Israeli military occupation, and Israeli settlers.<sup>19</sup> Additionally, we used a nine-item deprivation scale with two main subscales: sociopolitical deprivation and material deprivation.<sup>20</sup> All of these scales were developed by the Institute of Community and Public Health, building on qualitative research, and were piloted and validated using factor analysis to ensure validity and reliability. Detailed scale items are presented in Tables 2, 3, and 4.

The instrument also included several demographic and socioeconomic variables, including age group (18–24, 25–40, 41–60, 61–92), sex (man, woman), marital status (never married, currently married, widowed/divorced), number of children (none, 1–3, 4–6, 7 or more), and education level (less than higher education (Tawjihi), passed Tawjihi, post-Tawjihi). Additional variables included work status (working, unemployed, housewife, other), reported economic status (excellent/good, less than good, bad), governorate (Jenin, Ramallah and al-Bireh, Bethlehem), locality (urban, refugee camp), and area classification based on the Oslo Accords of 1995 (Area A, Area B, Area C).<sup>21</sup> Questions on displacement in the past two years, refugee status, health insurance coverage, and the presence

TABLE 1. Sample-size calculation by stratum using simple random sampling (95% confidence interval, 5% margin of error)

Stratum	Low well-being prevalence (p)	Required sample size (n <sub>0</sub> )	Formula applied
Urban – north	0.418	374	$n_0 = \frac{1.96^2 p(1-p)}{0.05^2}$
Urban – center	0.376	360	
Urban – south	0.400	369	
Camp – north	0.470	383	
Camp – center	0.538	382	
Camp – south	0.571	376	

of chronic disease were also included. Fieldworkers were trained in administering the research instruments following piloting to ensure clarity, relevance, timing, reliability, and consistency.

*Statistical analysis*

Descriptive (univariate) analyses were first performed to summarize participants’ demographic, socioeconomic, and health characteristics. Bivariate analyses were then conducted to examine the associations between each independent variable and the WHO-5 well-being outcome, using chi-square tests (see Table 5). WHO-5 was analyzed as a binary variable. Independent variables were selected based on the socio-ecological framework and the World Health Organization’s framework

on the social determinants of health, encompassing factors at the personal, household, community, and broader contextual levels. Scales measuring exposure to political violence and human rights violations were recoded as binary indicators (0 = not exposed, 1 = ever exposed), while deprivation items were analyzed as ordinal variables. A factor analysis of the deprivation items yielded two distinct components: material deprivation and sociopolitical deprivation.

All multi-item scales demonstrated acceptable internal consistency, with Cronbach’s alpha values higher than 0.65. A multiple binary logistic regression model was then fitted to identify independent predictors of poor well-being. Adjusted odds ratios (ORs) with 95% confidence intervals (CIs) were re-

TABLE 2. Human rights violation scale

General human rights scale	<i>Prompt:</i> Have you ever experienced deprivation or violation of any of the following rights?
	<i>Response options:</i> 1 = not at all; 2 = a little; 3 = a lot; 4 = an extreme amount
	<p><i>Items:</i></p> <ol style="list-style-type: none"> <li>1. The right to be treated with respect</li> <li>2. The right to have your decisions be respected regardless of gender, age, or ideas</li> <li>3. The right to have your personal freedoms respected</li> <li>4. The right to safety</li> <li>5. The right to education</li> <li>6. The right to freedom of expression</li> <li>7. The right to health</li> <li>8. The right to have adequate infrastructure (e.g., sewage, water, electricity, and road networks)</li> <li>9. The right to be treated with equality and without discrimination</li> <li>10. The right to movement and mobility without restrictions</li> <li>11. The right to live</li> <li>12. The right to work</li> <li>13. The right to live with freedom</li> <li>14. The right to maintain your dignity</li> <li>15. The right to practice political rights without any restrictions</li> </ol>
<p><i>Scale building:</i></p> <ul style="list-style-type: none"> <li>• Responses of 3 or 4 are recoded to “yes,” with a code of 1.</li> <li>• Responses of 1 and 2 are recoded as “no,” with a code of 0.</li> <li>• Scores are summed to create a scale ranging from 0 to 15.</li> <li>• The scale can be analyzed continuously, with a range from 0 to 15, or can be recoded into binary variables, with 0 = no violation and 1 = at least one violation.</li> </ul>	
Perpetrator-specific subscales	<i>Any participant who answers 2, 3, or 4 in the general scale is asked:</i> Who deprived you of your right to [mention the right that was violated]?
	<p><i>Response options:</i> family, society, Palestinian Authority, Israeli occupation [participant may select all that apply]</p> <p>Four different specific scales can be generated:                      Human rights violations by the family                      Human rights violations by the community                      Human rights violations by the Palestinian Authority                      Human rights violations by the occupation</p>
	<p><i>Scale building:</i></p> <p>Each scale can be analyzed continuously, with a range from 0 to 15, or can be recoded into binary variables, with 0 = no violation and 1 = at least one violation.</p>

TABLE 3. Political violence exposure scale

<p>Personal exposure to political violence scale</p>	<p><i>Prompts:</i></p> <ol style="list-style-type: none"> <li>1. Have you been beaten by the Israeli army?</li> <li>2. Have you been beaten by the Palestinian Authority?</li> <li>3. Have you been used as a human shield?</li> <li>4. Have you been exposed to tear gas?</li> <li>5. Have you been exposed to sound bombs?</li> <li>6. Have you been shot at and/or hit?</li> <li>7. Have you been detained and/or arrested?</li> <li>8. Have you been humiliated (cursed, bullied, shoved, dragged)?</li> <li>9. Have you been stripped in public?</li> <li>10. Have you been interrogated?</li> <li>11. Have you been tortured?</li> </ol> <p><i>Response options:</i> 0 = never experienced; 1 = once; 2 = twice or more</p> <p><i>Scale building:</i></p> <ul style="list-style-type: none"> <li>• This scale is computed as the unweighted sum of all 12 items.</li> <li>• Scores range from 0 to 24.</li> <li>• Higher scores indicate greater direct personal exposure to political violence.</li> <li>• Internal reliability is assessed using Cronbach's <math>\alpha</math>.</li> <li>• The scale can be recoded into binary variables, with 0 = no exposure and 1 = at least once.</li> <li>• The scale asks about whether participants were "ever exposed" and is not linked to a specific time reference.</li> </ul>
<p>Household exposure to political violence scale</p>	<p><i>Prompts:</i></p> <ol style="list-style-type: none"> <li>1. Has your house ever been searched?</li> <li>2. Has your house ever been occupied while you were in it?</li> <li>3. Has your house ever been occupied and you were thrown out?</li> <li>4. Has your house ever been sealed or demolished?</li> <li>5. Has your house ever been shot at?</li> <li>6. Has your house ever been burnt?</li> <li>7. Has your house ever been bombed or shelled?</li> <li>8. Has your neighborhood ever been shelled?</li> </ol> <p><i>Response options:</i> 0 = never experienced; 1 = once; 2 = twice or more</p> <p><i>Scale building:</i></p> <ul style="list-style-type: none"> <li>• This scale is computed as the unweighted sum of all 8 items.</li> <li>• Scores range from 0 to 16.</li> <li>• Higher scores indicate greater exposure to household-level political violence.</li> <li>• Internal reliability is assessed using Cronbach's <math>\alpha</math>.</li> <li>• The scale can be recoded into binary variables, with 0 = no exposure and 1 = at least once.</li> <li>• The scale asks about whether participants were "ever exposed" and is not linked to a specific time reference.</li> </ul>
<p>Witnessing political violence scale</p>	<p><i>Prompts:</i></p> <ol style="list-style-type: none"> <li>1. Have you seen or witnessed shooting?</li> <li>2. Have you seen or witnessed explosions or shelling directly (not on television or social media)?</li> <li>3. Have you seen a family member being humiliated?</li> <li>4. Have you seen a family member being arrested?</li> <li>5. Have you seen a family member being injured?</li> <li>6. Have you seen a family member being killed?</li> <li>7. Have you seen a friend or neighbor being humiliated?</li> <li>8. Have you seen a friend or neighbor being arrested?</li> <li>9. Have you seen a friend or neighbor being injured?</li> <li>10. Have you seen a friend or neighbor being killed?</li> <li>11. Has a member of your family been killed by the occupation during your lifetime?</li> <li>12. Has a member of your family been injured by the occupation during your lifetime?</li> <li>13. Has a member of your family been imprisoned by the occupation during your lifetime?</li> </ol> <p><i>Response options:</i> 0 = never experienced; 1 = once; 2 = twice or more</p> <p><i>Scale building:</i></p> <ul style="list-style-type: none"> <li>• This scale is computed as the unweighted sum of all 13 items.</li> <li>• Scores range from 0 to 26.</li> <li>• Higher scores indicate greater exposure to witnessed political violence.</li> <li>• Internal reliability is assessed using Cronbach's <math>\alpha</math>.</li> <li>• The scale can be recoded into binary variables, with 0 = no exposure and 1 = at least once.</li> <li>• The scale asks about whether participants were "ever exposed" and is not linked to a specific time reference.</li> </ul>

ported. Correlations between deprivation, political violence, and human rights violation variables were examined, and multicollinearity diagnostics were assessed before fitting the final multivariate model. Variance inflation factors were within acceptable limits, suggesting that multicollinearity was not a concern in the final model. A Spearman correlation heat map was also generated to visually assess the degree of overlap between these variables (see Figure 1). All analyses were conducted using Stata 18.

*Ethical considerations*

Ethical approval was obtained from the Research Ethics Committee at the Institute of Community and Public Health, Birzeit University (Ref. 2025(2-1)). Verbal informed consent was obtained from all participants in accordance with Birzeit University’s ethical guidelines on confidentiality, anonymity, and voluntary participation.

**Results**

Of the 3,147 persons invited to participate, 3,000 consented (95.3%). The mean age was 41 ± 24 years; most were aged 25–40 (38.5%) or 41–60 (31.7%), and 51.4% were women. Most participants were married (65.8%), and about half had fewer than four children. Half had less than a high school educa-

tion, and 40.5% were employed, while 34.2% were housewives. Economically, 31.3% reported good or better status, 39.9% less than good, and 28.8% bad compared with people around them. Participants were evenly distributed across Jenin, Ramallah, and Bethlehem, with half living in urban areas and half in refugee camps or displaced settings. Most lived in Area A (73.4%); 18.2% had been displaced in the past two years; 68.4% were registered refugees; 79.2% had health insurance; and approximately one-third reported being diagnosed with a chronic illness. (See Table 6.)

As shown in Figure 2, most participants (77.1%) reported experiencing at least one form of human rights violation. Violations by family members were the least common, reported by 18.2% of participants, followed by violations by the Palestinian Authority (32.3%) and the community (33.8%). The most frequently reported human rights violation was by the Israeli military occupation (74.1%). With regard to exposure to political violence, 77.1% of participants reported at least one personal exposure to such violence. Nearly 60% of participants reported household-level exposure, and 81.1% reported directly witnessing political violence outside the media. Moderate to high material deprivation was reported by 40.5% of study participants, and 58.4% reported moderate to high levels of sociopolitical deprivation.

TABLE 4. Deprivation scale

<p><i>Prompts:</i></p> <ol style="list-style-type: none"> <li>1. Do you feel deprived in general?</li> <li>2. Do you feel deprived of material things such as money, food, house, or clothes?</li> <li>3. Do you feel deprived because of an inability to find work?</li> <li>4. Do you feel deprived because of an inability to pursue education?</li> <li>5. Do you feel deprived because of an inability to move easily within the West Bank?</li> <li>6. Do you feel deprived because of an inability to move between the West Bank and the Gaza Strip?</li> <li>7. Do you feel deprived because of the Palestinian political split?</li> <li>8. Do you feel deprived because of the Israeli occupation?</li> <li>9. Do you feel deprived because of the lack of democracy in Palestine?</li> <li>10. Do you feel deprived because of the conservative nature of society and constraints on personal freedom?</li> </ol>
<p><i>Response options:</i> 0 = not at all; 1 = a little; 2 = a lot; 3 = an extreme amount</p>
<p><i>Scale building:</i></p> <ul style="list-style-type: none"> <li>• The material deprivation scale is computed as the unweighted sum of items 2, 3, and 4. Scores range from 0 to 9, with higher scores indicating greater reported material deprivation.</li> <li>• The sociopolitical deprivation scale is computed as the unweighted sum of items 5 to 10. Scores range from 0 to 18, with higher scores indicating greater reported sociopolitical deprivation.</li> <li>• Internal consistency is assessed using Cronbach’s <math>\alpha</math>.</li> <li>• Each scale can be recoded into binary variables, with 0 = not deprived and 1 = deprived.</li> <li>• The scale asks about whether participants were “ever exposed” and is not linked to a specific time reference.</li> </ul>

TABLE 5. Bivariate analyses

Description	Categories	N (%) poor well-being score $\leq 50$	N (%) good well-being score $> 50$	p-value
Age group	18–24	326 (65.2)	174 (34.8)	< 0.001
	25–40	841 (72.8)	315 (27.2)	
	41–60	732 (76.9)	220 (23.1)	
	61–92	316 (80.8)	75 (19.2)	
Sex	Man	1,097 (75.2)	361 (24.8)	0.088
	Woman	1,118 (72.5)	424 (27.5)	
Marital status	Never married	511 (67.8)	243 (32.2)	< 0.001
	Currently married	1,483 (75.2)	490 (24.8)	
	Widowed/divorced	220 (80.9)	52 (19.1)	
Number of children	None	836 (69.3)	371 (30.7)	< 0.001
	1–3	612 (73.9)	216 (26.1)	
	4–6	569 (79.4)	148 (20.6)	
	7–17	184 (81.1)	43 (18.9)	
Educational level	Less than Tawjihi	1,197 (79.2)	315 (20.8)	< 0.001
	Passed Tawjihi	347 (69.1)	155 (30.9)	
	Post-Tawjihi	671 (68.1)	315 (31.9)	
Work status	Working (full/part time)	886 (72.9)	329 (27.1)	0.018
	Unemployed	301 (80.5)	73 (19.5)	
	Housewife	752 (73.3)	274 (26.7)	
	Other (retired, disabled, student, not seeking work)	275 (71.8)	108 (28.2)	
Reported economic status	Excellent/good	564 (60.3)	372 (39.7)	< 0.001
	Less than good	924 (77.5)	268 (22.5)	
	Bad	719 (83.4)	143 (16.6)	
Governorate	Jenin	747 (74.7)	253 (25.3)	< 0.001
	Ramallah	776 (77.6)	224 (22.4)	
	Bethlehem	692 (69.2)	308 (30.8)	
Place of residence	Urban	1,068 (71.2)	432 (28.8)	0.001
	Refugee camp	1,147 (76.5)	353 (23.5)	
Area according to Oslo Accords	Area A	1,605 (73.0)	595 (27.0)	0.008
	Area B	31 (59.6)	21 (40.4)	
	Area C	50 (75.8)	16 (24.2)	
	Do not know	527 (77.7)	151 (22.3)	
Displacement since 2023	Yes	456 (83.7)	89 (16.3)	< 0.001
	No	1,757 (71.6)	696 (28.4)	
Refugee status	Refugee	1,555 (75.8)	496 (24.2)	< 0.001
	Non-refugee	660 (69.7)	287 (30.3)	
Health insurance	Yes	1,772 (74.6)	603 (25.4)	0.076
	No	443 (71.1)	180 (28.9)	
Chronic disease	None	1,368 (70.0)	587 (30.0)	< 0.001
	At least one	847 (81.1)	197 (18.9)	
Human rights violations by family	No	1,765 (72.0)	685 (28.0)	< 0.001
	At least one	446 (81.8)	99 (18.2)	
Human rights violations by community	No	1,385 (69.8)	598 (30.2)	< 0.001
	At least one	826 (81.6)	186 (18.4)	
Human rights violations by Palestinian Authority	No	1,419 (69.9)	610 (30.1)	< 0.001
	At least one	792 (82.0)	174 (18.0)	
Human rights violations by Israeli military occupation	No	498 (64.1)	279 (35.9)	< 0.001
	At least one	1,713 (77.2)	505 (22.8)	

TABLE 5. *Continued*

Description	Categories	N (%) poor well-being score ≤ 50	N (%) good well-being score > 50	p-value
Personal exposure to political violence	No	497 (73.2)	182 (26.8)	0.533
	At least once	1,705 (74.4)	587 (25.6)	
Household exposure to political violence	No	832 (67.9)	394 (32.1)	< 0.001
	At least once	1,383 (78.0)	391 (22.0)	
Witnessing exposure to political violence	No	412 (73.3)	150 (26.7)	0.653
	At least once	1,789 (74.2)	621 (25.8)	
Material deprivation	None (score 0)	675 (62.0)	414 (38.0)	< 0.001
	Score 1–2	511 (73.5)	184 (26.5)	
	Score 3–9	1,026 (84.7)	186 (15.3)	
Sociopolitical deprivation	None (score 0)	219 (66.0)	113 (34.0)	< 0.001
	Score 1–8	639 (69.8)	276 (30.2)	
	Score 9–18	1,355 (77.5)	394 (22.5)	

FIGURE 1. Spearman correlation matrix of main exposure variable

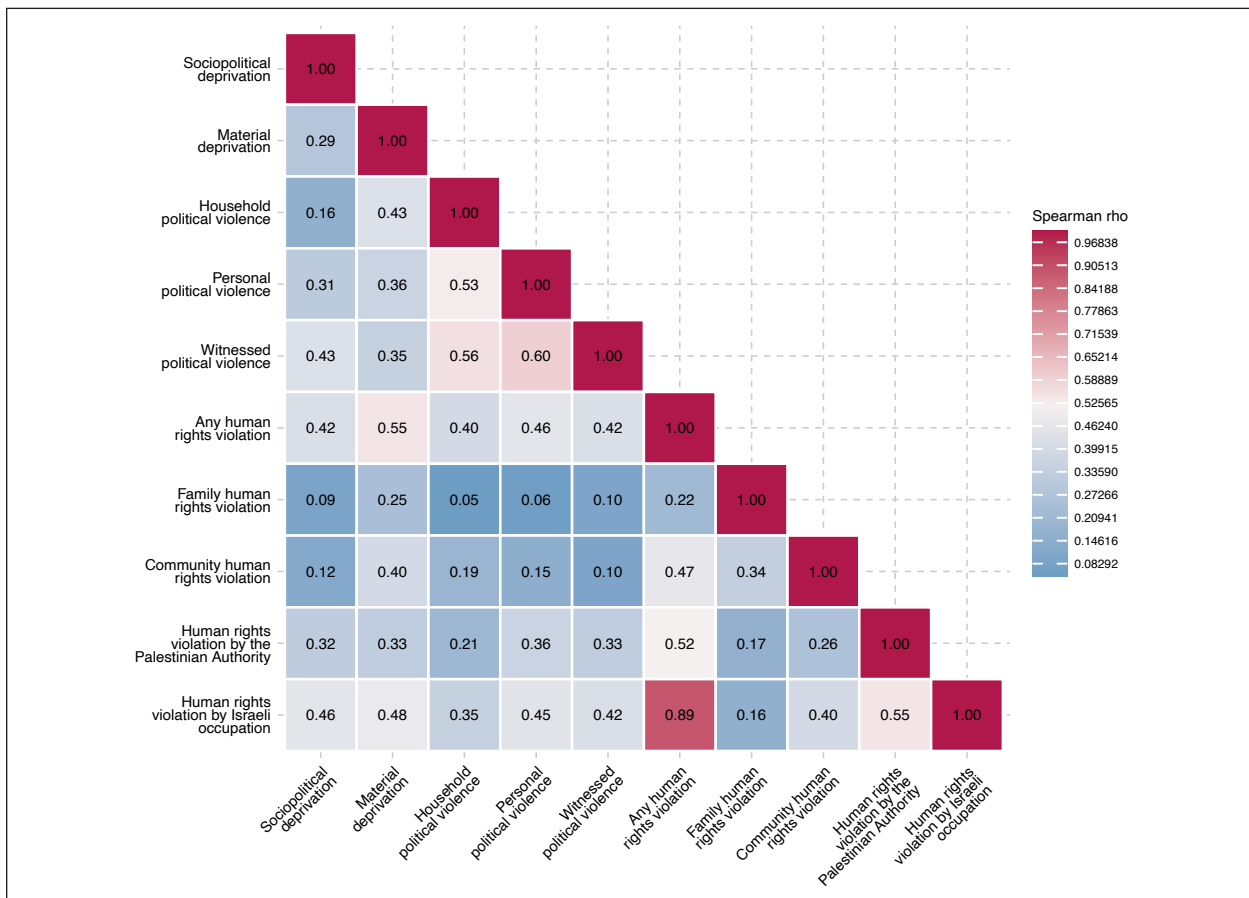


TABLE 6. Descriptive characteristics

Variable	Category	n (%)
Age group (years)	18–24	500 (16.7)
	25–40	1,156 (38.5)
	41–60	952 (31.7)
	61–92	391 (13.0)
Sex	Man	1,458 (48.6)
	Woman	1,542 (51.4)
Marital status	Never married	754 (25.1)
	Currently married	1,973 (65.8)
	Widowed/divorced	272 (9.1)
Number of children	None	1,207 (40.5)
	1–3	828 (27.8)
	4–6	717 (24.1)
	7–17	227 (7.6)
Educational level	Less than Tawjihi	1,512 (50.4)
	Passed Tawjihi	502 (16.7)
	Post-Tawjihi	986 (32.9)
Work status	Working (full/part time)	1,215 (40.5)
	Unemployed	374 (12.5)
	Housewife	1,026 (34.2)
	Other (retired, disabled, student, not seeking work)	383 (12.8)
Reported economic status	Excellent/good	936 (31.3)
	Less than good	1,192 (39.9)
	Bad	862 (28.8)
Governorate	Jenin	1,000 (33.3)
	Ramallah	1,000 (33.3)
	Bethlehem	1,000 (33.3)
Locality	Urban	1,500 (50.0)
	Refugee camp	1,500 (50.0)
Oslo area classification*	Area A	2,200 (73.4)
	Area B	52 (1.7)
	Area C	66 (2.2)
	Do not know	678 (22.6)
Displacement in the past two years	Yes	545 (18.2)
	No	2,453 (81.8)
Refugee status	Refugee	2,051 (68.4)
	Non-refugee	947 (31.6)
Health insurance	Yes	2,375 (79.2)
	No	623 (20.8)
Chronic disease	None	1,955 (65.2)
	At least one	1,044 (34.8)

\* Areas A, B, and C refer to the Oslo Accords' classifications of West Bank land: Area A is under Palestinian Authority control, Area B is under Palestinian civil and joint security control, and Area C is under full Israeli control. These areas are fragmented and noncontiguous across the West Bank.

Figure 3 shows a smoothed kernel density distribution of WHO-5 scores, with the curve peaking at lower scores and gradually declining toward higher scores. The median WHO-5 score was 28, with an interquartile range of 16–52, and 74% of participants scored  $\leq 50$ , indicating low well-being, while 26% scored  $> 50$ , indicating good or moderate well-being.

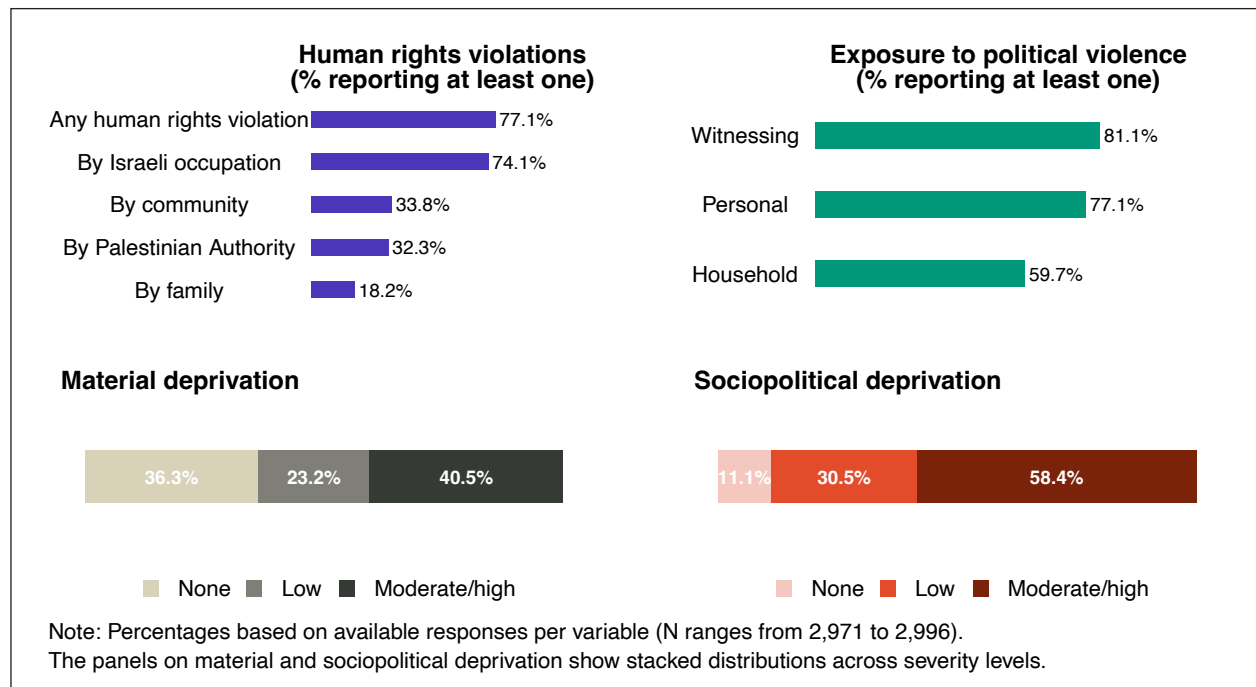
The multivariate logistic regression showed that having more children increased the odds of poor well-being (OR = 1.09, 95% CI: 1.03–1.15). Secondary education (OR = 0.79, 95% CI: 0.63–0.99) and being a housewife (OR = 0.68, 95% CI: 0.50–0.91) were associated with lower odds compared with post-secondary education and employment, respectively. Poorer economic status was strongly associated with poor well-being, with higher odds among those reporting “less than good” (OR = 1.63, 95% CI: 1.31–2.02) and “bad” conditions (OR = 1.90, 95% CI: 1.44–2.50). Region was also significant, as residents of Ramallah and al-Bireh had higher odds of poor well-being than those in Jenin (OR = 3.68, 95% CI: 2.63–5.17).

Having at least one chronic illness was asso-

ciated with higher odds of poor well-being (OR = 1.35, 95% CI: 1.07–1.71). Among forms of political violence, only household exposure was significantly associated with poor well-being (OR = 1.35, 95% CI: 1.08–1.69), whereas personal exposure or witnessing violence was not. Material deprivation showed a strong gradient: low deprivation was associated with higher odds of poor well-being (OR = 1.70, 95% CI: 1.33–2.18), increasing to more than twofold among those with moderate to high deprivation (OR = 2.38, 95% CI: 1.81–3.13). Sociopolitical deprivation was not significant. Exposure to human rights violations was also associated with poor well-being, including violations by the Palestinian Authority (OR = 1.72, 95% CI: 1.34–2.20) and the Israeli military (OR = 1.51, 95% CI: 1.19–1.93) (Table 7).

Our findings showed a significant interaction between residence locality and displacement status in relation to well-being. Urban non-displaced participants served as the reference group. Compared with this group, displaced urban residents had lower odds of poor well-being (OR = 0.36,  $p = 0.003$ ), as did residents of stable refugee camps who were not recently displaced (OR = 0.50,  $p < 0.001$ ). In con-

FIGURE 2. Distribution of human rights violations, political violence, deprivation, and well-being in the study sample (N = 3,000)



trast, participants originating from refugee camps who had been displaced within the past two years had higher odds of poor well-being (combined OR = 1.59,  $p < 0.001$ ), reflecting the combined effects of camp origin, displacement, and their interaction (Table 8).

## Discussion

In this study, we found high levels of poor well-being among adults living in three Palestinian refugee camps and their surrounding urban areas in the West Bank, with nearly three-quarters reporting poor well-being. These findings emerged during a period of intensified political violence, coinciding with the war on the Gaza Strip that began in late 2023. The results highlight the central role of economic and material conditions in shaping well-being. Poorer well-being was associated with lower economic status, higher levels of material deprivation, residence in the central West Bank, and specific combinations of locality and displacement status, particularly among displaced refugee camp residents. Household exposure to political violence and human rights violations—whether

by the Palestinian Authority or the Israeli military occupation—was also associated with poorer well-being, underscoring how direct exposure to violence and violations permeates everyday family life. At the personal level, living with a chronic disease or condition was likewise associated with lower well-being.

As noted above, nearly three-quarters of study participants reported poor well-being, a high estimate compared with other national and regional studies, but comparable to findings from areas with high war intensity or high levels of political instability. For example, an earlier study in the oPt found that 33.8% of adults reported poor well-being based on the WHO-5 index during a period without significant political escalation in the West Bank (2012–2013).<sup>22</sup> A cross-sectional study from Syria, conducted during the Syrian conflict that began in 2011, found a drastic decline in mental well-being compared to previous years. Key indicators from the study, which analyzed data from 2008 to 2015, showed a 41.4% increase in negative emotions and a 50% reduction in life satisfaction. Additionally, hope levels declined significantly, reflecting a pervasive sense of despair among the study population.<sup>23</sup>

FIGURE 3. Kernel density estimate of WHO-5 well-being scores

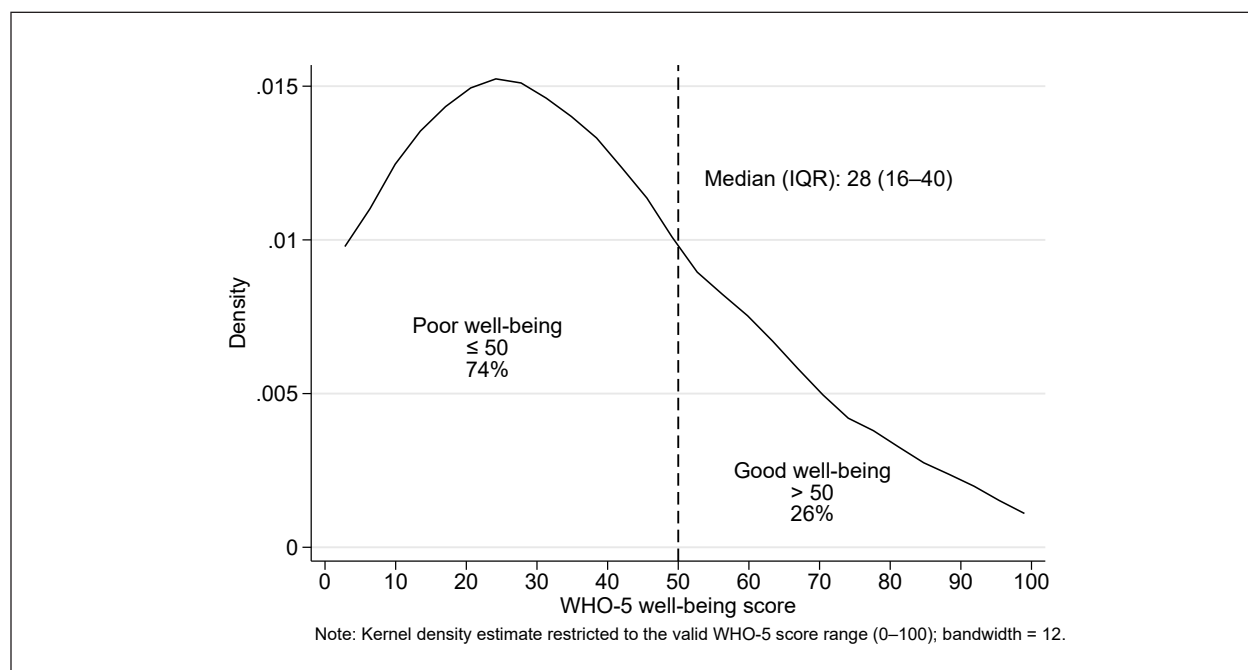


TABLE 7. Multiple binary logistic regression analysis of factors associated with low well-being (N=2,935)

Variable	Category	Adjusted OR (95% CI)	p-value
Age	Continuous	1.00 (0.99–1.00)	0.314
Sex	Men (ref.)	—	—
	Women	1.04 (0.81–1.35)	0.756
Marital status	Married (ref.)	—	—
	Never married	0.92 (0.70–1.21)	0.547
	Widowed/divorced	1.16 (0.80–1.70)	0.430
Number of children	Continuous	1.09 (1.03–1.15)	0.002
Education	Post-Tawjihi (ref.)	—	—
	Passed Tawjihi	0.77 (0.59–1.01)	0.056
	Less than Tawjihi	0.79 (0.63–0.99)	0.043
Employment status	Employed (ref.)	—	—
	Unemployed	0.83 (0.59–1.16)	0.276
	Housewife	0.68 (0.50–0.91)	0.010
	Other	0.88 (0.64–1.19)	0.400
Reported economic status	Excellent/good (ref.)	—	—
	Less than good	1.63 (1.31–2.02)	< 0.001
	Bad	1.90 (1.44–2.50)	< 0.001
Region	Jenin (ref.)	—	—
	Ramallah	3.68 (2.63–5.17)	< 0.001
	Bethlehem	1.16 (0.86–1.56)	0.323
Locality*	Urban (ref.)	—	—
	Refugee camp	0.50 (0.39–0.64)	< 0.001
Displacement (past two years)*	No (ref.)	—	—
	Yes	0.36 (0.18–0.70)	0.003
Interaction*	Camp × Displaced	8.84 (4.32–18.12)	< 0.001
Chronic disease	None (ref.)	—	—
	At least one	1.35 (1.07–1.71)	0.013
Personal exposure to political violence	None (ref.)	—	—
	At least once	0.79 (0.61–1.03)	0.087
Household exposure to political violence	None (ref.)	—	—
	At least once	1.35 (1.08–1.69)	0.008
Witnessing political violence (personal)	None (ref.)	—	—
	At least once	0.81 (0.61–1.07)	0.144
Material deprivation	None (score 0) (ref.)	—	—
	Score 1–2	1.70 (1.33–2.18)	< 0.001
	Score 3–9	2.38 (1.81–3.13)	< 0.001
Sociopolitical deprivation	None (score 0) (ref.)	—	—
	Score 1–8	1.19 (0.84–1.68)	0.325
	Score 9–18	1.21 (0.85–1.72)	0.292
Human rights violation by the family	None (ref.)	—	—
	At least one	1.25 (0.95–1.66)	0.116
Human rights violation by the community	None (ref.)	—	—
	At least one	1.20 (0.95–1.51)	0.122
Human rights violations by the Palestinian Authority	None (ref.)	—	—
	At least one	1.72 (1.34–2.20)	< 0.001
Human rights violations by the Israeli military occupation	None (ref.)	—	—
	At least one	1.51 (1.19–1.93)	0.001

\* The interaction results are explained in Table 8 and within the text.

Similarly, a study in northern Uganda found that approximately 75% of internally displaced persons reported experiencing “overthinking,” a condition linked to trauma that can lead to severe mental health issues.<sup>24</sup> These studies, along with our study, illustrate how political instability and war can dramatically deteriorate mental well-being.

In our study, the assessment of structural constraints emphasized that place matters. Regional differences emerged even after adjusting for socioeconomic and political variables. Residents of Ramallah and al-Bireh Governorate, in the central West Bank, had markedly higher odds of low well-being compared with those living in Jenin, in the northern West Bank. Although Ramallah and al-Bireh Governorate is the administrative and economic center of the West Bank, it is also characterized by extreme socioeconomic stratification, high living costs, the dense presence of Palestinian Authority structures, and frequent Israeli military offensives and invasions, factors that generate daily stressors and uncertainty.<sup>25</sup> In contrast, Jenin Governorate in the northern West Bank and Bethlehem Governorate in the southern West Bank are characterized by strong community cohesion, extended kinship networks, and shared collective coping mechanisms that might act as social buffers that help sustain well-being despite high levels of political violence and other structural constraints.<sup>26</sup>

Regression results also showed significant spatial disparities in well-being. The interaction between locality of residence, defined as urban area or refugee camp, and displacement status showed a differentiated pattern of vulnerability that cannot be understood without considering the social meaning of place in the West Bank. People living in

urban areas who were displaced from their original place of residence showed lower odds of low well-being compared with urban residents who were not displaced. This might reflect a possibility that this displacement was associated with a move to a relatively safer urban neighborhood, with improved security and greater access to resources, which temporarily enhanced their well-being despite the hardship of the displacement.<sup>27</sup> This finding should not be interpreted as displacement being protective in itself. Rather, it may indicate that some displaced urban residents had moved away from more threatening or insecure conditions and that their reported well-being reflected relative relief from prior fear, threats, or exposure to violence.

Our results also showed that refugee camp residents who were not displaced, primarily those in the central and southern West Bank, had lower odds of poor well-being than non-displaced urban residents. This finding may reflect the protective role of social cohesion and community-based solidarity in refugee camps, which tend to provide emotional and practical support under chronic adversity. Studies from Palestine and elsewhere have similarly documented this protective role. A qualitative study conducted in West Bank refugee camps during the COVID-19 pandemic found that strong community engagement and collaboration among local refugee camp committees fostered solidarity and acted as a protective factor for residents’ psychological well-being. The study suggests that the social fabric and collective organization within refugee camps can provide a sense of security and belonging that helps buffer the effects of chronic stress and instability.<sup>28</sup> Similarly, a study in Cameroon found that internally displaced per-

TABLE 8. Interaction between locality and displacement

Group	OR (vs. urban non-displaced)	Interpretation
Urban, non-displaced	1 (ref.)	Reference
Urban, displaced	0.36 (0.18–0.70)	Lower odds of poor well-being among displaced urban residents; may reflect relocation from more threatening conditions
Camp, non-displaced	0.50 (0.39–0.64)	Lower odds of poor well-being among non-displaced camp residents; may reflect stable social networks and community solidarity
Camp, displaced	1.59	Highest-risk group (0.36*0.5*8.84)

sons with higher levels of community solidarity reported improved psychological health outcomes and greater community satisfaction and that this solidarity served as a protective factor against psychological distress. The findings suggest that the social cohesion fostered within these communities provides essential emotional and practical support, which is crucial in mitigating the adverse effects of displacement.<sup>29</sup>

In contrast, people who had been living in Palestinian refugee camps and were displaced, primarily from the northern refugee camps, had the highest combined odds of low well-being. This group experienced displacement from environments that are typically protective to them. Expulsion from socially dense, collectively organized communities into more fragmented and uncertain settings may involve the sudden loss of a major psychosocial resource, which could worsen well-being among Palestinians experiencing forced displacement.<sup>30</sup> This pattern challenges dominant global displacement frameworks, which often conceptualize displacement as uniformly harmful or focus predominantly on material losses while overlooking the protective role of stable social ecologies.<sup>31</sup> Our findings suggest that the impact of displacement is deeply conditioned by the characteristics of the place from which people are uprooted and the structural conditions of the places to which they relocate.

Moreover, our results highlight that material deprivation and poor relative economic status consistently predicted lower well-being. This finding is consistent with extensive evidence from the oPt and other settings suggesting that material deprivation, rather than sociopolitical deprivation, is the strongest and most consistent determinant of mental health and subjective well-being. In the oPt, evidence indicates that both material and subjective deprivation exert powerful effects on psychological well-being.<sup>32</sup> Similarly, a global meta-review confirmed that material and subjective deprivation were stronger predictors of depression and low well-being than social or political variables.<sup>33</sup> A study in Switzerland found that restricted standards of living were significantly associated

with poorer psychological health even among the employed population, showing that deprivation impacts well-being independently of employment status.<sup>34</sup> Research in Ethiopia and Indonesia has further shown that perceived low social and economic status strongly correlates with poorer mental health among adolescents and families, independent of structural constraints.<sup>35</sup> In a study in Wales, researchers using a large population survey to assess how financial strain shapes psychological well-being found that persons experiencing material deprivation had nearly double the prevalence of low well-being compared with those who were financially secure, showing how economic hardship alone can generate a substantial mental health burden.<sup>36</sup> Together, this evidence suggests that the lived experience of economic scarcity and comparison to others profoundly affects psychological well-being. The consistent pattern across contexts confirms that material deprivation functions as a core structural determinant of mental health in protracted crises.

While material deprivation clearly undermines well-being by limiting access to basic needs and security, its effects are deeply intertwined with exposure to political violence, which shapes daily life in the West Bank of the oPt. Our findings indicate that household exposure to political violence, rather than personal experience or witnessing political violence, was the key predictor of well-being, suggesting that the impact of war and political instability in the oPt is collective as well as personal. This aligns with broader evidence showing that violence echoes through families, communities, and shared living environments, creating a sustained atmosphere of fear and insecurity. Earlier evidence from a large survey of Palestinian adolescents similarly found that while both personal and collective exposure to political violence worsened mental health, collective or household exposure affected psychological well-being through shared instability and disrupted social functioning.<sup>37</sup>

Similarly, research across Palestinian households has found that human insecurity and economic deprivation, experiences typically shared within families, have stronger associations with de-

pressive-like symptoms and trauma-related stress than does direct personal exposure to violence.<sup>38</sup> Household exposure magnifies psychological burden because family members' suffering through displacement, loss, or violence extends trauma into the collective emotional fabric of the home, deepening feelings of helplessness and loss of control.<sup>39</sup> This pattern mirrors global findings from other conflict zones, where collective or familial trauma predicts more persistent and severe distress than isolated personal experiences because it erodes the social and emotional support systems essential for resilience and recovery.<sup>40</sup>

The negative association between household exposure to political violence and people's well-being in the oPt becomes more complex when human rights violations are understood as an embedded part of that exposure. Violations stemming from both internal and external sources—family, community, the Palestinian Authority, and the Israeli military occupation—collectively shape the psychosocial environment.<sup>41</sup> Although family- or community-level human rights violations were not significantly associated with poor well-being in our study, this does not mean that these violations are unimportant; rather, this may reflect the strong cohesion and mutual support within Palestinian families and communities in this population, which often buffer the psychological impact of interpersonal or localized stressors. In contrast, violations committed by governing or occupying authorities showed stronger associations with poor well-being and may overwhelm these coping mechanisms by targeting entire households and communities through systemic and prolonged oppression. Studies confirm that persistent human rights abuses, such as arbitrary arrests, home demolitions, and mobility restrictions, undermine well-being and create chronic insecurity, which predicts depression, trauma, and a sense of “being broken or destroyed” among Palestinians.<sup>42</sup> Therefore, human rights violations, especially when enacted by authorities or occupying powers, extend beyond physical harm, institutionalizing poor psychological well-being and reinforcing the cycle of collective distress already rooted in household exposure.

It is important to note that some person-

al-level characteristics, such as age and sex, were not significantly associated with well-being in this study, while chronic illness, poorer economic status, and material deprivation remained important predictors. This pattern suggests that well-being in the Palestinian context is shaped less by fixed demographic characteristics than by socioeconomic, collective, and political conditions. In most high-income and low- and middle-income country settings, higher education, income, and social capital are consistently associated with better self-rated health and subjective well-being, even among people with chronic illness.<sup>43</sup> Studies show that disparities in well-being are often explained by socioeconomic resources and access to care rather than illness alone.<sup>44</sup> However, the significance of chronic illness in Palestine reflects the intersection of health vulnerability and structural deprivation. Under conditions of prolonged occupation, movement restrictions, economic instability, and health care shortages, managing chronic disease becomes a source of continuous psychological distress rather than simply a medical concern.<sup>45</sup>

Research in the oPt and other politically constrained and conflict-affected contexts has shown that barriers to health care access, medication shortages, and the erosion of medical infrastructure exacerbate both physical suffering and emotional strain.<sup>46</sup> This is consistent with findings from other protracted crises, such as Ethiopia, where anxiety and depression among displaced populations are better explained by displacement frequency and social support than by demographic characteristics.<sup>47</sup> Taken together, these findings suggest that in the Palestinian context, chronic illness functions as both a medical and psychosocial burden, reflecting how enduring instability transforms health vulnerability into a continuous source of stress that reinforces broader cycles of collective distress.

## Conclusion

This study has shown that in the Palestinian context, well-being is shaped by cumulative socioeconomic and political vulnerabilities. Consistent with earlier research, our study suggests that daily stressors,

material deprivation, poverty, and political violence are far stronger predictors of well-being than most fixed demographic characteristics, such as age and sex.<sup>48</sup> Our findings show that displacement, poverty, political violence, and human rights violations are powerful structural and political determinants of low well-being. Displacement, however, is not uniformly harmful; its effects depend on social and spatial contexts. Long-lasting Palestinian refugee camps often provide cohesive environments that buffer against distress, whereas displacement from such protective spaces, combined with ongoing instability, deepens psychological suffering.<sup>49</sup> These patterns highlight that place, stability, and collective belonging are critical dimensions of health under prolonged occupation.

While addressing structural constraints that undermine health and well-being remains essential, this may be difficult to target or achieve under current political and social conditions. Still, there are practical steps that can help reduce daily hardship and promote well-being. Strengthening social protection systems is important for easing material deprivation, especially for displaced families who remain excluded from formal safety nets. Supporting community-based networks of solidarity and collective strength can also help sustain psychosocial well-being during ongoing adversity. Integrating contextually and culturally appropriate mental health care into primary care, through community-led and locally grounded approaches, may further promote recovery and preserve dignity in local settings.

Improving well-being in Palestine requires recognizing that displacement, fragmentation, and continuing political violence are not only political or social issues but central public health concerns. The right to health depends on addressing long-term structural constraints, in addition to enhancing the collective strength of communities to protect life and dignity under occupation.

### Strengths and limitations

This study has several strengths. We relied on a large, diverse sample and used locally validated

measures that captured the lived realities of Palestinians under occupation. By integrating the socio-ecological framework and the World Health Organization's framework on the social determinants of health, we highlighted how structural constraints affecting groups in the population, rather than personal traits affecting individuals, shape well-being. However, the purposive sampling limits generalizability, and the cross-sectional design prevents causal inference. Self-reported data may involve bias, and mobility restrictions constrained access to some areas.

In relation to exposure to political violence, although the survey captured the reported perpetrator of political violence, including Israeli settlers, settler violence was not analyzed separately in this paper because the selected study locations were more directly exposed to military occupation practices, while settler violence is more geographically concentrated in specific areas of the West Bank and was less frequently reported in our sample.

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### References

1. C. A. Sousa, "Political Violence, Collective Functioning and Health: A Review of the Literature," *Medicine, Conflict and Survival* 29/3 (2013).
2. O. Tanous, "Structural Violence and Its Effects on Children Living in War and Armed Conflict Zones: A Palestinian Perspective," *International Journal of Health Services* 52/1 (2022).
3. W. Hammoudeh, S. Mitwalli, R. Kafri, et al., "The Mental Health Impact of Multiple Deprivations Under Protracted Conflict: A Multi-Level Study in the Occupied Palestinian Territory," *PLOS Global Public Health* 2/12 (2022); C. McNeely, B. K. Barber, C. Spellings, et al., "Prediction of Health with Human Insecurity and Chronic Economic Constraints in the Occupied Palestinian Territory: A Cross-Sectional Survey," *Lancet* 382/S25 (2013).
4. H. Schmitz and K. Sikkink, "International Human Rights," in W. Carlsnaes, T. Risse, and B. A. Simmons (eds), *Handbook of International Relations*, 2nd edition (Sage, 2013).
5. S. Sivakumaran, "Re-Envisaging the International

- Law of Internal Armed Conflict,” *European Journal of International Law* 22/1 (2011); S. C. S. Guerra, L. E. Nagle, and Á. S. F. da Silva, “Human Rights Violations Perpetrated by State Agents in Military Occupations: Analysis of the IncurSION of International Human Rights Law to the Normative Territory of the Armed Conflicts,” *Revista Opinião Jurídica* 19/32 (2021).
6. Tanous (see note 2); McNeely et al. (see note 3).
  7. Tanous (see note 2).
  8. R. Giacaman, H. S. Shannon, H. Saab, et al., “Individual and Collective Exposure to Political Violence: Palestinian Adolescents Coping with Conflict,” *European Journal of Public Health* 17/4 (2007).
  9. R. Giacaman, R. Ghandour, and W. Hammoudeh, “Measuring Human Rights Violations from an Ecological Perspective Using a Locally Generated Instrument: A Cross-Sectional Study of Palestinians in the Israeli-Occupied West Bank,” *Frontiers in Public Health* 13 (2025).
  10. R. Giacaman, “Reframing Public Health in Wartime: From the Biomedical Model to the ‘Wounds Inside,’” *Journal of Palestine Studies* 47/2 (2018).
  11. Hammoudeh et al. (see note 3).
  12. K. Bates, T. Leone, R. Ghandour, et al., “Women’s Health in the Occupied Palestinian Territories: Contextual Influences on Subjective and Objective Health Measures,” *PLOS One* 12/10 (2017); Hammoudeh et al. (see note 3); McNeely et al. (see note 3).
  13. World Health Organization, “A Conceptual Framework for Action on the Social Determinants of Health,” Discussion Paper (2010).
  14. S. D. Golden and J. A. L. Earp, “Social Ecological Approaches to Individuals and Their Contexts: Twenty Years of Health Education and Behavior Health Promotion Interventions,” *Health Education & Behavior* 39/3 (2012).
  15. Giacaman et al. (2025, see note 9).
  16. Ibid.
  17. C. W. Topp, S. D. Østergaard, S. Søndergaard, and P. Bech, “The WHO-5 Well-Being Index: A Systematic Review of the Literature,” *Psychotherapy and Psychosomatics* 84/3 (2015).
  18. R. Ladadwa, S. Nasr, and R. Giacaman, *Investigating Human Rights Violations Experienced by Palestinians on the West Bank of the Occupied Palestinian Territory (Opt)* (Institute of Community and Public Health, Birzeit University, 2022); Giacaman et al. (2025, see note 9).
  19. Giacaman et al. (2007, see note 8).
  20. Hammoudeh et al. (see note 3).
  21. Giacaman et al. (2025, see note 9).
  22. N. Harsha, L. Ziq, R. Ghandour, and R. Giacaman, “Well-Being and Associated Factors Among Adults in the Occupied Palestinian Territory (Opt),” *Health and Quality of Life Outcomes* 14/1 (2016).
  23. F. Cheung, A. Kube, L. Tay, et al., “The Impact of the Syrian Conflict on Population Well-Being,” *Nature Communications* 11 (2020).
  24. B. Roberts, V. N. Odong, J. Browne, et al., “An Exploration of Social Determinants of Health Amongst Internally Displaced Persons in Northern Uganda,” *Conflict and Health* 3 (2009).
  25. L. Taraki, “Urban Modernity on the Periphery: A New Middle Class Reinvents the Palestinian City,” *Social Text* 26/2 (2008).
  26. I. Kawachi and L. F. Berkman, “Social Ties and Mental Health,” *Journal of Urban Health* 78/3 (2001).
  27. A. Nikuze, R. Sliuzas, J. Flacke, and M. van Maarseveen, “Livelihood Impacts of Displacement and Resettlement on Informal Households: A Case Study from Kigali, Rwanda,” *Habitat International* 86 (2019).
  28. L. Shakhshir and W. Hammoudeh, “Responding to the COVID-19 in West Bank Palestine Refugee Camps: Lessons and Role of Community Engagement,” *BMC Public Health* 25/1 (2025).
  29. A. E. Tassang, S. Guoqing, T. Y. Akintunde, et al., “Social Integration, Solidarity, and Psychological Health of Internally Displaced Persons in Cameroon: Exploring the Role of Community Satisfaction,” *Heliyon* 9/10 (2023).
  30. Y. E. Masri, “72 Years of Homemaking in Waiting Zones: Lebanon’s ‘Permanently Temporary’ Palestinian Refugee Camps,” *Frontiers in Sociology* 5 (2020); Y. El-Zakka and J. L. Diab, “Youth Development and Spatial Configurations: Socio-Spatial Inequalities in Palestinian Refugee Camps in Lebanon,” *Frontiers in Sociology* 8 (2023).
  31. M. Porter and N. Haslam, “Predisplacement and Postdisplacement Factors Associated with Mental Health of Refugees and Internally Displaced Persons: A Meta-Analysis,” *JAMA* 294/5 (2005).
  32. Hammoudeh et al. (see note 3).
  33. I. Dougall, M. Vasiljevic, J. D. Wright, and M. Weick, “How, When, and Why Is Social Class Linked to Mental Health and Wellbeing? A Systematic Meta-Review,” *Social Science & Medicine* 343 (2024).
  34. S. Vetter, J. Endrass, I. Schweizer, et al., “The Effects of Economic Deprivation on Psychological Well-Being among the Working Population of Switzerland,” *BMC Public Health* 6 (2006).
  35. C. Owens and C. Hadley, “Subjective Social Status and Mental Health Among Adolescents in Ethiopia: Evidence from a Panel Study,” *SSM – Population Health* 22 (2023); I. Borualogo, S. Kusdiyati, and H. Wahyudi, “Subjective Well-Being and Material Deprivation During COVID-19 Pandemic: A Study in Children and Adolescents in Indonesia,” *Jurnal Psikologi* (2022).
  36. J. Allen, A. Cotter-Roberts, O. Darlington, et al., “Understanding Health Inequalities in Wales Using the Blinder-Oaxaca Decomposition Method,” *Frontiers in Public Health* 10 (2022).
  37. Giacaman et al. (2007, see note 8).
  38. McNeely et al. (see note 3).

39. B. K. Barber, C. McNeely, J. A. Olsen, et al., “Effect of Chronic Exposure to Humiliation on Wellbeing in the Occupied Palestinian Territory: An Event-History Analysis,” *Lancet* 382/S7 (2013).
40. Hammoudeh et al. (see note 3).
41. Giacaman et al. (2025, see note 9).
42. A. Christian, O. Sanuade, M. Okyere, and K. Adjaye-Gbewonyo, “Social Capital Is Associated with Improved Subjective Well-Being of Older Adults with Chronic Non-Communicable Disease in Six Low- and Middle-Income Countries,” *Globalization and Health* 16/1 (2020).
43. K. Hauck, S. Martin, and P. Smith, “Priorities for Action on the Social Determinants of Health: Empirical Evidence on the Strongest Associations with Life Expectancy in 54 Low-Income Countries, 1990–2012,” *Social Science & Medicine* 167 (2016).
44. A. Lohana, A. Gulati, J. Kumar, et al., “The Silent Victims: How the Israel-Palestine War Impacts the Management of Chronic Kidney Disease and End-Stage Renal Disease Patients,” *Cureus* 16/3 (2024).
45. R. Giacaman, R. Khatib, L. Shabaneh, et al., “Health Status and Health Services in the Occupied Palestinian Territory,” *Lancet* 373/9666 (2009); Bates et al. (see note 12).
46. Giacaman et al. (2009, see note 45); Bates et al. (see note 12).
47. S. Bekeko, F. Mekonnen, and R. E. Teklu, “Post-Traumatic Stress Disorder, Depression, Anxiety, and Their Predictors Among Internally Displaced Persons in a Conflict-Affected Area of Metekel Zone, Northwest Ethiopia: Structural Equation Modeling,” *Frontiers in Psychiatry* 16 (2025).
48. K. E. Miller and A. Rasmussen, “War Exposure, Daily Stressors, and Mental Health in Conflict and Post-Conflict Settings: Bridging the Divide between Trauma-Focused and Psychosocial Frameworks,” *Social Science & Medicine* 70/1 (2010).
49. Cheung et al. (see note 23); Tassang et al. (see note 29).



# Expanding Safe Hospital Access for Overdose Care in Lebanon

MICHELLE WAZAN, TATYANA SLEIMAN, DIMA EL HAJJ, AND RAMZI HADDAD

## Abstract

In Lebanon, the criminalization of drug use and the misapplication of ministerial directives have led hospitals to report overdose cases to law enforcement, deterring people who use drugs from seeking urgent medical care and increasing the risk of preventable death. This paper examines overdose response as a right to health issue, using civil society advocacy in Lebanon to illustrate how law enforcement involvement in health care settings undermines access to emergency care. Drawing on repeated nationwide mappings of hospital practices when receiving overdose cases conducted between 2016 and 2024, the paper documents patterns of compliance and noncompliance with Ministry of Public Health directives prohibiting the reporting of overdoses to the police. While sustained advocacy has contributed to multiple policy milestones, including ministerial and syndicate circulars reaffirming hospitals' duty of care without police involvement, implementation has remained uneven. Although more hospitals have stopped reporting overdose cases to the police, continued reporting remains tied to limited staff awareness, fear of liability, and stigmatizing attitudes toward people who use drugs. The Lebanese case highlights both the critical role and the structural limits of civil society monitoring in safeguarding access to emergency medical care under conditions of criminalization, crisis, and weak accountability. We argue that incremental protective policies are insufficient where emergency care remains entangled with punitive drug policy.

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## Introduction

The United Nations Office on Drugs and Crime *World Drug Report 2025* estimates that 316 million people used an illicit drug in 2023, representing a 28% increase over the past decade.<sup>1</sup> Drug overdoses remain a critical global public health issue, with an estimated 100,000–150,000 cases annually, placing a significant burden on health systems.<sup>2</sup>

Despite these alarming figures, evidence consistently shows that emergency services are often not contacted during drug-related emergencies. Studies in Canada have found that emergency services are called in less than half of overdose cases.<sup>3</sup> Fear of police presence, potential criminal charges, and negative past encounters with law enforcement are cited as key barriers.<sup>4</sup> In the United States, a survey examining incarceration in a county jail within six hours following an emergency medical service response reported that 21% of people experiencing stimulant-involved overdoses were subsequently incarcerated.<sup>5</sup> Together, these findings underscore the significant role that law enforcement involvement plays in shaping health decisions, ultimately increasing the risk of overdose-related mortality.

In response to this reluctance to seek emergency care, several countries have introduced legal protections aimed at encouraging calls for help during overdoses. One prominent example is “good Samaritan” laws (GSLs) adopted by numerous US states that provide limited immunity from arrest or prosecution for drug possession when emergency services are contacted.<sup>6</sup> Evidence suggests that jurisdictions implementing GSLs experience a 14% lower incidence of overdose-related fatalities compared to those that have not implemented such laws.<sup>7</sup> However, persistent deterrents remain in jurisdictions where GSLs are passed.<sup>8</sup> Studies continue to document fears related to police presence at overdose scenes, risk of arrest, and limited knowledge of or trust in GSLs.<sup>9</sup>

In Lebanon (population just over 5 million), where the use of drugs and possession for personal use is criminalized and carries prison sanctions of up to three years, data on drug use prevalence and overdose rates are scarce. The most recent estimates suggest that there are 9,000 people nationwide who

inject drugs.<sup>10</sup> In 2015, the estimated number of people who injected drugs in Greater Beirut was approximately 3,000.<sup>11</sup> More than 195 individuals reported having experienced a non-fatal opioid overdose in the same year.<sup>12</sup> In Lebanon, the risk of overdose is closely linked to incarceration, prior treatment experiences, and repeated arrests, reflecting interconnected risks faced by communities of people who use drugs and providing critical context for examining the country’s overdose response.<sup>13</sup>

The International Guidelines on Human Rights and Drug Policy, endorsed by several United Nations agencies, affirm that, in line with the right to health under international human rights law, particularly the Universal Declaration of Human Rights and the International Covenant on Economic, Social and Cultural Rights, states must ensure that individuals who experience or witness an overdose are protected from criminal prosecution or punishment when seeking medical assistance.<sup>14</sup> These standards clarify that people who use drugs hold an inalienable right to health and that states, including Lebanon, are obligated to ensure safe access to emergency medical care during overdoses.

Nevertheless, criminalization reinforces stigma and discrimination that extends beyond the criminal justice system into health care settings, effectively “undermin[ing] access to services for people who use drugs.”<sup>15</sup> Criminalization thus impedes the enjoyment of human rights, including access to emergency medical services.

Over the past two decades, the legal framework governing overdose reporting to law enforcement in Lebanon has evolved, yet significant implementation challenges persist. In 2006, the Ministry of Interior issued Circular 55/1, requiring hospitals to report emergency cases resulting from “harm caused by others” to the Internal Security Forces.<sup>16</sup> Although this provision does not apply to overdose or drug-related cases, its vague wording, coupled with entrenched stigma, has led many hospitals to report drug overdoses to law enforcement. As a result, police have visited emergency departments to interrogate or arrest patients following overdose events. This practice has fostered a climate of fear that discourages people who use drugs from

seeking urgent medical care, increasing the risk of preventable death. A 2015 unpublished survey conducted by Skoun—a harm reduction and outpatient treatment center operating in Lebanon since 2003—among 300 service users of harm reduction centers in Lebanon found that 57% of those who had experienced an overdose did not seek hospital care during their first overdose for fear of arrest.

To mitigate the documented harms of criminalization, public health and human rights experts have increasingly advocated for the decriminalization of drug use as part of a rights-based approach to drug policy. Decriminalization is widely understood to reduce barriers to harm reduction services, including access to emergency medical care, and to improve health outcomes.<sup>17</sup> The United Nations Committee on Economic, Social and Cultural Rights has repeatedly linked the criminalization of drug use to impediments to the right to health and to increased engagement in risky practices that increase the likelihood of drug-related emergencies.<sup>18</sup> The recognition of these harms has led a growing number of countries and jurisdictions to pursue varying drug use decriminalization models.<sup>19</sup> Portugal is frequently cited as a leading example of decriminalization, where results have shown a significant decrease in overdose deaths since 2001.<sup>20</sup>

This paper uses advocacy conducted in Lebanon as a case study to examine how legal ambiguity, institutional practices, and stigma converge to undermine access to emergency care and to explain why overdose-linked protective policies are insufficient without broader structural reform. In doing so, it contributes to ongoing debates on drug policy and human rights by foregrounding overdose response as a site where the consequences of criminalization are both immediate and fatal.

## Civil society advocacy and monitoring in Lebanon

### *Survey of service users*

In 2015, in response to growing concerns among service users and their families about overdose, Skoun conducted a survey among 300 service users of harm reduction centers operating in Lebanon to

better understand drivers and obstacles to emergency-seeking behavior. The survey found that 35% of service users had overdosed and that 49% knew someone who had overdosed. Among those who overdosed, 57% did not go to a hospital the first time they overdosed, 21% did not go the second time they overdosed, and 13.3% refrained from going to a hospital on their third overdose. The main stated reason for this reluctance was fear of arrest. Of those who reported going to the hospital or knowing someone who overdosed and went to the hospital, 32% reported that the police were called.

As a result of these findings, and in partnership with Embrace—a Lebanese nongovernmental organization working on mental health and suicide prevention—and the National Mental Health Program at the Ministry of Public Health, Skoun held a panel in 2016 with ministerial representatives as well as representatives from two major hospitals in Lebanon to discuss the life-threatening consequences of the misapplication of the ministry's 2006 circular. The panel's conclusion was that reporting overdose cases to the police contravened the Hippocratic Oath and violated medical ethics. Accordingly, the Ministry of Public Health released Circular 44/2016 to clarify that overdose cases fall outside the scope of Circular 55/1, since they do not constitute "harm caused by others."<sup>21</sup> However, even after this clarification, many hospitals continued to disregard the policy.

In 2016, Skoun launched a series of initiatives to ensure safe and timely access to emergency medical care—without fear of arrest—in cases of overdose for people residing in Lebanon. These efforts consist of conducting repeated mappings of hospitals to document those that implement the ministerial directives, as well as advocating with decision-makers and governmental entities to secure additional guarantees and directives that protect the rights of people who use drugs when accessing health care services.

### *"Safe hospitals" mapping*

To assess the implementation of the Ministry of Public Health's Circular 44/2016 prohibiting the reporting of overdose cases to law enforcement,

Skoun initiated repeated mappings of hospital practices across Lebanon beginning in 2016. The initial 2016 mapping served as a pilot phase, through which the methodology was refined, with subsequent rounds from 2018 onward producing more consistent and reliable data. The mappings aimed to document whether hospitals report overdose and drug-related emergencies to law enforcement upon admission to emergency departments and to identify patterns of compliance, noncompliance, and underlying justifications. The number of hospitals successfully reached varied across mapping rounds due to a variety of factors, including non-response and broader health system disruptions, particularly in the context of Lebanon's overlapping economic and political crises (see Table 1). In the first round, Skoun targeted all 141 private and public hospitals listed on the Ministry of Public Health's website; subsequent rounds targeted the 133 hospitals that responded during the first round. The final sample reflects those that were reachable and responsive at the time of data collection.

The mappings were conducted through structured phone surveys by Skoun's outreach team using a standardized questionnaire focused on reporting practices for overdose and drug-related emergencies, as well as awareness of relevant ministerial circulars. The unit of analysis was the hospital. Interviews were conducted with the most senior emergency department staff available, typically one or two individuals per hospital (a senior doctor or a senior emergency room nurse), as they are the primary decision-makers regarding whether to report cases to law enforcement. In some instances, emergency staff indicated that such decisions required referral to hospital administration, in which case Skoun contacted the administration directly. This purposive selection aimed to capture institutional practice through those with decision-making

authority, rather than to survey a representative sample of all emergency department staff.

A hospital was classified as "safe" for people who use drugs if overdose and drug-related emergency cases were not reported to law enforcement, irrespective of staff familiarity with the circulars themselves. This classification was used as an operational proxy for whether individuals could seek care without risk of legal repercussions. Where reporting occurred, reasons and areas of concern were documented. In cases where multiple respondents were interviewed within the same institution and provided contradictory responses, the hospital was conservatively classified as "unsafe," reflecting the potential risk faced by individuals in practice.

In parallel with data collection, the mappings served an advocacy and accountability function. Hospitals that were unaware of the circulars were informed of their content and of the human rights and health implications of reporting overdose cases. Copies of the relevant directives were shared with emergency staff and hospital administrations to foster internal dissemination and compliance.

Once identified, lists of hospitals that did not report overdose cases were compiled and disseminated through social media and harm reduction networks to enable people who use drugs to access emergency care without fear of arrest.

Repeated mappings were conducted between 2016 and 2024, with interruptions during periods of compounded crisis, economic collapse, the COVID-19 pandemic, and intensified conflict, allowing for the observation over time of trends in compliance and institutional practice.

## Growth of a national network of "safe hospitals"

Figure 1 shows that after 2018, there was a sharp

TABLE 1. Number of hospitals contacted and responding per mapping round

Year	Number of hospitals contacted	Number of hospitals that responded
2018	141	133
2022	133	107
2023	133	91
2024	133	100

increase in the percentage of hospitals considered “safe” and a sharp decrease in the number of hospitals declaring not to have received the Ministry of Health’s 2016 circular. The number of hospitals that received the circular but nevertheless continued to report overdose cases to the police decreased between 2018 and 2024.

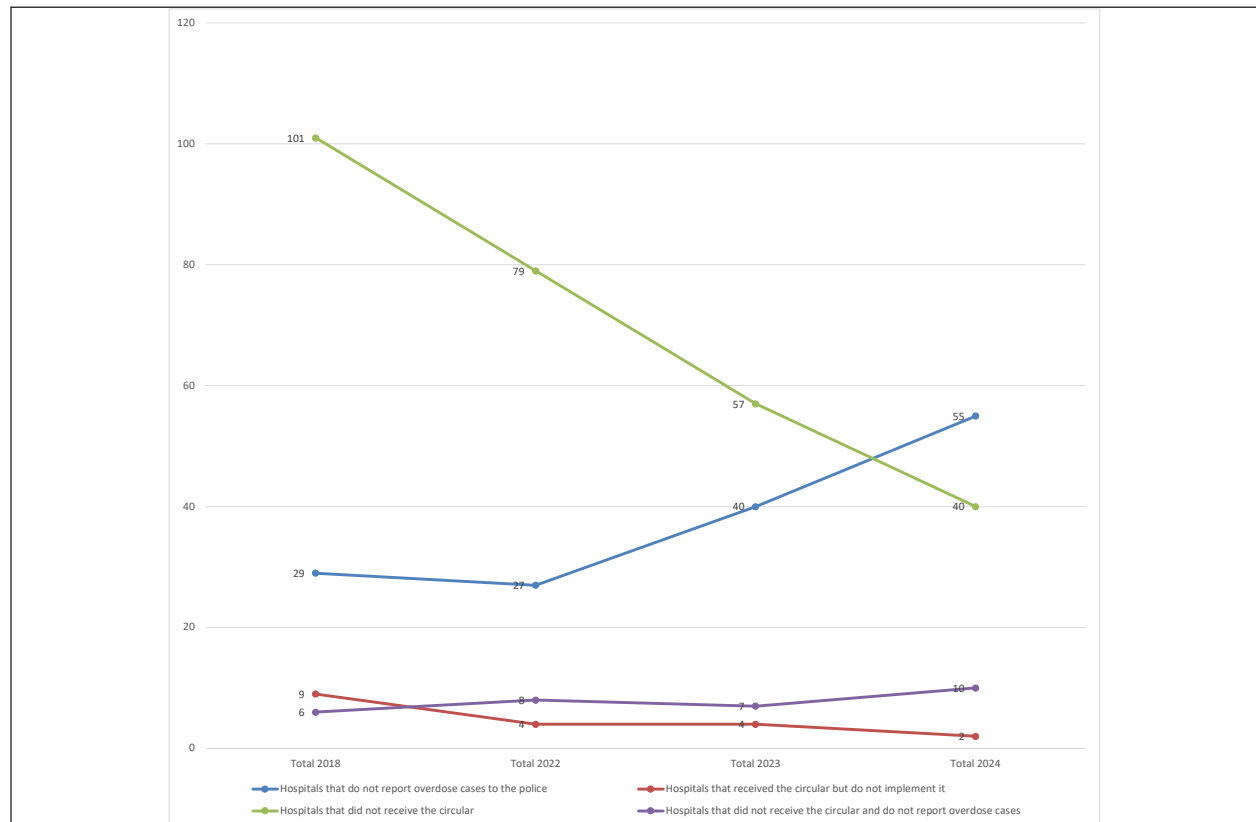
The mappings coincided with sustained advocacy that led to additional normative measures reinforcing the right of people who use drugs to access emergency medical care. The increase in the number of hospitals refraining from reporting overdoses appears to be driven by three factors: the issuance of complementary circulars in 2019 by the Ministry of Public Health and the Ministry of Interior clarifying non-reporting obligations and law enforcement jurisdiction; the repetition of mappings, which reinforced awareness of these obligations among hospital staff; and the 2024 circular issued by the Syndicate of Hospitals, which

provided further institutional reassurance to hospital administrations. These measures directly responded to concerns raised by hospitals during the mappings and were pursued through targeted advocacy with relevant stakeholders.

*Reasons for continued reporting*

Despite the increase in the number of “safe hospitals,” structural impediments to the implementation of the circular persisted. Over the years, interviews with staff in private and governmental hospitals revealed a consistent pattern of reporting overdose cases to law enforcement, often driven by lack of awareness of the Ministry of Public Health and Ministry of Interior circulars and a widespread belief, sometimes driven by social and political pressure, that notifying the police is part of their duty. Hospital staff often expressed worry that they would face prosecution for not reporting or that the hospital would be legally liable for the same

FIGURE 1. Hospitals’ compliance with Ministry of Health circular, 2018–2024



reasons. A hospital director echoed the social and political pressures they face, with one explaining that “the tongue of people is stronger than the law” and another admitting fear of media exposure: “If someone dies of an overdose and [we] didn’t report, what will the media say?”

Additional justifications for reporting included suspicion of suicide attempts or poisoning, patient agitation, or behavior deemed unusual. Many respondents conflated overdose and drug use with violence, stating that they report cases when “[the patients] are violent, or if they come alone and stay for a long time,” or claiming that they report because drug use suggests accompanying criminal activity, as reflected in comments such as “because this person might be harming someone else.”

In heavily militarized areas, hospital staff noted that “having the Army at the hospital checkpoint means we must report” or “there is a police checkpoint at the entrance, they already know.” Regular oversight by security agencies was also cited. For instance, one hospital highlighted that local law enforcement “regularly comes in to check on what’s happening and ask about death cases and overdose cases.” Several admitted reporting to multiple parties, including hospital security, the Lebanese Army’s Intelligence Directorate, the Internal Security Forces’ intelligence unit, and the General Security Directorate, raising serious concerns about breaches of patient confidentiality.

Stigmatizing opinions and attitudes among medical staff members are particularly concerning because they directly hinder access to medical services but could also translate into defiance of the Ministry of Public Health’s circulars. One staff member argued that “these circulars are a mistake, and these cases should be reported to the police, if not to arrest them, at least to take them to treatment.” Another declared more harshly that “people who use drugs should be killed ... it’s against religion, and they’re harming others and might harm children.” Surprisingly, that staff member worked at a hospital that did not report overdose cases to the police, yet he was adamant about expressing his disagreement with the hospital’s policy during the survey.

### *Mapping in crisis and conflict*

The economic collapse of Lebanon triggered a severe medical brain drain in 2021, with approximately 40% of physicians and 30% of nurses leaving the country.<sup>22</sup> This exodus contributed to high staff turnover and fragmented awareness of ministerial directives among emergency department personnel. As of 2022, the results of the mappings documented disruptions in the continuity of overdose response practices within health care institutions, reflected in inconsistent compliance across mapping cycles. Hospitals previously identified as “safe” no longer appeared on “safe hospitals” list due to staff changes, hospital closures, or the suspension of emergency departments. Conflict escalation starting in late 2023 further affected health care institutions, demonstrating that in contexts of crisis and conflict, protection directives are ineffective without sustained institutionalization, monitoring, and reinforcement.

### Advocacy

Skoun’s advocacy efforts were informed by findings from its repeated mappings and targeted institutions identified as central to addressing health care workers’ fears and institutional hesitations around non-reporting. In 2019, following sustained advocacy, the Ministry of Public Health reiterated its directives through Circular 76/2019, reaffirming that hospitals should refrain from reporting overdose cases to the police. The Ministry of Interior subsequently issued a complementary circular addressed to law enforcement agencies, clarifying that overdose cases reported by hospitals fall outside their mandate and explicitly acknowledging the right to health of people who use drugs.

Subsequent mappings conducted between 2022 and 2024 demonstrated that despite these directives, continued advocacy remained necessary. In August 2024, Skoun engaged key stakeholders to strengthen dissemination and monitoring of the circulars, resulting in the Syndicate of Hospitals issuing Circular 22/2024 reminding all private hospitals of their duty of care and of their obligations under the ministerial directives. In parallel, Skoun

launched a video addressed to health care workers, emphasizing their role in safeguarding the lives of people who use drugs and reinforcing compliance with non-reporting policies.<sup>23</sup>

## Lessons learned

The Lebanese case illustrates how criminalization continues to produce adverse health outcomes even where policies formally seek to mitigate its effects. Protective policies, while necessary, are insufficient when they are not embedded within institutional practice. The mapping of “safe hospitals” revealed that ministerial directives prohibiting the reporting of overdoses to law enforcement were often not integrated into hospital protocols, staff training, or internal accountability mechanisms. This lack of institutionalization undermined continuity, weakened knowledge among health care workers, and allowed discretionary and arbitrary practices to persist. This is particularly relevant in a context of crisis and conflict where staff turnover is high.

The absence of systematic monitoring and enforcement by relevant ministries further weakened accountability, allowing hospitals to selectively interpret or disregard official guidance with few consequences. While Skoun’s mapping played a critical role in disseminating life-saving information and reminding health care institutions of their obligations, it also exposed the limits of civil society action in the absence of formal state endorsement. In several cases, hospital administrations questioned the legitimacy of a nongovernmental organization to assess or publicize compliance with ministerial directives.

At a deeper level, the Lebanese example underscores how criminalization operates not only through law but through social norms and professional cultures. Moralizing attitudes among health care workers toward people who use drugs reinforce fear, stigma, and discriminatory practices, effectively reproducing the harms of criminalization within health institutions themselves. This dynamic captures the core harm of punitive drug policy in the context of health: Even where protective policies exist, criminalization reshapes perceptions of

deservingness, trust, and care, ultimately placing lives at risk.

Finally, it was not possible to assess the impact of protection directives and the growing network of “safe hospitals” on overdose-related mortality, as drug overdoses remain systematically underreported due to stigma and the absence of consistent data collection mechanisms.

## Conclusion

Across jurisdictions that criminalize drug use and possession, evidence shows that protection directives aimed at safeguarding the fundamental right to health of people who use drugs are insufficient on their own. While contexts and contributing factors may vary, the common denominator remains the criminalization of drug use. Punitive drug policies continue to shape health-seeking behavior and health outcomes. In a context of criminalization, overdose deaths can result from foreseeable and preventable rights violations. Only by embracing evidence-based and rights-based approaches to drugs can states reduce overdose mortality, protect human dignity, and uphold their international commitments.

## References

1. United Nations Office on Drugs and Crime, *World Drug Report 2025* (2025).
2. World Health Organization, *Global Status Report on Alcohol and Health and Treatment of Substance Use Disorders* (2024).
3. K. M. Follett, A. Piscitelli, M. Parkinson, et al., “Barriers to Calling 9-1-1 During Overdose Emergencies in a Canadian Context,” *Critical Social Work* 15/1 (2014).
4. S. Bozat-Emre, S. G. Marshall, C. Zhong, et al., “Lessons Learned from Launching the Manitoba Take-Home Naloxone Program,” *Health Promotion and Chronic Disease Prevention in Canada* 38/6 (2018).
5. B. Ray, B. J. Hedden, J. J. Carroll, et al., “Prevalence and Correlates of Incarceration Following Emergency Medical Services Response to Overdose,” *Drug and Alcohol Dependence* 238 (2022).
6. H. Nguyen and B. R. Parker, “Assessing the Effectiveness of New York’s 911 Good Samaritan Law: Evidence from a Natural Experiment,” *International Journal of Drug Policy* 58 (2018).

7. S. Moallem and K. Hayashi, "The Effectiveness of Drug-Related Good Samaritan Laws: A Review of the Literature," *International Journal of Drug Policy* 90 (2021).
8. E. Van der Meulen, S. K. H. Chu, and J. Butler-McPhee, "That's Why People Don't Call 911: Ending Routine Police Attendance at Drug Overdoses," *International Journal of Drug Policy* 88 (2021).
9. H. Byles, N. Sedaghat, N. Rider, et al., "Barriers to Calling Emergency Services Among People Who Use Substances in the Event of Overdose: A Scoping Review," *International Journal of Drug Policy* 132 (2024).
10. Middle East and North Africa Harm Reduction Association, *Assessment of Situation and Response of Drug Use and Its Harms in the Middle East and North Africa* (2024).
11. Middle East and North Africa Harm Reduction Association. Project Crossroads: Size Estimation, Risk Behavior Assessment, and Disease Prevalence Among Key Populations in Lebanon (2015).
12. Ministry of Public Health, *National Report on Drug Situation in Lebanon* (2017).
13. Middle East and North Africa Harm Reduction Association (2024, see note 10).
14. United Nations Development Programme, World Health Organization, Joint United Nations Programme on HIV/AIDS, Office of the United Nations High Commissioner for Human Rights, *International Guidelines on Human Rights and Drug Policy* (2019).
15. Joint United Nations Programme on HIV/AIDS, *Health, Rights and Drugs: Harm Reduction, Decriminalization and Zero Discrimination for People Who Use Drugs* (2019).
16. Skoun, *Impediments to the Right to Life: Monitoring Overdose Reception Practices in Emergency Rooms Across Lebanese Hospitals* (2023), <https://www.skoun.org/storage/publications/nexAOvzIec9ooBqSNJTVt-BIwYyNKbSpmz6zzRHJx.pdf>.
17. Public Health Degrees, "The Decriminalization of Drugs and Public Health" (March 28, 2026), <https://www.publichealthdegrees.org/resources/drugs-decriminalization-and-public-health/>.
18. United Nations General Assembly, Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, UN Doc. A/65/255 (2010).
19. Talking Drugs, "Drug Decriminalisation Across the World," <https://decriminalisation-map.talkingdrugs.org.uk/>.
20. Drug Policy Alliance, *Drug Decriminalization in Portugal: Learning from a Health and Human-Centered Approach* (2023).
21. Skoun (2023, see note 16).
22. World Health Organization Regional Office for the Eastern Mediterranean, "Joint Statement by Dr Tedros Adhanom Ghebreyesus, WHO Director General, and Dr Ahmed Al Mandhari, Regional Director for the Eastern Mediterranean, on Lebanon" (September 19, 2021), <https://www.emro.who.int/media/news/joint-statement-by-dr-tedros-adhanom-ghebreyesus-who-director-general-and-dr-ahmed-al-mandhari-regional-director-for-the-eastern-mediterranean-on-lebanon.html>.
23. Skoun, "Skoun Overdose Awareness Campaign 2024," YouTube (August 29, 2024), <https://www.youtube.com/watch?v=wtRLfvpLovM>.

# Intentions to Care, Structures That Restrain: The Reality of Secure Units in Residential Social Care Institutions in Slovenia

JUŠ ŠKRABAN AND ANDRAŽ KAPUS

## Abstract

Despite ongoing criticism, the practice of involuntary admissions to locked units remains widespread globally. In this paper, we focus on secure units within residential social care institutions in Slovenia, which are intended to provide special protection for individuals deemed dangerous to themselves or others. We conducted semi-structured individual and group interviews with institutional management, secure unit staff, and residents in all secure units across the country. The findings reveal three key issues. First, the spatial congregation of residents within secure units tends to exacerbate, rather than reduce, risk. Second, instead of addressing the specific risks that prompted admission, secure units often implement generalized restrictions aimed at maintaining internal safety. Third, the overall institutional structure significantly limits the provision of individualized care and constrains both staff and resident agency. Although secure units are formally defined as protective environments, the study suggests that they function primarily as institutional containers. As such, they are not only in violation of human rights but are also ineffective in fulfilling their intended purpose due to inherent institutional limitations. We argue that secure units should be abolished and replaced by community-based services.

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## Introduction

Since the mid-20th century, social movements, especially those led by people with disabilities, have advocated for the right to live in the community, rather than in institutions.<sup>1</sup> This stance has been given special emphasis by article 19 of the Convention on the Rights of Persons with Disabilities (CRPD) and continuously by the activities of the Committee on the Rights of Persons with Disabilities.<sup>2</sup>

Despite the significance of the CRPD, its implementation has faced substantial challenges and obstacles.<sup>3</sup> In practice, people's rights are often not upheld, particularly for people with the most intensive needs, who are frequently denied the opportunity to live in the community and instead remain segregated in institutional settings.<sup>4</sup> This remains the case despite increased research attention in recent decades on restrictive and coercive practices and a broad international consensus on the need to reduce their use.<sup>5</sup> While some disagreement persists regarding the circumstances under which nonconsensual treatment may be permissible, there is universal agreement that such treatment must not be justified on the basis of disability or perceived disability.<sup>6</sup> Despite a growing body of evidence suggesting that such practices can be significantly reduced or even abolished altogether, institutionalization and coercion continue to serve as cornerstones of contemporary mental health services.<sup>7</sup>

Social work and other helping professions in mental health are characterized by an immanent contradiction between care and control. This tension marks a point of collision between divergent social and ethical positions and mirrors the dual mandate of these professions.<sup>8</sup> On one hand, practitioners are tasked with supporting individuals in becoming as independent as possible within society, while on the other hand, they simultaneously exercise responsibilities on behalf of the state that represent a form of social control. This contradiction has been well documented in scholarship addressing risk, institutional care, and coercive practices.<sup>9</sup>

This paper is based on qualitative research conducted in locked “secure units” within residen-

tial social care institutions (RSCIs) in the Central European country of Slovenia. These settings offer a valuable context for examining how care and control operate in practice within institutional environments.

The paper pursues two aims. First, its scholarly aim is to examine the implications of “care” delivered behind closed doors for both residents and staff. This inquiry is urgent from a scientific point of view because this type of care is highly neglected in research while at the same time representing the most intrusive and restrictive “support” setting for people with disabilities. Second, the paper has a practical objective. Given that our research is guided by human rights and social justice perspectives, we aim to analyze the limitations of institutional care in secure units to inform and influence changes toward a rights-based mental health policy and to support the development of community-based alternatives. To address these dual aims, we ask the following research questions: (1) How does formally coercive care in secure units shape care practices? and (2) What effects does formally coercive care in secure units have on residents?

## The service and legal national context

Mental health services in Slovenia are marked by a division between acute treatment in psychiatric hospitals and long-term placement in RSCIs. The number of beds in psychiatric hospitals began to decline in the 1970s, as long-term patients were increasingly transferred to RSCIs that had been established after the Second World War. Today, Slovenia—a country with around two million inhabitants—still relies heavily on institutional forms of care. As of 2023, 4,565 children and adults with intellectual and mental disabilities lived in RSCIs, with the vast majority (75%) living in facilities housing more than 25 residents.<sup>10</sup>

Institutional care in Slovenia, as defined by the Social Care Act, encompasses all forms of assistance provided in an institution, by another family, or in another organized setting that replaces or supplements the functions of a person's home and family. This includes, in particular, accom-

modation, organized meals, care, and health care. RSCIs provide institutional care for adults with intellectual and psychosocial disabilities. RSCIs predominantly consist of open units, where only voluntary placements are permitted under the Social Care Act. However, most of these institutions also include locked “secure units.”

Locked units are not a recent phenomenon in Slovenia. RSCIs in which secure units operate today were traditionally—until the early 2000s—entirely closed, with residents’ movement restricted and departure from the institution permitted only with staff authorization. In addition, RSCIs had various prototypes of secure units serving different functions, such as admission units, units for persons with “challenging behavior,” and units used for disciplinary purposes.

The first Mental Health Act, adopted in 2008, defined secure units within RSCIs as the only setting in which the formal deprivation of liberty was permitted. As stated in the act’s explanatory memorandum, the key principles underlying this formalization were proportionality, the use of the least restrictive measures, and the requirement that restrictions be imposed solely on the basis of a court decision.<sup>11</sup> As we demonstrate in our paper, however, this legalization did not achieve its intended effect. While RSCIs formally opened their doors, closed and restrictive spaces within them—secure units—were preserved.<sup>12</sup>

Slovenia represents a rather unique legal situation in Europe since we are not aware of any other European country where it is possible to formally deprive persons of their liberty if they are not in need of acute psychiatric treatment. In most countries in which deprivation of liberty in the social care sector is lawful, it is regulated through mental capacity legislation according to which a person can be formally detained if they lack capacity to consent.<sup>13</sup> However, formal social care detention internationally largely applies to “community settings,” while the Mental Health Act applies to detention in psychiatric—that is, medical—institutions.<sup>14</sup>

According to the Mental Health Act, a secure unit is a unit in a social care institution (e.g., an

RSCI) where people, due to their needs, receive continuous special protection and care and cannot leave the institution of their own free will (article 2(17)).<sup>15</sup> As established in article 74, admission to a secure unit requires meeting the following cumulative criteria: the person has completed or does not need acute psychiatric treatment; the person requires continuous care and protection that cannot be provided elsewhere; the person poses a danger to themselves or others; the danger results from a mental disorder impairing their judgment and behavior control; the danger cannot be mitigated by other forms of care; and the person meets the other conditions for admission to a RSCI. Admission to secure units may be either voluntary or involuntary under the Mental Health Act. Additionally, the use of mechanical restraints with belts and seclusion is permitted (article 29).

Detention in secure units therefore regulates living arrangements (and is not intended to “cure” a “mental illness,” as is the case with mental health detention), which makes it aligned with the stated rationale of social care detention internationally.<sup>16</sup> However, the fact that it is implemented within a social care institution may be explained by the institutional model, which predominated in Slovenian social care since the aftermath of the Second World War.

In Slovenia, there are 13 secure units within six RSCIs, with a total capacity of 187 beds.<sup>17</sup> The average number of beds per unit is 14.4 (minimum 5, maximum 24). In 2023, 69% of the units were operating over capacity, with an average occupancy of 130%. Single rooms are rare; most rooms accommodate two or three residents. Because the doors are kept closed, the units are often spatially cramped, with limited common areas.

Secure units have received limited research attention to date, a gap that this paper seeks to address. A legal analysis conducted as part of this research found that secure units significantly violate the rights enshrined in the CRPD.<sup>18</sup> Quantitative data further reveal concerning trends: a high rate of involuntary admissions (98%), a substantial proportion of residents deprived of their legal capacity (67%), and two dominant pathways to

admission—44% of residents were admitted following discharge from psychiatric hospitals and 34% were transferred from open units within the same RSCI.<sup>19</sup> The data also point to prolonged confinement in secure units, with an average duration of 64 months and a notably low discharge rate (14%), particularly to community-based settings.

In this paper, we draw on findings from the research project “Transformation of Secure Units into Community Services for Adults and Children with Disabilities”—the first national-level study focused on secure units within RSCIs. The study addresses a significant gap in qualitative data concerning secure units, particularly in relation to the discrepancy between their legally defined role under the Mental Health Act and their implementation in practice. We seek to illuminate the everyday realities of life within secure units, with specific attention to institutional practices, obstacles to individualized care, and limitations on user autonomy.

## Methods

We conducted qualitative research in secure units. We gathered empirical data in all six RSCIs with secure units in Slovenia. In each RSCI, we conducted semi-structured group interviews with the institutional management (directors, heads of staff, and head nurses) and staff members in secure units (nurses, social care assistants, and social workers). We also conducted individual semi-structured interviews with heads of the unit and group or individual semi-structured interviews with residents in secure units.

We constructed interview guidelines for each target group. Interview guidelines for the members of institutional management included the following themes: the history of the institution’s secure units; challenges in managing the secure units; views about the role of secure units in the system of health and social services; and views on the future of secure units. Interview guidelines for the staff members in secure units included the following themes: users’ needs before and during

placement in a secure unit and for a successful discharge; methods of and approaches to care; the use of seclusion and restraint; examples of successful interventions; and collaboration with other actors. Interview guidelines for the heads of secure units included the following themes: spatial characteristics of the secure units; organizational aspects of care; information about the staff; and the role of secure units within the institution. Interview guidelines for users included the following themes: life before the placement; the perception of everyday life at the unit; and hopes for future.

A total of 30 members of institutional management, 31 secure unit staff members, 10 heads of secure units, and 30 residents in secure units participated in the study. Interviews with institutional management were conducted without sampling, as the intention was to include all members of the management team. For interviews with staff members in secure units, we sought participation from key roles, including the head of the unit, a social worker, a nurse, and a social care assistant. In the case of residents within secure units, we employed a more flexible, convenience sampling approach. Upon entering the unit, we spent time engaging with residents and explaining the purpose of the interview. We interviewed only those who expressed interest in participating. Interviews took place in a location of their choice within the unit, without the presence of staff members. Additionally, we conducted rapid participant observation (up to two hours) in each secure unit. We produced thick descriptions immediately after each observation.

Data collection lasted from March to September 2024. Interviews were audio recorded and transcribed. In a few cases in which participants (mostly residents) did not want to be audio recorded, a thick description of the interview was written. We analyzed the data using thematic analysis.

All participants received information about the study and provided either their written or oral informed consent. The study was granted ethics approval by the University of Ljubljana Faculty of Social Work Ethics Committee (approval no. 033-3/2023-26).

## Results

### *Theme 1: Congregation of residents and consequent problems*

Residents of secure units represent a highly diverse population, with the sole common denominator being that they meet the legal requirements for involuntary placement—namely, that they pose a danger to themselves or others. This heterogeneity is often perceived by staff as a significant challenge: “There is the problem that our secure units are too mixed. There are people with addictions, older people, younger people, and each needs specific support, and also people who have had forensic treatment” (head of staff).

The accumulation of residents with diverse needs has numerous consequences, ranging from minor everyday challenges in the provision of care to serious safety issues: “There is a woman with intellectual disability. She is undressing herself and there is a young guy after forensic treatment who can get irritated by a smallest thing” (head nurse).

This congregation of people in closed space complicates the provision of care; it also significantly impacts the daily life within the unit and can lead to increased tensions and frequent disturbances. A resident of a secure unit reported that “we hardly get any rest because we have no room for it, only in seclusion room you can be alone, but there is always a camera.” Rapid participant observation in secure units clearly showed that these problems are structural in nature and depend less on how the units are arranged, the type of spaces they offer, how modern or welcoming these spaces are, or how overcrowded they are.

In some cases, tensions escalate into the use of restrictive practices. In one unit, staff reported a case of a resident constantly banging on the door, throwing himself on the floor, crying, and screaming for hours on end. Staff reported:

*In the case of our loud resident who disturbs the whole unit—in most cases we put him in the seclusion room for the very reason of protecting him. We withdraw him so that he does not get hurt by other residents. Sometimes we do it more to calm*

*the whole unit down, to leave him alone and to get him to back off.* (head of secure unit)

### *Theme 2: Controlling risk in secure units*

**Generalized restrictions.** In order to manage potential risks, all secure units implement generalized restrictions, which include the prohibition of belts, shoelaces, cables and cords, and any object that could potentially cause injury. In some units, plates are made of unbreakable material. Cigarettes are distributed according to a schedule and lit by staff, while lighters are attached to the courtyard fence because residents are not allowed to have them on their person. There are also restrictions on the use of phones, which residents are allowed to use only at certain times.

Some restrictions are written in house rules. In some cases, house rules appear to override legislation, since they restrict residents more than is required by law and deprive them of important rights guaranteed by the law. During our research, we detected notable restrictions on phone and internet access, along with limitations on visits. In one case, phone use was limited to twice a day for half an hour, and visits were limited to one hour daily. Some users considered the measures too strict, while staff emphasized that all measures were implemented in the best interest of the residents, as they help prevent dangerous situations.

**Crisis management.** In secure units, verbal communication is the primary method employed by staff to manage crisis situations. During interviews, staff emphasized their awareness of the importance of providing individualized support during such episodes. In addition to conversation, staff also employ various non-verbal strategies to help residents de-escalate, including engagement in structured activities, participation in interest groups, and accompanied walks—all aimed at promoting relaxation and redirecting attention.

When these approaches are insufficient, more intensive interventions are used, such as admission to a psychiatric hospital or the use of seclusion and mechanical restraint. These measures are used,

according to interviewees, only in exceptional situations—primarily in cases of severe self-harm, repeated suicide attempts, or aggression toward others. However, admissions to acute treatment in psychiatric hospitals during placement in a secure unit remain relatively infrequent, affecting only 14% of residents per year.<sup>20</sup> The use of seclusion and restraint varies significantly across secure units. An analysis of secondary data obtained from the competent ministry indicated that in 2023, one institution did not employ any such measures, a second used seclusion with one resident, a third with two residents, and a fourth institution applied both seclusion and mechanical restraint with twenty-one residents. Data from two institutions are unavailable. Our study identified the need for improvements in both the ministry’s methodology for obtaining official records and the record-keeping practices of the institutions themselves.

The variation in practices across institutions indicates that the use of seclusion and restraint depends largely on the working methods in individual secure units. In one interview, it was noted that staff tend to prefer using the seclusion room over physical restraint. Staff explained that they perceive seclusion as a “softer” form of restriction. Interviewees at several other institutions pointed out that physical restraint is also more demanding to implement from an organizational perspective, given that it requires at least five staff members. This may be another reason why staff more often choose seclusion over restraint.

### *Theme 3: Institutional limits to care*

**Restricted time for individual support.** Staff believe that having a good relationship with users plays an important role in ensuring quality care and a pleasant environment. They consider it important to adapt to individual needs, build trust, and create a positive atmosphere that enables cooperation. In interviews, staff highlighted their efforts to establish an individualized approach to each resident, paying attention to specific needs, communication styles, and personal characteristics. They see staff flexibility and in-depth knowledge of the residents as the key to a successful relationship.

Spending the entire day with residents allows them to gain insight into residents’ current mood and to focus on what matters in the moment, rather than on past incidents. As one head of unit—reflecting a broader sentiment among interviewees—noted, “We engage in a lot of conversation and strive for cooperation. It is the only way we can function” (head of unit). In order to create a pleasant atmosphere, staff also spend time with users through shared activities such as board games, walks, and watching television.

Staff provide care to residents within a fixed institutional schedule, which includes medication dispensation, meals, escorted leave from the unit, occupational therapy, and other structured activities. As described by one head of unit, service delivery is heavily dependent on daily staff routines, which are primarily institution-centered rather than person-centered:

*I must arrange in the morning to distribute 21 residents to three employees. But if two residents have one-to-one attention, there’s a big difference, don’t you think? It would provide much better-quality care. But in the morning, you are tied to certain hours, for example already in terms of medication ... Basically, the problem is that there is not much time to spend with users, to be honest.*

More focused attention is typically provided only in acute crises or in situations of residents’ increased needs, when a staff member works individually with a resident to de-escalate and provide emotional support: “Residents always come to us because of deteriorating health or mental health—threats of self-harm or even attempted suicide or whatever. Above all, they need us. To take your time, but that’s the hardest thing” (head of unit). However, such responses are reactive rather than part of a sustained, individualized care approach.

**Limitations to person-centered care.** Staff in secure units reported that, in addition to their general approaches, they primarily use two social work methods to assess situations and provide individualized care: individual planning and risk assessment, both required by national sub-reg-

ulations. Individual care plans are created by multidisciplinary teams—including social workers, therapists, and care staff—and aim to reflect a particular user’s interests, needs, and goals. Users are involved in the planning process when they express preferences, and relatives or key staff may contribute based on their close knowledge of the individual. Risk assessments are used to identify individual risks and tailor the environment and support strategies—for example, adapting furniture or checking footwear to prevent falls. Staff make adjustments such as lowering beds or providing helmets, cushions, or railings, and regularly reevaluate these measures as residents’ conditions change. In cases where a safety measure presents more risk than benefit, alternatives are sought. The overarching goal is to ensure safety while respecting the individual’s needs and supporting a more autonomous and meaningful life.

A pronounced institutional paradox is evident within secure units. On one hand, staff operate within a framework of rules, regulations, and structured daily schedules that shape their routines and constrain available time. On the other, some staff members express a clear commitment to providing individualized support to residents; however, such personalized care is often constrained by the institutional context itself. This tension becomes particularly salient in light of residents’ expressed needs and desires, which predominantly concern life outside the unit. In interviews, residents frequently articulated wishes such as being able to visit shops, attend events, reconnect with family or friends, or return home. In essence, they were articulating a desire for ordinary, everyday experiences. Yet secure units can offer only controlled activities that mimic such experiences—a regulated simulacrum of everyday life.

#### **Theme 4: Challenges to user choice, agency, and empowerment**

##### *Doing time*

Residents in secure units mostly spend time in common areas or hallways with couches (watching television or playing board games); some remain in

bed after breakfast until the next meal or smoking time. This pattern of “hanging around” was observed across all secure units included in the study. Residents participate in various activities, usually within the secure unit itself, including occupational therapy sessions where they can draw, create, and occasionally earn small allowances. They may also help with daily tasks such as folding bibs or cleaning floors. For those unable or unwilling to attend occupational therapy, there are alternatives aimed at encouraging independence, such as the supervised use of the kitchen to prepare food or coffee, as observed in two units. Overall, the lives of residents remain largely confined to the secure unit.

Institutions differ in the extent to which they prioritize activities outside the unit—such as vacations, excursions, public events, sports activities, religious gatherings, performances, or shopping trips—which staff consider important for socialization. However, data show that there is no uniform practice across institutions; access to such activities varies from one unit to another and depends on the willingness of the management and staff.

##### **Restricted capacity for activities outside the unit.**

Since secure units operate under locked-door policies that restrict residents’ movement, the question of leave from the unit (e.g., short walks, day trips, or weekend stays with family) often arises in practice. Leave may be accompanied or unaccompanied. Some institutions allow one staff member to accompany all residents at a time, while others limit accompaniment to no more than three residents per staff member. One institution allowed three residents unaccompanied leave, reportedly following a court suggestion. Another had a resident who regularly went home for several days at a time: “It is not just going out for a coffee, it is going home for several days” (head of staff).

Participation in outside activities was repeatedly highlighted by staff and management as good practice. An important part of the activities in institutions are daily leave or walks; however, they also expose the limitations of secure units in providing individualized support. Staff reported that although they try to ensure that residents go

outside daily, not all residents have this opportunity: “Those who do not get a turn on a given day can go next time” (social worker). Limited staff and the unit’s organization restrict residents’ opportunities to exit the unit: “They don’t allow it. They don’t even allow me visits without their escort ... So, it is very poorly arranged for me” (resident). In one institution, the lack of physical accessibility was the primary reason some residents did not go outside—the secure units were on the first and second floors, there was no elevator, and there was no terrace attached to the units. We observed that residents with limited mobility who used wheelchairs had not been outside the unit for a long time.

Decision-making concerning leave varies across secure units. In one institution, a professional board approve leave requests; in others, the psychiatrist’s opinion is decisive. As one social worker noted, “The previous psychiatrist used to approve unaccompanied exits. Now the current psychiatrist does not choose to do that” (social worker). In some cases, institutions have deferred leave decisions to the courts, which may approve or reject requests based on their interpretation of movement restrictions. However, the Supreme Court has held that the courts are responsible only for determining whether admission to a secure unit complies with the conditions set out in the Mental Health Act, leaving decisions about (un)accompanied leave to the discretion of professionals within the institution.<sup>21</sup>

**General lack of autonomy.** Similar to the issue of exits, other examples demonstrate that residents in secure units lack autonomy in decision-making about their own lives. Institutional control extends to daily activities, care provision, medication, and living arrangements: “You cannot choose who you are in a room with ... They just make sure men and women are not mixed” (resident). Consequently, residents’ freedom to make decisions is significantly limited. While some residents have contact with mental health advocates, their efforts often fail to bring about meaningful change, as ultimate decisions rest with the professional team in agreement with the psychiatrist.

However, some positive examples exist. In one institution, assemblies allow residents to express wishes and needs, fostering increased participation—for example, a resident who had previously avoided going out expressed a desire to spend more time outside. Another institution holds group discussions to gather residents’ feelings and opinions, including those of non-verbal residents, whose perspectives are gleaned through facial expressions and behavior: “Yes, they are present. We observe their facial expressions—they express discomfort very clearly” (registered nurse). One institution reported that residents participate in all decisions, including financial matters, with written and signed agreements on money for cigarettes, coffee, and personal needs, which residents can review anytime.

## Discussion

As we can deduce from the findings, the concept of risk is central to understanding the function and rationale of secure units. These facilities can be characterized as “containers” for individuals deemed “risky,” a designation rooted in the Mental Health Act, which permits admission to secure units only for those assessed as posing a risk to themselves or others. This approach is not unique to Slovenia; rather, it reflects a broader trend, both across European Union member states and globally, where risk or danger constitutes a common criterion for involuntary admission to mental health facilities.<sup>22</sup> Our findings strongly suggest that the concentration of “risky” users exacerbates, rather than mitigates, risk.

As has been suggested, a court order that places a person in a secure unit makes care more vigilant to risks, and, ultimately, the notion of risk is likely to overrule the notion of care.<sup>23</sup> This reflects a well-documented trend in health and social care, whereby care practices become “defensive” in the face of an intensified focus on risk.<sup>24</sup> Consequently, the concept of risk has been heavily criticized as morally conservative and repressive.<sup>25</sup> In the context of secure units, this critique is particularly relevant, as the management of “risky” residents

renders care more defensive and less inclined to embrace risk-taking, resulting in generalized restrictions, limited activities outside the unit, constrained leave, and a general lack of user autonomy.

The presence of generalized restrictions and other risk-management strategies within secure units might appear logical due to their stated protective role implied by their legal definition. However, social work theory emphasizes that risk is situated primarily within situations and contexts rather than being an inherent characteristic of an individual.<sup>26</sup> Admission to a secure unit does not, in itself, alter or address the underlying risk-related situations that initially led to the admission; rather, it removes the person from those contexts and places them behind the closed doors of the unit. For example, while the data are rich about general restrictions within the unit, no professional reported efforts to address the risks identified as the reason for placement as defined by a court order. This has important implications for social policy, particularly in relation to the effectiveness and appropriateness of secure care as a means of managing risk.

While the Mental Health Act defines secure units not only in terms of risk but also with reference to the provision of continuous protection and care, our findings suggest a significant divergence between this stated objective and the realities of practice. The research did not reveal deficiencies in staff capacity or motivation to deliver individualized support. Rather, it is the structural and institutional design of secure units that inherently limits the possibility of such care by constraining attention to specific needs, communication styles, and personal characteristics due to scheduled activities such as medication dispensation, meals, and escorted group leaves. The institutional context, defined by fixed daily schedules and house rules (which in some cases override restrictions posed by the legislation), offers little opportunity for spontaneous, authentic human interaction between staff and residents, which is essential for recovery.<sup>27</sup> Moreover, the secure setting imposes significant constraints on the application of core so-

cial work methods—particularly person-centered planning—which were developed for, and are most effectively implemented within, community-based and non-restrictive environments.<sup>28</sup>

As our research demonstrates, residents in secure units are offered limited access to daily activities, face significant restrictions in accessing external services, and are generally deprived of opportunities for meaningful agency. These conditions reflect the enduring influence of an institutional model of “care,” which continues to shape practice despite longstanding critiques. Indeed, the experiences documented in our study closely mirror the dynamics described by Erving Goffman in his seminal analysis of total institutions, suggesting that despite the passage of time, many of the core features he identified remain present in contemporary secure care settings.<sup>29</sup> The institutional environment, routines, and enclosed spaces do not support residents in recovery but instead require them to adapt to the rules and restrictions imposed by secure units. In other words, our study suggests that care is not the main task but a secondary activity within the framework of protection and institutional management in secure units. Care adapts to security and institutional culture, and not the other way around. Despite the introduction and widespread influence of normalization theory several decades ago, the aspiration of “gloriously ordinary lives” remains elusive for many individuals with disabilities, particularly those with high or complex support needs.<sup>30</sup>

While staff noted that limited personnel constrain their ability to devote sufficient time to individual residents, we contend that increasing staffing levels would only partially address the underlying structural problems. The challenges are primarily structural in nature and do not depend on staffing level and unit design; rather, they stem from the institutional character of the units. In short, secure units not only breach the human rights of residents but fundamentally undermine residents’ recovery and the ability of staff to facilitate that recovery.

## Implications for practice and research

Our implications for practice are grounded in human rights as articulated in the CRPD. The noncompliance of secure units with the CRPD, together with the ineffectiveness of institutional “containment” strategies for individuals deemed “risky,” as suggested by our findings, carries significant implications for social policy in Slovenia. In particular, the Mental Health Act, which currently provides the legal basis for secure units, requires fundamental reform. Our research highlights the urgent need to establish intensive, community-based care that avoids congregating users; ensures housing and support within the community; eliminates generalized restrictions; delivers individualized, person-centered care (addressing people’s diverse needs); and promotes meaningful activities, community inclusion, and flexible support without imposing unnecessary limitations on residents’ freedom of movement.

We believe that such a shift would ensure compliance with article 19 of the CRPD. Beyond their indisputable noncompliance with the CRPD, secure units should be abolished due to their inherent structural limitations in providing care and their prioritization of protection over individualized support; efforts should focus on replacing these units, as opposed to merely improving conditions within them.<sup>31</sup> Intensive, community care, once established, must be fully integrated into networks of community-based services. An increase in users’ needs should not result in institutionalization. Additionally, any service designed to provide intensive support should be grounded in principles other than “risk,” considering the substantial criticism of this concept and its repressive implications in practice.<sup>32</sup> This approach aligns with the CRPD’s emphasis on autonomy and inclusion.<sup>33</sup>

In short, while human rights provide a crucial normative foundation, deinstitutionalization offers a practical framework for implementing necessary future reforms. Within the broader framework of the deinstitutionalization of RSCIs, residents in secure units must be prioritized for resettlement, and secure units themselves should be prioritized for closure. This is imperative, as these settings are

associated with the most severe breaches of human rights enshrined in the CRPD, particularly articles 12, 14, 15, and 19. Establishing this priority is particularly important given international evidence indicating that, in practice, individuals with less complex support needs are often prioritized in deinstitutionalization processes, while those in secure units are frequently overlooked.<sup>34</sup> We recognize that this entails a fundamental shift in society’s approach to long-term mental health crises—one that extends well beyond incremental reform.<sup>35</sup>

Our implications for future research arise from the observation that secure units have received limited scholarly attention. First and foremost, sustained research on secure units and their alternatives is urgently needed at the national level to build a robust evidence base for reform. To support this process, it is essential that decision-makers, service users, practitioners, and researchers collaboratively develop a core set of indicators to guide and evaluate reform. This dataset should include high-quality data on the use of seclusion and mechanical restraint, as these are the most invasive and restrictive practices currently in use. Crucially, the minimal dataset must incorporate both quantitative and qualitative data to ensure a comprehensive understanding of the practices, their impacts, and potential alternatives.

## Strengths and limitations

While the sample included all RSCIs with secure units and key staff members within them, making the data representative of secure units in RSCIs, the study does have some limitations. First, the study design did not adequately capture the perspectives of residents themselves. Consequently, it may be critiqued as yet another study conducted about people with disabilities rather than with them, lacking a collaborative or participatory research approach.<sup>36</sup> Second, a more ethnographic methodology involving long-term researcher presence might have yielded richer, more nuanced, and contextually grounded data, thereby reducing reliance on staff-reported accounts.<sup>37</sup> Third, there is a need for concrete strategies to facilitate meaningful in-

ternational comparison. This remains challenging due to the structural organization of mental health care provision in Slovenia, particularly the division between acute care provided in psychiatric hospitals and long-term care in RSCIs.

## Conclusion

Although secure units are formally defined as protective environments for individuals whose support needs cannot be met elsewhere, our findings indicate that they primarily function as institutional containers for individuals labelled as “risky” or “challenging.” Rather than providing meaningful support, these units serve to isolate service users from the community and congregate them for the purposes of control and management.

Our data indicate that care adapts to security and institutional culture, which enforces a form of control that goes beyond what the law anticipates, significantly restricting the individual and violating their human rights. Secure units, therefore, are not only rights-violating but also ineffective due to their structural limitations, which prioritize protection and containment over individualized, person-centered support. These observations are informed by a human rights perspective grounded in the CRPD, as well as by empirical evidence and the structural constraints of institutional care, which is disabling for both residents and staff.

We argue that secure units, like other institutional forms of care, should be abolished and replaced with community-based services. The deinstitutionalization of residential social care institutions must start with residents in secure units because they endure the most severe rights violations and are often neglected in reform efforts that favor individuals with less complex support needs.

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## References

1. D. F. Stroman, *The Disability Rights Movement: From Deinstitutionalization to Self-Determination* (University Press of America, 2003).
2. Convention on the Rights of Persons with Disabilities, G.A. Res. 61/106 (2006); Committee on the Rights of Persons with Disabilities, General Comment No. 5, UN Doc. CRPD/C/GC/5 (2017).
3. L. Davidson, “A Key, Not a Straitjacket,” *Health and Human Rights* 22/1 (2020).
4. A. Thomas, *The State of Play of Independent Living and Deinstitutionalisation for Persons with Disabilities in the EU* (European Union, 2024).
5. N. Hallett, R. Whittington, D. Richter, and E. Eneje (eds), *Coercion and Violence in Mental Health Settings: Causes, Consequences, Management*, 2nd edition (Springer, 2024); D. Richter, *Human Rights in Psychiatry: Prospects and Dilemmas of Abolishing Coercion in Mental Health Care* (Springer Nature Switzerland, 2025); S. P. Sashidharan, R. Mezzina, and D. Puras, “Reducing Coercion in Mental Healthcare,” *Epidemiology and Psychiatric Sciences* 28/6 (2019).
6. W. Martin and S. Gurbai, “Surveying the Geneva Impasse: Coercive Care and Human Rights,” *International Journal of Law and Psychiatry* 64 (2019); C. Maylea, “Does New Mental Health Legislation in Victoria, Australia, Advance Human Rights?” *Health and Human Rights* 25/1 (2023); S. Gurbai, “Beyond the Pragmatic Definition? The Right to Non-Discrimination of Persons with Disabilities in the Context of Coercive Interventions,” *Health and Human Rights* 22/1 (2020).
7. P. Gooding, B. McSherry, and C. Roper, “Preventing and Reducing ‘Coercion’ in Mental Health Services: An International Scoping Review of English-Language Studies,” *Acta Psychiatrica Scandinavica* 142/1 (2020).
8. F. Kessler, “Soziale Arbeit als Regierung. Eine machtanalytische Perspektive,” in S. M. Weber and S. Maurer (eds), *Gouvernementalität und Erziehungswissenschaft* (S Verlag, 2006).
9. R. Alfandari, B. J. Taylor, M. Baginsky, et al., “Making Sense of Risk: Social Work at the Boundary Between Care and Control,” *Health, Risk and Society* 25/1–2 (2023); A. Milne and S. Nieman, “Revisioning Social Work with Older People Living in a Care Home: Promoting Rights and Reducing Social Control,” *Critical and Radical Social Work* 13/1 (2025); W. Qiang, “Care and Control in Mental Health Social Work: A Case Study,” *Academic Journal of Management and Social Sciences* 7/3 (2024); R. Hawkins, M. Redley, and A. J. Holland, “Duty of Care and Autonomy: How Support Workers Managed the Tension Between Protecting Service Users from Risk and Promoting Their Independence in a Specialist Group Home,” *Journal of Intellectual Disability Research* 55/9 (2011).

10. Ministrstvo za solidarno prihodnost (Ministry of Solidarity-Based Future), *Strategija Republike Slovenije za deinstitucionalizacijo v socialnem varstvu za obdobje 2024–2034 (Strategy of the Republic of Slovenia of deinstitutionalization in social care 2024–2034)* (2024), <https://www.gov.si/assets/ministrstva/MSP/Dolgotrajna-oskrba/Strategija-RS-za-deinstitucionalizacijo-v-socialnem-varstvu-za-obdobje-20242034.pdf>.
11. Vlada Republike Slovenije (Government of the Republic of Slovenia), *Predlog zakona o duševnem zdravju (The Proposal of the Mental Health Act)*, EVA no. 1999-2711-0006.
12. V. Flaker and A. Rafaelič, *Deinstitucionalizacija II: nedokončana (Deinstitutionalization II: Unfinished)* (University of Ljubljana Press, 2023), p. 306.
13. L. Series, *Deprivation of Liberty in the Shadows of the Institution* (Bristol University Press, 2022), pp. 12–31.
14. *Ibid.*, p. 18.
15. Zakon o duševnem zdravju (Mental Health Act), *Uradni list RS*, št. 77/362 08, 46/15 – odl. US in 44/19–US 2008, <http://www.pisrs.si/Pis.web/pregledPredpisa?id=ZAKO2157>.
16. Series (see note 13), p. 20.
17. J. Škraban and V. Grebenc (eds), *Preobrazba varovanih oddelkov v skupnostne oblike oskrbe odraslih in otrok z oviranostmi: Poročilo o raziskavi (Transformation of Secure Wards into Community-Based Care for Adults and Children with Disabilities: Research Report)* (Založba Univerze v Ljubljani, 2025).
18. L. G. Prestor, J. Arnež, and M. M. Plesničar, “Putting People Behind Closed Doors: An Analysis of Social Care Detention in Slovenia,” *Revija za kriminalistiko in kriminologijo* 75/4 (2024).
19. J. Škraban, K. Prevodnik, and A. Rafaelič, “User, Admission and Discharge Characteristics in Secure Units in Residential Social Care Institutions in Slovenia,” *Slovenian Journal of Public Health* 64/4 (2025).
20. *Ibid.*
21. A. A. v. Slovenia, Vrhovno sodišče (Supreme Court), judgment of February 22, 2018, case no. II Ips 31/2018.
22. European Union Agency for Fundamental Rights, *Involuntary Placement and Involuntary Treatment of Persons with Mental Health Problems* (Publications Office of the European Union, 2012); A. Saya, C. Brugnoli, and G. Piazza, et al., “Criteria, Procedures, and Future Prospects of Involuntary Treatment in Psychiatry Around the World: A Narrative Review,” *Frontiers in Psychiatry* 10/271 (2019).
23. J. Škraban, “Kritični pogled na postopke namestitve na varovani oddelek in odpustov z njega v posebnem socialnovarstvenem zavodu” (“A Critical Look at the Procedures for Admission to and Discharge from a Secure Ward in a Special Social Welfare Institution”), *Socialno delo* 64/1–2 (2025).
24. H. Kemshall, *Risk, Social Policy and Welfare*, 1st edition (Open University Press, 2002); D. Green, “Risk and Social Work Practice,” *Australian Social Work* 60/4 (2007).
25. S. Stanford, “Taking a Stand or Playing It Safe? Resisting the Moral Conservatism of Risk in Social Work Practice,” *European Journal of Social Work* 11/3 (2008).
26. V. Flaker, “Analiza tveganja” (“Risk Analysis”), *Socialno delo* 33/3 (1994).
27. A. Topor, M. Borg, R. Mezzina, et al., “Others: The Role of Family, Friends, and Professionals in the Recovery Process,” *American Journal of Psychiatric Rehabilitation* 9/1 (2006).
28. P. Beresford, J. Fleming, and M. Glynn et al., *Supporting People: Towards a Person-Centred Approach* (Policy Press, 2011).
29. E. Goffman, *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates* (Anchor Books, 1961).
30. W. Wolfensberger, *The Principle of Normalization in Human Services* (National Institute of Mental Retardation, 1972).
31. C. H. Maylea, “A Rejection of Involuntary Treatment in Mental Health Social Work,” *Ethics and Social Welfare* 11/4 (2017).
32. Kemshall (see note 24); Stanford (see note 25).
33. Convention on the Rights of Persons with Disabilities and Committee on the Rights of Persons with Disabilities (see note 2); cf. Martin and Gurbai (see note 6).
34. European Expert Group on the Transition from Institutional to Community-Based Care, *Common European Guidelines on the Transition from Institutional to Community-Based Care: Guidance on Implementing and Supporting a Sustained Transition from Institutional Care to Family-Based and Community-Based Alternatives for Children, Persons with Disabilities, Persons with Mental Health Problems and Older Persons in Europe* (European Expert Group on the Transition from Institutional to Community-Based Care, 2012).
35. J. Russo and S. Wooley, “The Implementation of the Convention on the Rights of Persons with Disabilities: More Than Just Another Reform of Psychiatry,” *Health and Human Rights* 22/1 (2020).
36. P. Beresford, “Developing the Theoretical Basis for Service User/Survivor-Led Research and Equal Involvement in Research,” *Epidemiologia e Psichiatria Sociale* 14/1 (2005).
37. K. Featherstone and A. Northcott, *Wandering the Wards: An Ethnography of Hospital Care and Its Consequences for People Living with Dementia* (Routledge, 2020); E. Rossero, *Care in a Time of Crisis: An Ethnography of Coercive Practices in Italian Acute Mental Health Provision* (Palgrave Macmillan, 2023).

# From International Commitments to Local Practice: Examining Staff Attitudes Toward Human Rights in Lithuanian Mental Health Care Facilities

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## Abstract

This study explores the attitudes of mental health care professionals in Lithuania toward human rights principles, provisions, and standards as defined by the United Nations Convention on the Rights of Persons with Disabilities (CRPD) and their application in mental health care. Employing a mixed-methods convergent design, the study integrates survey data (n = 390) with qualitative findings from six focus groups with professionals and service users (n = 36). The results reveal notable differences across professional roles, institutional settings, and experience levels. Medical psychologists consistently

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demonstrated more human rights-supportive attitudes, while nurse assistants and professionals in large inpatient facilities were more likely to endorse coercive practices and question the full implementation of rights in practice. Additionally, mid-career professionals and those working in smaller facilities expressed greater openness to reform and the practical utility of the CRPD. Qualitative findings further highlighted systemic barriers such as stigma, biomedical dominance, and resource constraints. These findings underscore the importance of targeted training, institutional reform, and sustained political will to align Lithuania's mental health care services with international human rights standards. Further longitudinal research is warranted to examine how attitudes toward human rights in mental health care evolve, especially in response to policy changes, reforms, and targeted training initiatives.

## Introduction

Across the world, people with mental health conditions or psychosocial disabilities often face stigma, discrimination, and limitations on their political, civil, social, and economic rights.<sup>1</sup> Fostering their human rights is essential to advancing overall well-being. Mental health care professionals have a key role in this process: They are responsible for ensuring that human rights principles guide mental health care interventions.<sup>2</sup> In light of recent global crises affecting health, economic stability, and social justice, it is more important than ever to recognize and prioritize the rights of persons who use mental health care services.<sup>3</sup>

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) has significantly reshaped the global understanding, implementation, and protection of the rights of people with psychosocial disabilities.<sup>4</sup> Its core aim is to ensure that all individuals with mental health conditions and disabilities fully and equally enjoy their human rights and fundamental freedoms, while also promoting respect for their inherent dignity.<sup>5</sup>

Although human rights in mental health care have only recently begun to receive broader recognition, their importance is increasingly

acknowledged across the world.<sup>6</sup> While human dignity is a foundational principle, research indicates that it is not always safeguarded or promoted within mental health systems and services.<sup>7</sup> The World Psychiatric Association has highlighted the protection of human rights in mental health care as one of its primary concerns.<sup>8</sup>

In the past decade, growing recognition of the rights of persons with mental health conditions and psychosocial disabilities has brought traditional psychiatric practices under scrutiny.<sup>9</sup> A key point of contention within the human rights community is whether coercive interventions, such as involuntary hospitalization and treatment, can ever be considered compatible with human rights standards.<sup>10</sup> Some mental health care professionals and advocates argue that such practices may be justified if they are necessary, proportionate, and implemented with strong legal safeguards.<sup>11</sup> Others maintain that coercion is inherently a violation of human rights and can never be justified.<sup>12</sup> This ongoing debate has led to a significant standstill in the human rights discourse, often referred to as the "Geneva impasse."<sup>13</sup> A relatively new direction in academic research on the promotion of human rights in mental health care may offer a way to resolve this impasse, which has dominated discussions in the field in recent years.<sup>14</sup>

In the case of Lithuania, the government ratified the CRPD and its Optional Protocol in 2010, prompting significant legal and systemic reforms, including updates to quality standards for services within the health care system. A clear political commitment to improving mental health care and protecting human rights is reflected in the 19th Government Program of 2024. These priorities are further embedded in national development strategies, which outline specific targets to be achieved by 2030. Key goals include strengthening mental health literacy, combating stigma, improving primary-level mental health care, expanding and diversifying specialized outpatient services, and streamlining inpatient care. According to the Ministry of Health, these objectives are central to the ongoing reform of Lithuania's health care sector.

Since 2021, Lithuania has been conducting human rights monitoring in mental health care facilities using the QualityRights methodology of the World Health Organization (WHO), which aims to support countries in reforming their health care systems to be more person-centered, recovery-oriented, and respectful of human rights.<sup>15</sup> The initiative aims to drive lasting change in attitudes and practices, empowering stakeholders to promote dignity, rights, and recovery for individuals with mental health conditions and disabilities.<sup>16</sup> In 2023, Lithuania's Ministries of Health and Social Security and Labor adopted official guidelines for assessing, monitoring, and providing methodological support to ensure that mental health and social care services meet human rights standards, demonstrating a firm national commitment to improving both the quality of services and the protection of human rights.

Although some progress has been made globally, stigmatizing attitudes and human rights violations continue to occur within mental health care facilities.<sup>17</sup> Across many countries, mental health care professionals face significant barriers to implementing practices grounded in human rights, often working within systems shaped by paternalistic values. For example, in Spain, mental health care professionals cite a lack of financial and human resources, limited social support, and the

persistence of paternalistic and biomedical models as key obstacles to upholding service users' human rights; they also identify stronger professional training as a potential pathway to address these issues.<sup>18</sup> Across South American countries, progress has been made in reducing coercive practices, but further improvements in service quality are still needed.<sup>19</sup> Recognizing the role of human rights in supporting the well-being of both service users and professionals is essential for advancing these standards. In India, implementing new mental health legislation faces major hurdles due to underfunded services, insufficient social support, and a shortage of trained personnel; sustained political will is critical to improving care quality and protecting human rights.<sup>20</sup>

On a global scale, achieving human rights-based mental health care requires much broader and ongoing commitment from health care providers, families, social stakeholders, policy makers, and the wider public.<sup>21</sup> Emerging evidence suggests that professionals' attitudes play a critical role in shaping everyday practices, including the use of coercion, respect for autonomy, and support for decision-making. Studies have shown that stigmatizing or paternalistic attitudes among mental health professionals are associated with the persistence of rights-restrictive practices, whereas more rights-oriented attitudes are linked to improved quality of care and recovery-oriented approaches.<sup>22</sup> Studies have shown that personal attitudes and socially constructed norms strongly influence whether professionals intend to apply human rights principles and standards in their work.<sup>23</sup> As a result, mental health care practitioners frequently encounter challenges when striving to uphold human rights in their day-to-day practice.<sup>24</sup>

In Lithuania, too, despite recent progress and initiatives, deeply entrenched stigmatizing attitudes continue to pose a major barrier to the effective realization of the rights of people with mental health conditions and psychosocial disabilities. This issue is particularly evident in national assessments of the mental health care system.<sup>25</sup> A study commissioned by the Mental Health Centre at the Lithuanian Institute of Hygiene found that

discriminatory and human rights-averse views are still widespread among the general public and mental health care professionals.<sup>26</sup>

Until the present study, no research in Lithuania had specifically examined mental health care professionals' attitudes toward human rights principles or their implementation in practice. Our study addresses that gap by evaluating these professionals' views on human rights in everyday service delivery. Lithuania's mental health system is undergoing a transition from institutional to community-based care, reflecting broader dynamics seen in Central and Eastern Europe. That said, rather than aiming for direct generalizability, the study contributes to the limited empirical evidence on how professionals' attitudes are shaped by training, institutional culture, and reform processes, while offering context-sensitive insights to inform comparative research on the barriers and enabling conditions affecting human rights implementation.

The specific objectives of this paper are as follows:

- to evaluate how mental health care professionals perceive the principles, provisions, and standards for ensuring human rights as defined by the CRPD, and how these are applied within mental health care services;
- to assess professionals' attitudes toward potential reforms in mental health care services, whether organizational, managerial, or clinical, that would bring practices into greater alignment with the CRPD principles, provisions, and standards; and
- to explore the associations between, on the one hand, professionals' attitudes toward human rights and service reforms and, on the other, their sociodemographic characteristics, as well as the organizational features of the facilities in which they work.

## Methods

### *Study design*

We utilized a convergent mixed-methods design.<sup>27</sup>

The quantitative component involved a survey administered online, by telephone, and in person by the market research company RAIT.<sup>28</sup> It provided statistical insights into the prevalence and patterns of human rights implementation and professionals' attitudes. The qualitative component was exploratory and grounded in an experiential framework.<sup>29</sup> It included six focus group discussions with mental health care professionals and service users, as well as open-ended questions within the survey.<sup>30</sup> Including qualitative methods enabled a deeper investigation of participants' attitudes and the underlying reasons behind the quantitative findings.<sup>31</sup> They also captured subtle systemic and sociocultural dynamics, as well as other human factors, that numbers alone may not reveal.<sup>32</sup>

This paper is part of a broader study titled "Protection of Human Rights in Mental Healthcare Facilities," for which the research team developed a methodology based on the human rights standards outlined in the CRPD, along with relevant tools from the WHO QualityRights initiative.<sup>33</sup>

### *Survey*

Drawing on the CRPD and the methodological tools developed under the WHO QualityRights initiative, we developed a survey questionnaire consisting of 30 closed-ended questions and two open-ended questions. Ten questions were dedicated to collecting sociodemographic and workplace-related data; another 10 questions were formulated to evaluate participants' knowledge of relevant human rights principles, provisions, and standards, as well as their relevance to mental health care; and a further 10 questions were used to evaluate participants' attitudes toward human rights and reforms in mental health care services. (Supplementary materials are available from the authors, including Supplementary Table 1 on the collected sociodemographic and workplace-related data, and Supplementary Tables 2, 3, and 4 on the specific questions and attitudinal statements presented in the survey.)

Additionally, the two open-ended questions in the survey asked participants, "What do you know about the CRPD, and what are its key principles, provisions, and standards relevant to providing

mental health care services?” and “What should be changed or improved first and without delay in the provision of mental health care services in Lithuania to implement human rights?”

For the specific analysis presented in this paper, we drew on the responses to 20 closed-ended questions, including 10 sociodemographic questions, and one open-ended question. These were the questions focused specifically on participants’ “attitudes” rather than their “knowledge.”

We collected the data using three survey formats:

- Online survey: Participants completed the questionnaire independently online. The survey was distributed through email invitations sent to health care institutions and representatives of target groups; links shared in professional social media groups; phone calls to health care institutions inviting participation; and snowball sampling.
- Telephone survey: Participants were contacted directly and invited to answer the questionnaire over the phone. Trained interviewers read the survey questions aloud and recorded participants’ responses in real time. This format helped reach professionals who may not have had access to or who preferred not to use the online format.
- Self-administered paper-based survey: Participants completed printed questionnaires independently. Paper surveys were delivered to staff representatives of several hospitals, who then distributed them to members of the target group.

### *Focus groups*

The fifth and sixth authors conducted six focus group discussions (FGDs), each involving an average of six participants, for a total of 36 participants. We used FGDs as a qualitative method to explore participants’ experiences, perceptions, and opinions in greater depth, allowing for a detailed examination of key themes and the underlying factors shaping them.

Five FGDs were conducted online with mental

health care service providers via Microsoft Teams platform. One FGD with service users was held in person in Vilnius. Although the primary focus of the study was on professionals’ attitudes, the inclusion of service users helped contextualize those attitudes by relating them to lived experiences of care and to the everyday realization of human rights within mental health services.

We used purposive sampling to select FGD participants, which helped ensure a diverse representation of service providers across different institutions, professions, levels of care (inpatient and outpatient), and geographic regions. Professionals from Vilnius, Kaunas, Klaipėda, Alytus, Šiauliai, and Panevėžys took part. We recruited participants through email and telephone. The service user group included individuals with at least five years of experience using mental health services and who reported no recent deterioration in their mental health at the time of the study. (Participants’ sociodemographic information is summarized in Supplementary Table 5, available from the authors).

The FGDs lasted approximately 90 minutes each and took place between October and November 2024. They were guided by a semi-structured protocol that included a set of guiding questions but allowed facilitators flexibility when participants introduced personally meaningful topics. In such cases, the conversation was allowed to flow naturally before being gently steered back to the core discussion points. Throughout the sessions, the research team made conscious efforts to foster a psychologically safe and supportive environment. The facilitators acted as active listeners, using questions primarily to encourage reflection, clarify responses, and guide the dialogue, while prioritizing participants’ voices and experiences.

All discussions were audio-recorded, transcribed verbatim, and analyzed using reflexive thematic analysis.

### *Quantitative data analysis*

We analyzed the survey data to examine relationships between participants’ attitudes toward mental health care practices and human rights, particular-

ly in the context of Lithuania's implementation of the CRPD. We assessed responses by gender, age, professional experience, workplace location, and institution type and size. Descriptive statistics included absolute (n) and relative (%) frequencies for categorical variables. We tested bivariate associations using the chi-square or Fisher's exact tests, as appropriate. Our main method was binary logistic regression, in which 10 attitudinal statements served as dependent variables and were dichotomized into agreement versus non-agreement. We included sociodemographic and workplace characteristics as independent variables and estimated odds ratios (Exp(b)). We applied a significance level of  $\alpha = 0.05$  and conducted analyses using SPSS.

### *Qualitative data analysis*

We conducted a reflexive thematic analysis of the qualitative survey data and focus groups using the MAXQDA software. The first author repeatedly reviewed the open-ended responses and transcripts, coded text segments, and organized them into themes using an inductive approach. We then formulated and reviewed the themes as a team, discussing and refining them in light of emerging patterns both within and across thematic categories.

### *Data integration strategy*

In this mixed-methods study, we employed a convergent data integration strategy to ensure a comprehensive understanding of the research topic. We collected and analyzed quantitative and qualitative data separately but concurrently and brought together the findings during the interpretation phase. This allowed us to compare, contrast, and complement statistical patterns with narrative insights, enriching the overall analysis. Integration took place at the level of interpretation and discussion, where themes emerging from FGDs and open-ended survey responses were used to contextualize and explain trends observed in the quantitative data.

This strategy facilitated a more nuanced exploration of human rights implementation in mental health care facilities, ensuring that both measurable outcomes and the lived experiences of

participants informed our conclusions.

### *Research team and reflexivity*

The authors of this study contribute a diverse range of personal and professional expertise spanning the fields of human rights, mental health, disability, public health, health care service evaluation, academic scholarship, and civic activism. Several of us have been directly involved in advancing the rights of persons with mental health conditions and psychosocial disabilities in Lithuania, including through work on deinstitutionalization, monitoring human rights conditions in mental health and social care institutions, and advocacy related to the implementation of the CRPD. This multidisciplinary background is a key asset, consistent with the principles and values of qualitative research, which acknowledge and harness researchers' subjectivity as an integral part of the research process. Rather than aiming for neutrality, we acknowledge that our perspectives shape how data are collected, interpreted, and understood.<sup>34</sup>

The study is therefore informed by a shared commitment to a human rights-based and recovery-oriented approach to mental health care, taking a critical stance toward practices that restrict autonomy, such as involuntary treatment, institutionalization, and limits on legal capacity. These normative commitments shaped how we interpreted concepts such as risk, care, and protection and may have influenced the analysis, particularly when examining practices normalized within psychiatric systems. At the same time, our experience within and alongside mental health services fostered awareness of the structural, legal, and ethical constraints faced by professionals. This dual positioning—both critical of and engaged with these systems—enabled the examination of tensions between human rights standards and everyday clinical practice without reducing them to individual attitudes alone.

We actively practiced reflexivity throughout the research process. We engaged in ongoing discussions to examine how our values, assumptions, and professional positions shaped data collection, coding, and interpretation. Particular attention

was given to moments where participants' perspectives diverged from our own, ensuring that these views were presented accurately even when they did not fully align with a human rights-based analytical framework. This approach balanced a critical human rights lens with methodological rigor, transparency, and respect for the field's complexity.

### Research ethics

All research participants provided their informed consent to participate. All personal information and any data shared by participants in the survey or during the focus groups were treated as strictly confidential and were accessible only to members of the research team involved in data collection and analysis.

To protect participants' privacy, we do not use the real names of individuals, locations, or institutions in this paper or any other publications arising from the study. When describing participants, we provide only general sociodemographic information.

Ethical approval for the study was obtained from the Ethics Committee for Research Compliance of the Institute of Sociology and Social Work and the Institute of Educational Sciences, Faculty of Philosophy, Vilnius University (Protocol No. (1.13E)250000-KT-162, September 25, 2024).

## Results

### Quantitative results

A total of 390 mental health care professionals participated in the survey, including psychiatrists, medical psychologists, social workers, nurses and nurse assistants working in the mental health care sector. Of these, 89 participants completed paper-based questionnaires, 84 participated via telephone interviews, and 217 filled out the online survey.

Figure 1 shows the general distribution of attitudinal statements and their evaluation by professional group.

Statistically significant results reveal that medical psychologists show the lowest agreement

with stigmatizing or coercive practices, such as the belief that people with psychosocial disabilities are dangerous ( $Exp(b) = 0.116, p < 0.0001$ ) or that involuntary treatment and restraints are necessary ( $Exp(b) = 0.107, p < 0.0001$ ). Psychiatrists and social workers also demonstrate lower agreement with stigmatizing views in some cases. In contrast, nurses ( $Exp(b) = 2.225, p = 0.019$ ) and nurse assistants ( $Exp(b) = 4.719, p = 0.005$ ) are more likely to agree with statements endorsing coercive measures, such as the use of physical or mechanical restraints.

Professionals working in public psychiatric inpatient settings are more likely to support coercive measures and hold stigmatizing views ( $Exp(b) = 2.877, p = 0.001$ ). In contrast, those based in public mental health centers tend to disagree with such statements ( $Exp(b) = 0.353, p = 0.001$ ). Staff in institutions with more than 200 beds are more likely to perceive persons with mental health conditions as dangerous ( $Exp(b) = 6.274, p < 0.001$ ) and see physical or mechanical restraints as necessary ( $Exp(b) = 3.221, p < 0.001$ ). Further, professionals in institutions with more than 200 beds ( $Exp(b) = 2.524, p = 0.016$ ) and those in institutions with more than 200 employees ( $Exp(b) = 2.929, p = 0.012$ ) are more likely to support restrictions on people's legal capacity.

Those with 6–10 years of professional experience are significantly less likely to agree with the need for involuntary hospitalization ( $Exp(b) = 0.224, p = 0.001$ ). Professionals aged 26–35 are less likely to believe that the ratification of the CRPD has no practical significance ( $Exp(b) = 0.318, p = 0.036$ ). Professionals from larger facilities are more likely to agree with statements suggesting a limited impact of the CRPD ( $Exp(b) = 2.524, p = 0.016$ ) and the need for coercive measures ( $Exp(b) = 3.221, p < 0.001$ ).

Moreover, results show that medical psychologists consistently express more rights-oriented views. They are significantly less likely to agree with statements suggesting that patient choices are not essential for quality care ( $Exp(b) = 0.195, p = 0.003$ ), that human rights are already well protected in Lithuania ( $Exp(b) = 0.427, p = 0.008$ ), or that full human rights protection in practice is impossible

( $Exp(b) = 0.438, p = 0.007$ ). On the contrary, nurse assistants show higher agreement with more skeptical or system-supportive statements across multiple areas, including the perceived impossibility of fully ensuring human rights ( $Exp(b) = 3.158, p < 0.000$ ) and believing that it is not necessary to take into account each patient's wishes and choices in order to provide quality mental health care services ( $Exp(b) = 4.689, p < 0.000$ ).

### Qualitative results

Some survey participants (n = 228) provided their opinions on what should be changed or improved

in the provision of mental health care services in Lithuania to implement human rights. Our analysis of their answers in conjunction with the results of the six focus groups revealed five main themes:

- From control to respect: shifting professional mindsets
- From knowledge gaps to empowered practice
- Broadening the spectrum of services
- Caring for the caregivers: addressing staff needs and rights

FIGURE 1. Distribution of participants who responded “agree” or “more agree than disagree” to specific attitudinal statements, by profession (n = 390)



- Systemic misalignment between policy ideals and everyday realities

### Themes.

- From control to respect: shifting professional mindsets

The first theme captures a critically needed transformation identified by both professionals and service users in the study. Rather than merely describing attitudes, this theme reveals how these attitudes are actively constructed and negotiated within institutional cultures. Many professionals acknowledged the need to move away from paternalistic attitudes and toward a human rights-based approach in mental health care. This includes rethinking the culture of care, reducing stigma, and promoting respect in everyday interactions with patients and colleagues alike. Participants highlighted the limited autonomy often experienced by service users, calling for greater involvement in care planning, supported decision-making, and the recognition of their preferences. These accounts illustrate a tension between normative commitments to human rights and the persistence of routinized practices that limit autonomy.

Service users, in turn, pointed to persistent gaps in the system, such as professionals' lack of competence in communicating legal rights. The quality of care, as perceived by service users, varies significantly between facilities, with some settings demonstrating exemplary communication and shared decision-making. This variability underscores the uneven translation of human rights principles into practice across different institutional contexts.

Many service users also underscored the importance of generational change in the medical workforce, expressing hope that younger professionals would bring more progressive attitudes. Practices such as physical restraint in hospitals were described with fear and disapproval, further reinforcing the demand for humane, empowering, and rights-based approaches.

- From knowledge gaps to empowered practice

The second theme highlights a persistent disconnect between human rights principles and their practical application in mental health care, rooted in the fragmented education of professionals. This theme extends beyond identifying knowledge gaps by demonstrating how limited or informal knowledge translates into inconsistent and sometimes contradictory practices. While professionals across disciplines acknowledged the importance of human rights, many lacked a clear understanding of the CRPD, with most learning about it only through informal channels, occasional training, or workplace audits.

Psychiatrists, psychologists, and nursing staff frequently operate without explicit reference to the CRPD, often relying on ethical intuition rather than structured knowledge. This reliance on individual judgment contributes to variability in practice and reflects the absence of a shared, system-wide human rights framework. As a result, rights such as informed consent, privacy, freedom from coercion, and access to appropriate care are not consistently upheld.

Professionals strongly emphasized the need for targeted, ongoing education for all staff, especially for older professionals and nursing personnel, as well as the need to embed the CRPD into institutional policies, job regulations, and academic curricula. Despite these challenges, some professionals (particularly social workers and nurses) demonstrated proactive engagement by independently organizing training and promoting awareness. These examples highlight the presence of agency and bottom-up efforts for change, even within structurally constrained environments.

- Broadening the spectrum of services

The third theme reflects a strong call from both professionals and service users for more diverse, accessible, and person-centered mental health care services. It illuminates how current service limitations directly shape experiences of exclusion, dependency, and restricted choice. Professionals emphasized the need to expand day hospital options, outpatient services, and continuous services (particularly in underserved regions) and

to strengthen interdisciplinary, team-based care models.

There was a shared emphasis on increasing the availability of nonmedical interventions, such as psychotherapy and social support, especially for individuals for whom medication is not appropriate.

Service users expressed a desire for more holistic and recovery-oriented services, highlighting the value of emotional support, non-pharmacological treatments, and therapeutic options that foster inclusion, autonomy, and dignity.

These perspectives demonstrate that the realization of human rights is closely linked to the availability and diversity of services rather than solely to individual professional attitudes. Participants also emphasized the value of drawing on international promising practices, such as mobile crisis teams that provide home-based support to the entire family, thereby reducing the need for hospitalization and preserving the individual's social environment.

- Caring for the caregivers: Addressing staff needs and rights

This theme highlights the significant challenges faced by mental health care professionals in safeguarding both patient rights and their own well-being. The findings demonstrate that professionals' attitudes and practices cannot be understood in isolation from the conditions under which they work.

Participants across professions reported overwhelming workloads, low pay, high burnout risk, unclear professional boundaries, and a lack of systemic support. Psychiatrists described the moral and professional dilemmas arising from being tasked with both therapeutic and legal responsibilities, such as participating in court proceedings related to forced treatment or legal capacity, undermining their trust-based relationship with patients.

Psychologists and social workers saw themselves as advocates and intermediaries for service users, often compensating for systemic gaps in rights protection, yet felt limited in their power to influence decisions or systemic reforms. Social workers emphasized their role in promoting human

rights and social inclusion but noted increasing marginalization within interdisciplinary teams. Nurses, who spend the most time with patients, offer vital emotional and practical support, yet their role is often undervalued in discussions about rights-based care.

- Systemic misalignment between policy ideals and everyday realities

Participants identified a broad spectrum of systemic gaps that hinder the effective realization of human rights principles within mental health care services. This theme synthesizes how structural factors mediate the relationship between formal commitments to human rights and their practical implementation.

Despite policy advances and formal frameworks inspired by the CRPD, everyday practice remains fragmented and inconsistent across institutions and professionals. Key systemic challenges include chronic shortages of human and financial resources, lengthy waiting times, uneven regional service accessibility, insufficient intersectoral collaboration, data management issues, and confidentiality concerns.

While some psychiatrists noted regulatory changes and human rights audits as steps forward, many felt that these did not translate into palpable improvements in patient care. Psychologists and social workers similarly acknowledged growing awareness and training on mental health and human rights, while noting that practical application on the frontline often falls short, with lingering stigma and discriminatory attitudes affecting treatment decisions. Nurses observed positive shifts in privacy, communication, and patient-centered approaches, although these were seen as unevenly implemented. Participants also pointed to structural barriers, such as a lack of physical and informational accessibility and the complex dilemmas around legal capacity, where rights such as voting are retained symbolically while broader autonomy is restricted.

Taken together, these findings demonstrate that gaps in human rights implementation are not solely due to individual attitudes but are deeply

TABLE 1. Selected quotes from the survey (n = 228) and focus groups (n = 36)

Theme	Selected quotes from the survey (n = 228)	Selected quotes from focus groups (n = 36)
1) From control to respect: shifting professional mindsets	<p>“There is a severe lack of respect toward patients. Many pointless restrictions that limit people’s choices.” (nursing assistant, psychiatric inpatient facility in the public sector)</p> <p>“The entire culture needs to change: one where mobbing, indifference, and abuse of power are the norm and part of everyday life. Staff cannot treat patients better than they treat themselves or each other.” (psychiatrist, psychiatric inpatient facility in the public sector)</p>	<p>“The first thing is the attitude toward the person: Do I see a person, or do I see the disability first?” (social worker, FG 5)</p> <p>“Those old doctors from Soviet times have already stepped back from the hospital—young people have taken over, with new attitudes, new methods, and everything’s become easier.” (service user, FG 1)</p>
2) From knowledge gaps to empowered practice	<p>“It is necessary to improve the qualifications of medical staff, provide education in the field of human rights, and raise the minimum requirements for employees working with patients.” (psychiatrist, psychiatric inpatient facility in the public sector)</p> <p>“There is a need to organize more communication skills training for staff.” (medical psychologist, psychiatric inpatient facility in the public sector)</p>	<p>“In all the places I’ve worked, I don’t think I’ve ever come across a situation where we really had in-depth discussions about ethics or human rights issues.” (medical psychologist, FG 4)</p> <p>“I would say that ... all that information ... remains at—and I’ll put it quite bluntly—the level of higher-qualified professionals. But as we move down the hierarchy, we often encounter particular communication issues, for example, some basic, rather coarse remarks that could definitely be avoided.” (medical psychologist, FG 1)</p>
3) Broadening the spectrum of services	<p>“I see the importance of offering as many different interventions as possible, because not everyone needs/benefits from/is suited to medication and/or psychological counseling. I believe there should be more group-based, artistic, physical, social, and occupational services. So that people have somewhere to go/something to do after being discharged from the hospital following a severe relapse.” (medical psychologist, community mental health center in the private sector)</p> <p>“There is a need to strengthen outpatient health and social support through real action. Especially for patients who are alone or rejected by their families: after inpatient treatment, they are left ‘hanging’ between a poor and a tolerable mental state.” (nurse, psychiatric inpatient facility in the public sector)</p>	<p>“It was written into the government’s program that there would be mobile teams that would come to people’s homes. So, the knowledge is there, it’s in the program, but who’s going to implement it ... In this case, I would really hope that one day this would be at least partially implemented in Lithuania.” (service user, FG 7)</p>
4) Caring for the caregivers: addressing staff needs and rights	<p>“Pay more attention to the experiences, needs, and expectations of professionals working in mental health centers. The workloads are heavy.” (social worker, community mental health center in the public sector)</p> <p>“Improve working conditions, workload, and salaries for staff. Burnt-out and exhausted professionals provide lower-quality services.” (psychiatrist, psychiatric inpatient facility in the public sector)</p>	<p>“And all these roles [as a psychiatrist], at certain points of contact, contradict one another. And then the interaction with the patient, the patient’s willingness to accept help, to recover, is automatically severely affected ... because, well, you can’t be both good and bad at the same time.” (psychiatrist, FG 4)</p>
5) Systemic misalignment between policy ideals and everyday realities	<p>“There is a shortage of professionals, which is due to low salaries.” (medical psychologist, community mental health center in the public sector)</p> <p>“[There is a need for] more professionals who would agree to go and work in the regions.” (social worker, day hospital in the public sector)</p> <p>“[There is a need for] interagency cooperation among all professionals.” (medical psychologist, community mental health center in the public sector)</p>	<p>“[The facility] has received all kinds of complaints about physical inaccessibility in general ... and for about 10 years there has been no response ... It’s politely said [to the patients] that if it doesn’t suit you, you can go somewhere else.” (medical psychologist, FG 4)</p> <p>“Professionals are overworked and sometimes don’t do certain things or deliberately avoid making diagnoses because it would mean more paperwork, more workload.” (medical psychologist, FG 1)</p> <p>“... if a psychiatrist asks me what’s written in the law, then clearly something’s not right with the system.” (service user, FG 7)</p>

embedded in systemic, organizational, and policy-level misalignments. Table 1 presents selected quotes illustrating each of the five themes.

## Discussion

This mixed-methods study aimed to explore and assess the attitudes of mental health care professionals in Lithuania toward human rights defined in the CRPD and their application in mental health care settings. This is the first empirical study in the country to examine how professional, institutional, and sociodemographic factors influence these attitudes. Importantly, the integration of qualitative and quantitative findings allows for a more comprehensive understanding of not only what attitudes are held but also how they are constructed, negotiated, affected, and enacted within everyday practice contexts.

The study shows that profession is one of the strongest predictors of mental health care professionals' attitudes toward patients' human rights. Medical psychologists show the lowest agreement with stigmatizing or coercive practices, such as beliefs that people with psychosocial disabilities are dangerous or that involuntary treatment and restraints are necessary. Psychiatrists and social workers also demonstrate lower agreement with stigmatizing views in some cases. In contrast, nurses and nurse assistants are more likely to endorse coercive measures, including the need for physical or mechanical restraints.

These results are consistent with other studies, where mental health care professionals with psychological or social work training have often shown more rights-aligned attitudes, likely reflecting their training in person-centered and recovery-oriented approaches.<sup>35</sup> Conversely, nurses are more likely than other professionals to support coercive practices, possibly due to their frontline roles in enforcing such measures and feelings of unsafety.<sup>36</sup> In line with global trends, this underscores the need for targeted, specialized rights-based training, including de-escalation techniques, across professions in both academic curricula and continuous professional development.<sup>37</sup> The qualitative

findings support this division: Professionals and service users emphasize ending paternalistic practices, fostering supported decision-making, and recognizing physical restraints as harmful, while pointing to an urgent need for humane, rights-based approaches. Beyond reinforcing quantitative patterns, these insights show how professional roles are embedded in everyday moral reasoning, highlighting tensions between care, control, and responsibility that sustain coercive practices and demonstrating that attitudes are actively negotiated within institutional and relational contexts.

Generational differences are also evident, with younger professionals less likely to believe that ratification of the CRPD has no practical significance, indicating greater sensitivity to international human rights commitments. This is contrary to some former studies, where older staff expressed lower support for coercive practices.<sup>38</sup> In the present study, service users expressed optimism about generational change in the workforce, linking it to more progressive attitudes and greater awareness of service users' rights. Some findings may suggest that educational curricula are evolving to better incorporate human rights discourse, although this may also reflect broader societal changes in disability and inclusion. The qualitative data further deepen this insight, illustrating how generational shifts are experienced in practice through differences in communication styles, openness to shared decision-making, and willingness to question established hierarchies. This suggests that potential changes in attitudes are intertwined with broader cultural and systemic transformations rather than solely individual-level factors.<sup>39</sup>

The impact of years of professional experience revealed a nuanced pattern. Professionals with 16–20 years of experience demonstrated greater support for involuntary treatment and physical restraint, whereas those with 6–10 years of experience were less likely to endorse the need for involuntary hospitalization and other coercive measures. These findings are echoed in the qualitative data, where professionals spoke of heavy workloads, ethical dilemmas, and unclear professional boundaries, which may contribute to greater tolerance of co-

ercive or expedient practices under the systemic pressure. The divergence observed in this study may reflect the influence of institutional culture, professional burnout, or changes in the policy environment over time.<sup>40</sup> Importantly, the qualitative findings illuminate the mechanisms underlying this pattern, showing how prolonged exposure to resource constraints and risk-management pressures can normalize coercive practices over time, not as a result of individual attitudes alone but as an adaptation to structural conditions.

Institutional context, including facility type and size, also shapes attitudes. In this study, professionals in public psychiatric inpatient settings were more likely to endorse coercive and stigmatizing views, while those in public mental health centers expressed more rights-supportive perspectives. This aligns with international findings showing that inpatient settings tend to foster more custodial attitudes, partly due to environmental stressors, high patient acuity, and risk-management pressures.<sup>41</sup> The qualitative data in this study provide critical insight into how these environments shape practice, with participants describing institutional routines, staffing shortages, and safety concerns that constrain the implementation of rights-based approaches, even when professionals express support for them.

Notably, staff in large institutions (i.e., those with more than 200 beds or employees) were more likely to simultaneously endorse both perceived legal protections and coercive measures, revealing a potentially contradictory stance. The qualitative data echoed this contradiction, with participants acknowledging a gap between legal frameworks and daily practices, shaped by fragmented services, regional disparities, and limited intersectoral coordination. This ambivalence has also been reported in other post-institutional reform contexts in Central and Eastern Europe, where human rights commitments coexist with long-standing institutional cultures and resource limitations.<sup>42</sup> Taken together, the qualitative and quantitative findings of this study suggest that this apparent contradiction reflects not only an attitudinal inconsistency but a systemic dissonance between policy-level commit-

ments and practice-level realities. This underscores the importance of addressing structural conditions alongside professional attitudes.

## Conclusion

In Lithuania, professionals' attitudes toward human rights in mental health care vary meaningfully across professional roles, workplace sizes, and levels of experience. Medical psychologists and professionals in smaller institutions tend to support more rights-based approaches, while nurse assistants and those in larger facilities are more likely to endorse the current system or see limitations in the potential of human rights implementation.

These findings underscore the complex interplay between professional identity, institutional environment, and individual attitudes toward human rights in mental health care. They highlight the need for targeted interventions, such as professional training, institutional reform, and policy advocacy, to promote a stronger alignment with the principles of the CRPD. Future research should explore how specific institutional dynamics and professional development pathways influence the adoption of rights-based practices in mental health systems in different geographical and cultural environments. Moreover, further longitudinal research is warranted to examine how attitudes toward human rights in mental health care evolve, especially in response to policy changes, systemic reforms, and targeted training interventions.

## Strengths and limitations

This is the first empirical study in Lithuania to examine mental health care professionals' attitudes toward human rights principles enshrined in the CRPD, addressing a key gap in national and regional research. The convergent mixed-methods approach enabled a comprehensive understanding by integrating quantitative data with qualitative insights from focus groups. Including both professionals and service users enriched interpretation, while the inclusion of a broad range of professionals across different institution types and regions

enhanced the relevance of the findings. Grounding the research in international human rights frameworks, particularly the CRPD and the WHO QualityRights initiative, further strengthened its conceptual and ethical foundation.

Despite the strengths, the study also has some limitations. Some professional groups or institutional types may be over- or under-represented. Moreover, all data were self-reported and may therefore have been influenced by social desirability bias, especially on sensitive topics such as coercion and stigma. In addition, the quantitative data were gathered using different formats (telephone, online, and self-administered paper questionnaires), which may have introduced interviewer effects or mode-related variations in how openly participants responded. Finally, some subsamples in the analysis were small, which may have affected the stability of statistical estimates in the logistic regression models.

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## References

1. A. A. Mahdanian, M. Laporta, N. Drew Bold, et al., “Human Rights in Mental Healthcare: A Review of Current Global Situation,” *International Review of Psychiatry* 35/2 (2023).
2. C. A. A. Ventura, W. Austin, B. S. Carrara, and E. S. de Brito, “Nursing Care in Mental Health: Human Rights and Ethical Issues,” *Nursing Ethics* 28/4 (2021).
3. J. Probert, “Moving Toward a Human Rights Approach to Mental Health,” *Community Mental Health Journal* 57/8 (2021).
4. P. Harpur, “Embracing the New Disability Rights Paradigm: The Importance of the Convention on the Rights of Persons with Disabilities,” *Disability and Society* 27/1 (2012).
5. Convention on the Rights of Persons with Disabilities, G.A. Res. 61/106 (2006).
6. Human Rights Council, Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, UN Doc. A/HRC/35/21 (2017); M. Funk and N. Drew, “WHO QualityRights: Transforming Mental Health Services,” *Lancet Psychiatry* 4/11 (2017); M. Funk and N. Drew Bold, “WHO’s QualityRights Initiative: Transforming Services and Promoting Rights in Mental Health,” *Health and Human Rights* 22/1 (2020).
7. Ventura et al. (see note 2).
8. H. Herrman, J. Allan, S. Galderisi, et al., “Alternatives to Coercion in Mental Health Care: WPA Position Statement and Call to Action,” *World Psychiatry* 2/1 (2022).
9. M. Aragonés-Calleja and V. Sánchez-Martínez, “Evidence Synthesis on Coercion in Mental Health: An Umbrella Review,” *International Journal of Mental Health Nursing* 33/2 (2024); S. Every-Palmer, L. Kininmonth, G. Newton-Howes, and S. Gordon, “Applying Human Rights and Reducing Coercion in Psychiatry Following Service User-Led Education: A Qualitative Study,” *Health and Human Rights* 23/2 (2021).
10. Aragonés-Calleja and Sánchez-Martínez (see note 9); M. Chieze, C. Clavien, S. Kaiser, and S. Hurst, “Coercive Measures in Psychiatry: A Review of Ethical Arguments,” *Frontiers in Psychiatry* 12 (2021).
11. G. Danzer and A. Wilkus-Stone, “The Give and Take of Freedom: The Role of Involuntary Hospitalization and Treatment in Recovery from Mental Illness,” *Bulletin of the Menninger Clinic* 79/3 (2015).
12. K. Sugiura, F. Mahomed, S. Saxena, and V. Patel, “An End to Coercion: Rights and Decision-Making in Mental Health Care,” *Bulletin of the World Health Organization* 98/1 (2020).
13. W. Martin and S. Gurbai, “Surveying the Geneva Impasse: Coercive Care and Human Rights,” *International Journal of Law and Psychiatry* 64 (2019).
14. B. McSherry, P. Gooding, and Y. Maker, “Human Rights Promotion and the ‘Geneva Impasse’ in Mental Healthcare: Scoping Review,” *BJPsych Open* 9/3 (2023).
15. Funk and Drew Bold (2020, see note 6); U. Grigaitė, K. Levickaitė, D. Juodkaitė, and N. Goštautaitė-Midttun, “Promoting Human Rights-Based Deinstitutionalization in Lithuania by Applying the World Health Organization’s QualityRights Assessments,” *International Journal for Quality in Health Care* 37/1 (2025).
16. World Health Organization, “QualityRights Materials for Training, Guidance and Transformation” (November 12, 2019), <https://www.who.int/publications/i/item/who-qualityrights-guidance-and-training-tools>.
17. Mahdanian et al. (see note 1).
18. C. Febles-Arévalo, J. J. Martín-Domínguez, R.

García-Montesdeoca, et al., "Care Quality from the Perspective of Human Rights as Perceived by Mental Health Professionals in Gran Canaria: A Qualitative Study" (2023).

19. C. I. Aviles González, D. M. Cerchiaro Fernández, M. E. Guerra Muñoz, et al., "Mental Health Professionals' Perception of Respect for Human Rights and Organizational Well-Being in Three Countries of South America," *International Journal of Environmental Research and Public Health* 21/2 (2024).

20. B. D. Kelly, "Psychiatric Services, Mental Health Law, and Human Rights," *Indian Journal of Medical Research* 156 (2022).

21. M. G. Carta and D. Bhugra, "Human Rights and Mental Health: Critical Challenges for Health Professionals, Users, and Citizens," *International Review of Psychiatry* 35 (2023).

22. P. Doedens, J. Vermeulen, L. Lou Boyette, et al., "Influence of Nursing Staff Attitudes and Characteristics on the Use of Coercive Measures in Acute Mental Health Services: A Systematic Review," *Journal of Psychiatric and Mental Health Nursing* 27/4 (2020).

23. S. Davis Le Brun, S. Butchard, P. Kinderman, et al., "Applying the Theory of Planned Behaviour to Understand Mental Health Professionals' Intentions to Work Using a Human Rights-Based Approach in Acute Inpatient Settings," *Journal of Mental Health* 33/3 (2023).

24. Ventura et al. (see note 2).

25. D. Wijker, P. Sillitti, and E. Hewlett, "The Provision of Community-Based Mental Health Care in Lithuania," OECD Health Working Paper No. 143 (2022), [https://www.oecd.org/en/publications/the-provision-of-community-base-mental-health-care-in-lithuania\\_18de24d5-en.html](https://www.oecd.org/en/publications/the-provision-of-community-base-mental-health-care-in-lithuania_18de24d5-en.html).

26. N. Grigutyte, M. Jakubauskienė, and K. Levickaitė, "Stigmatizuojančios Lietuvos gyventojų nuostatos psichikos sveikatos srityje - tyrimo ataskaita" (2022).

27. J. W. Creswell and V. L. Plano-Clark, *Designing and Conducting Mixed Methods Research*, 3rd Edition (Sage Publications, 2017).

28. P. Dodemaide, L. Joubert, N. Hill, and M. Merolli, "Online Survey Design and Social Media," in ACM International Conference Proceeding Series, *Association for Computing Machinery* (2020).

29. S. Hall, *Representation: Cultural Representations and Signifying Practices* (Sage Publications, 1997).

30. V. Braun, V. Clarke, E. Boulton, et al., "The Online Survey as a Qualitative Research Tool," *International Journal of Social Research Methodology* 24/6 (2021).

31. M. M. Hennink, I. Hutter, and A. Bailey, *Qualitative Research Methods* (Sage Publications, 2020).

32. Creswell and Plano-Clark (see note 27); L. C. Houghton and A. Paniagua-Avila, "Why and How Epidemiologists Should Use Mixed Methods," *Epidemiology* 34/2 (2023).

33. E. Šumskienė, U. Grigaitė, K. Levickaitė, et al., *Žmogaus teisių apsauga psichikos sveikatos priežiūros įstai-*

*gose* (Vilnius University Press, 2025); Funk and Drew Bold (2020, see note 6); World Health Organization (2019, see note 16); World Health Organization, *WHO QualityRights Toolkit: Assessing and Improving Quality and Human Rights in Mental Health and Social Care Facilities* (2012).

34. V. Braun, V. Clarke, N. Hayfield, et al., "Doing Reflexive Thematic Analysis," in S. Bager-Charleson and A. McBeath (eds), *Supporting Research in Counselling and Psychotherapy: Qualitative, Quantitative, and Mixed Methods Research* (Palgrave Macmillan, 2022); V. Braun and V. Clarke, "Thematic Analysis," in F. Maggino (ed), *Encyclopedia of Quality of Life and Well-Being Research* (Springer, 2022); B. Gough and A. Madill, "Subjectivity in Psychological Science: From Problem to Prospect," *Psychological Methods* 17/3 (2012).

35. F. Agudelo-Hernández, H. Vélez-Botero, and M. C. González-Morales, "Human Rights Education and Attitudes Toward Mental Health Among Psychology, Medical, and Social Work Students," *Stigma and Health* (2024).

36. Doedens et al. (see note 22).

37. F. Begum, "Human Rights and Mental Health: A Review of Current Awareness and Emerging Developments," *Saudi Journal of Nursing and Health Care* 7/9 (2024).

38. I. Galbert, A. N. Azab, Z. Kaplan, and L. Nusbaum, "Staff Attitudes and Perceptions Towards the Use of Coercive Measures in Psychiatric Patients," *International Journal of Mental Health Nursing* 32/1 (2023).

39. D. O. Aluh, J. M. Caldas de Almeida, D. Richter, and R. Whittington, "Coercion in Contemporary Mental Health Services: Key Concepts, Historical Development and Contextual Factors," in N. Hallett, R. Whittington, D. Richter, and E. Eneje (eds), *Coercion and Violence in Mental Health Settings: Causes, Consequences, Management*, 2nd edition (Springer Nature Switzerland, 2024).

40. Human Rights Council (see note 6).

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

42. World Health Organization Regional Office for Europe, *Mental Health, Human Rights and Standards of Care: Assessment of the Quality of Institutional Care for Adults with Psychosocial and Intellectual Disabilities in the WHO European Region* (2018).



# Religious Leaders' Views on Rights of Khwaja Sira in Pakistan

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## Abstract

In Khyber Pakhtunkhwa, Pakistan, religious leaders play a significant role in shaping public attitudes toward khwaja sira, people who identify as third gender. This study explores the perspectives of Muslim religious scholars and leaders in District Mansehra, Khyber Pakhtunkhwa, on the human rights of khwaja sira. Applying a rights-based framework, we conducted 40 semi-structured, in-depth interviews with Muslim religious scholars and leaders. Through abductive analytical techniques, we identified three key themes: (1) perceptions of human rights for khwaja sira in Pakistan; (2) third gender recognition in Islam; and (3) third gender recognition by the state. Our findings illuminate tensions between human rights frameworks and local religious understandings, while also suggesting that the views of religious scholars and leaders may be leveraged to shape public opinion on cisheteronormative notions of gender and sexuality in the Pashtun context.

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## Introduction

The term “khwaja sira” is a culturally specific term in South Asia, particularly in Pakistan, that is used to describe individuals who do not conform to conventional gender binaries.<sup>1</sup> It is historically associated with communities recognized as a “third gender.” Constitutional rights (enshrined in articles 8–28), judicial activism, and statutory protections provide legal recognition of third gender persons in Pakistan.

Shaped by legal reforms, landmark judicial interventions, and a shifting sociopolitical discourse on gender diversity, Pakistani policies on gender, health, and human rights have changed dramatically over the past two decades. In a landmark 2009 decision, *Khaki v. Government of Pakistan*, the Supreme Court of Pakistan formally recognized the right of individuals to register as a third gender on various forms of identification, including voting registration cards and national identity cards.<sup>2</sup> In 2012, the chief justice of the Supreme Court of Pakistan declared that individuals identifying as a third gender are equal citizens under the law and entitled to constitutional protections.<sup>3</sup> In 2018, a petition was filed in the Federal Shariat Court seeking to safeguard the rights of third gender people, including their right to safety (article 9), respect for human dignity (article 14), and property (article 24(1)).<sup>4</sup> The petition followed increasing contemporary discourse and legal attention regarding the human rights of khwaja sira, with greater visibility in international human rights debates.<sup>5</sup> Additionally, the Transgender Persons (Protection of Rights) Act of 2018 affirmed the right to gender self-identification, secured inheritance rights, and prohibited discrimination in education, employment, and health care.<sup>6</sup> The Pakistani government also mandated affirmative action policies, expanding socioeconomic opportunities for the third gender community. The law further allows khwaja sira to receive formal legal recognition of their gender on their identity cards.

However, the implementation of this act has been hampered by bureaucratic inefficiencies and societal resistance. Ambiguities in the law have raised concerns about its practical application and

potential for misinterpretation.<sup>7</sup> Progressive legal reforms have come into tension with conservative Islamic interpretations of gender and sexuality.<sup>8</sup> The act has been explicitly rejected by multiple religious political parties and groups, who argue that it contradicts Islamic teachings.<sup>9</sup> A second petition filed in the Federal Shariat Court in 2023 challenged provisions in the Transgender Persons Act that endorsed gender fluidity and self-identification. The Sharia Court called for a review of the law to ensure its alignment with Islamic principles. Since then, debates over the act’s religious legitimacy have intensified, reflecting deeper cultural and theological divisions over gender identity.

Additionally, individuals who identify as a third gender in South Asia are often excluded from religious spaces and denied basic rituals, such as inclusion in funeral prayers, burials in community graveyards, and spiritual counseling, further deepening their alienation.<sup>10</sup> In rural parts of Khyber Pakhtunkhwa, such as Mansehra, religious authorities continue to wield significant influence over communal norms, political discourse, and law enforcement practices, contributing to the exclusion of khwaja sira.<sup>11</sup>

## Theoretical framework

This study applies an international human rights framework, as outlined in the United Nations Universal Declaration of Human Rights, emphasizing the protection of individuals from persecution.<sup>12</sup> Rather than relying on the benevolence or discretion of those in power, such an approach asserts that minorities possess inalienable entitlements.<sup>13</sup> This inclusivity is particularly important for sexual and gender minorities. Nonetheless, human rights frameworks can be limited in their applicability because these rights may be constrained or challenged by local cultural and religious practices.

Islamic moral and legal norms are often essentialized as being at odds with international human rights principles.<sup>14</sup> Many Islamic scholars argue that an interpretation of human rights that aligns with Islamic values should support culturally grounded understandings of rights.<sup>15</sup> Applying the human

rights framework to the rights of khwaja sira helps to make sense of how gender-diverse people in the Pashtun context are othered by social and legal institutions. In light of the recent passage of the Transgender Persons (Protection of Rights) Act, this study sought to explore how Muslim religious scholars and leaders in Khyber Pakhtunkhwa, Pakistan, understand issues regarding the human rights of khwaja sira.

## Materials and methods

This study was conducted in District Mansehra, a central district of the Hazara region in Khyber Pakhtunkhwa, in collaboration with the nongovernmental organization Social Empowerment through Education and Knowledge (SEEK). We conducted 40 semi-structured interviews with Muslim religious scholars and leaders to explore their understandings of human rights issues affecting khwaja sira. Participants were recruited through convenience sampling.

## Data collection

We conducted semi-structured interviews between April 2022 and January 2023. All participants met the following inclusion criteria: (1) at least eighteen years old; (2) resident of Mansehra; (3) proficient in speaking Urdu; and (4) self-identified as a religious leader or a religious scholar. Of the 205 individuals initially contacted, 159 declined to participate and six could not be reached. After providing their informed consent, 40 individuals ultimately agreed to participate in semi-structured in-depth interviews.

## Data analysis

All interviews were digitally audio-recorded in Pashto or Urdu and then translated and transcribed directly into English. After reviewing the first 10 transcripts, five evaluators—including the principal investigator, two research assistants based in the United States, and two researchers in Pakistan—collaboratively developed a codebook rooted in themes related to human rights frame-

works. We conducted line-by-line coding to break the data down into manageable analytic units. We then revised, consolidated, and removed codes as needed using the qualitative data analysis software Dedoose. Any coding discrepancies were resolved through consensus among the research team.

## Results

We identified three themes in our interviews with religious scholars and leaders: (1) perceptions of human rights for khwaja sira; (2) perspectives regarding gender and sexual diversity in Islam; and (3) third gender recognition by the state.

### Perceptions of human rights for khwaja sira

Muslim religious leaders (*ulema*) play a pivotal role in shaping societal attitudes in Khyber Pakhtunkhwa.<sup>16</sup> Several scholars emphasized that khwaja sira are “creations of Allah” and therefore deserve respect and dignity. As one scholar noted:

*My opinion is that just as there are boys and girls in creation, khwaja sira are another creation of Allah Almighty. (interview 4, April 10, 2023)*

Several participants expressed the belief that khwaja sira should be entitled to the same fundamental rights as other Pakistani citizens. For example, another scholar said:

*My personal point of view is that, as human beings, we should give everyone their rights and protect those rights. As human beings, we should treat them [khwaja sira] well. (interview 5, April 24, 2023)*

Some scholars affirmed the idea that Islamic principles uphold the human rights and dignity of all people, regardless of their gender. In the words of one scholar:

*As for guarding the rights and dignity of khwaja sira, Islam does not permit oppression, harassment, or looking down upon any individual. In Islam, there is equality among all people. No one is superior to another simply because of their gender or identity. Regarding the fatwas issued by the respected scholars and muftis, it is evident that they*

*have conducted research before issuing such verdicts ... Therefore, I respect their decisions.* (interview 16, July 1, 2023)

This respondent framed respect for khwaja sira as a religious obligation in line with modern principles requiring that all members of society be treated equitably. This respondent believed that Islamic teachings regarding the respect for persons should apply across social and gender identities, citing respect for the authority of muftis to issue *fatwas*, or religious decrees issued by experts in Islamic jurisprudence. This scholar affirmed the legitimacy of religious scholars and emphasized the Islamic values of equality, fairness, and human dignity.

Participants further argued that the Pakistani government has a duty to protect the rights of khwaja sira, particularly given this population's continued exposure to systemic injustices that reinforce cycles of poverty and marginalization:

*First and foremost, the state and government need to create policies and enact effective laws to protect the rights of khwaja sira and ensure their inclusion in society.* (interview 14, Jun. 25, 2023)

The right to gender self-determination, although not internationally recognized, involves the state's recognition of an individual's gender identity and is considered a "positive" human right. In the words of one participant:

*It is essential for the Pakistani state to provide them with a place in society, legally safeguard their rights, and first and foremost, resolve the issue of their identification.* (interview 12, May 15, 2023)

Access to gender-affirming care was identified as another positive right, with the state being viewed as responsible for ensuring equal access. Some participants argued that access to gender-affirming health care should be understood both as a medical necessity and as a fundamental human right that should not be denied under Muslim jurisdictions:

*These people should not be denied their rights, medical surgery or hormonal treatment. There is*

*nothing like that in Islam.* (interview 19, July 15, 2023)

Under this perspective, access to gender-affirming care, and access to evidence-based health care at large, should be conceptualized as a fundamental human right and a medical necessity, not only for khwaja sira but for all Pakistani citizens.

Alongside positive rights that require state involvement, the state also has a responsibility to protect negative rights by preventing human rights violations and safeguarding khwaja sira from systemic discrimination. Negative rights include freedoms from undue interference, such as freedom from discrimination, arbitrary arrest, and institutional exclusion. Multiple scholars reported that khwaja sira regularly experience discrimination in health care settings. Some of these discriminatory health care practices revolve around their association with HIV, reflecting long-held tropes about trans populations and HIV status. One respondent explained:

*The community is wrongly associated with HIV and other illnesses, fueling fear and avoidance. People already considered khwaja sira to be patients, thinking they had various sexual diseases, like HIV and AIDS. People were afraid to approach them. The government made no special arrangements for them, and neither the general public nor NGOs took tangible steps on their behalf. Some people even thought the pandemic was a punishment from Allah because of the moral depravity of the khwaja sira community. The community was the most affected by the Corona pandemic.* (interview 2, March 30, 2023)

Beliefs regarding the khwaja sira community's perceived filthiness shape their treatment within health care settings. These beliefs are often linked to their perceived infectiousness. Expectations to be mistreated in healthcare settings discourage khwaja sira from engaging with services at all:

*Many khwaja sira avoid hospitals altogether due to fear of humiliation or neglect.* (interview 18, July 10, 2023)

The avoidance of health care is not simply a mat-

ter of personal discomfort but a learned survival strategy, shaped by repeated experiences of being mocked, misgendered, and dismissed by health care workers. For many participants, medical facilities are sites of risk rather than of safety, where their bodies are scrutinized and their identities questioned.

### *Third gender recognition in Islam*

Perspectives among religious scholars regarding third gender recognition vary widely, often mirroring broader theological debates on gender identity and expression.<sup>17</sup> Some respondents argued that Islamic teachings recognize individuals who do not conform to binary gender categories. They referenced *fiqh*, or Islamic jurisprudence, which addresses the existence of *mukhannath* (effeminate men) and *khunsa* (intersex individuals), as evidence that gender diversity has historically been recognized within Islamic traditions. One participant reported:

*Fiqh delves into the rights of khwaja sira as prescribed by Islamic jurisprudence, within our Muslim society. In practice, it is the government's responsibility to implement these rights. If they create a platform or mechanism in accordance with these principles, khwaja sira can indeed access their rights. It's not about whether the Quran explicitly mentions them, but rather about discussing their issues within the framework of Islam.* (interview 5, April 24, 2023)

Similar views were reflected by another participant:

*Islam and Sharia have given all the rights to the khwaja sira that a man, a woman, and a human being get in a Muslim society. Our religious leaders, our mulvis, our muftis do not talk about these rights and do not treat them well. They incite hatred towards these people, arguing that their supposed immorality has no place in Islam. Islam and Sharia have given all rights to khwaja sira. If we study fiqh, we can see that entire chapters have been devoted to the problems of khwaja sira and their rights.* (interview 26, August 23, 2023)

According to these perspectives, rights are guaranteed to khwaja sira by Islamic jurisprudence; it

is the intolerant behavior of local religious leaders who fail to acknowledge these rights. Nonetheless, khwaja sira may be unable to get married:

*According to Islam, khwaja sira are the only ones who are called khunsa mushkil in Arabic, those who are difficult to recognize as a man or a woman. It is very difficult for them to enter into a marriage contract with a man or a woman.* (interview 27, August 25, 2023)

Although the Quran does not explicitly address the rights of khwaja sira, religious scholars in Khyber Pakhtunkhwa tended to agree that recognizing their human rights is consistent with Islamic legal principles. This perspective challenges dominant global narratives portraying Islam as opposed to queer rights. One scholar challenged these hegemonic views about the intolerance of Muslims toward queer communities:

*From the point of view of Islam, all human beings are equal, and no single human being has the right to oppress or discriminate against another human being on the basis of gender, race or caste.* (interview 23, August 6, 2023)

Several scholars also emphasized that Islam prohibits discrimination against the inhumane treatment of khwaja sira. Some argued that because women are granted rights under Islam, khwaja sira should likewise be entitled to similar protections, including equal ownership and inheritance rights. One participant observed:

*It is not written anywhere in Islam that on the basis of gender, a woman will get more rights and a man will not, or a man will get more rights, and a woman will not get those rights ... Just as a man gets these basic human rights, a woman does too. No distinction in rights is made on the basis of gender.* (interview 19, July 15, 2023)

Several scholars asserted that it is the government's responsibility to uphold these rights. As one respondent explained in relation to the right to education and to earn a living:

*In Khyber Pakhtunkhwa, many Islamic scholars*

*believe that just as a common man has the right to live, so do khwaja sira. They should be given their rights, including the right to education and to operate a business. There should be no restrictions on them.* (interview 31, September 4, 2023)

Religious leaders who support third gender registration highlighted the practical challenges involved in implementing such policies, as reflected in the following account:

*I mentioned earlier that the neocolonial system in our country and in this region has given rights only to specific groups. For example, consider the weaker and impoverished class, particularly those who are sexually marginalized. Society doesn't accept them. So, who can secure their rights?* (interview 7, May 15, 2023)

Some scholars argued that only “real” or authentic khwaja sira should be entitled to full legal rights and protections. One respondent stated:

*My personal view aligns with what Islam, scholars, and the Shariah say. Real khwaja sira, those born neither male nor female, should be given rights, protection, and legitimate employment opportunities. They should be provided with the same facilities to progress in life as any other person. However, those who adopt the guise of khwaja sira for worldly or sexual desires should be identified and, if possible, stopped through psychological treatment.* (interview 34, September 16, 2023)

While the distinction between “real” and “fake” khwaja sira remains contested, public discourse frequently frames individuals as being “authentic” khwaja sira if they are presumed to have been born intersex, as opposed to those who have undergone gender affirmation surgeries (namely, the removal of the penis or testicles). One respondent echoed this view:

*Those who have made themselves khwaja sira are not real khwaja sira, and this negatively impacts the rights of real khwaja sira. When scholars talk about the rights of real khwaja sira, people often misunderstand and think they are advocating for those involved in immoral activities. Thus,*

*our religious community cannot speak for them.* (interview 23, August 6, 2023)

While “authentic” members of this group are constructed as being intersex, the vast majority of khwaja sira are actually not born intersex but rather identify as a third gender. This confounding of identities, namely intersex versus transgender, is reflected in the views of scholars:

*In reality, they are khwaja sira, those who are intersex individuals. They identify as a third gender, known by various names. They are indeed a creation of Allah, but they are individuals with sexual disabilities. They, too, should be granted the same rights as other people, such as access to education, health care, freedom, employment, participation in politics, religion, and all other social and human rights. We should also ensure their rights are protected.* (interview 3, April 5, 2023)

In the above case, the participant labels khwaja sira as intersex individuals—a common interpretation of gender diversity in the South Asian context and reflecting a differing social construction of sexual orientation and gender identity from Western contexts—one that nonetheless sees gender diversity as a “sexual disability.” Khwaja sira are encouraged to engage in “psychological treatment,” with the expected benefit being the resolution of their homosexual or gender-nonconforming tendencies.

Some respondents emphasized that the absence of legal recognition further deepens the marginalization of khwaja sira. As one noted:

*While the Quran identifies only two genders, male and female, it is necessary to recognize and provide rights to the third gender that exists. We cannot ignore their existence or force them into the binary categories of male or female. It is better to accept them as a third gender and provide them with human rights.* (interview 32, September 8, 2023)

Previous research indicates that some Pakistani religious leaders view advocacy for the rights of khwaja sira as a secular or foreign agenda that threatens the moral fabric of the Muslim community.<sup>18</sup> Such advocacy is often perceived to be the adoption of

Western perspectives on queer issues, allowing for moral “corruption” associated with homosexuality and gender nonconformity. Respondents in this study acknowledged this tension:

*This is a nuanced question, and I do not want to discuss it much, but I must say that people in our society are very narrow-minded. Even if some scholars stand up for the rights of khwaja sira, society will say that religious leaders are following the agenda of a foreign country or that he is an agent of a foreign country. (interview 38, February 10, 2023)*

This resistance has implications not only for health and social service access but also for the mental well-being of khwaja sira, who frequently experience exclusion and shame.<sup>19</sup>

Other religious leaders expressed concern over the broader implications of third gender registration, viewing it as a challenge to traditional gender roles and family structures. They argued that gender self-identification is inconsistent with Sharia (Islamic law) and could contribute to the perceived moral decline of society. As one respondent stated:

*It is an illegal act and it is against the morals and values of our society. Because what they are doing is not right. It is neither halal nor permissible. (interview 27, August 25, 2023)*

Some religious leaders resist acknowledging the self-determined gender identities of khwaja sira, viewing such recognition as incompatible with prevailing Islamic interpretations. These scholars oppose the notion that individuals should have the authority to define their own gender identity. One respondent explained:

*Many people who are born as men or women later rebel against the creation of Allah and identify themselves differently. This is un-Islamic, and there is no provision in Islam for someone to rebel against the creation of Allah and make their identity something else. (interview 20, July 20, 2023)*

Some respondents, like the participant above, questioned whether contemporary interpretations of gender identity align with Islamic teachings and

emphasized the importance of achieving scholarly consensus before endorsing such interpretations. Those scholars who opposed the recognition of a third gender identity often cited corrupting Western influences to have caused these acts of perceived moral depravity.

### *Third gender recognition by the state*

This theme demonstrates how state-level recognition, particularly access to official identification, functions as a decisive structural mechanism that shapes the lives of khwaja sira in Pashtun society. Legal recognition of gender identity is a fundamental right that enables individuals to access essential services, including education, employment, voting, and travel. The Transgender Persons Act introduced a significant shift by allowing individuals to self-identify as “male,” “female,” or a third gender (“X”) without undergoing medical testing or interventions. However, obtaining the official “X” identification marker remains a significant barrier for many khwaja sira in Pakistan. Without national identity cards, khwaja sira are excluded from numerous aspects of civic participation and social engagement within Pashtun society. One respondent described the situation:

*The first issue is that they don't have identity cards so they can't access government services, enroll in schools, or get admitted to hospitals. They are often expelled from their homes ... Schools and madrasas [religious schools] don't admit them, citing the environment or social norms. Their religious education is also affected. In hospitals, they face issues in both men's and women's wards. They are denied jobs in shops, factories, and government offices. Despite laws prohibiting discrimination, the Federal Sharia Court has nullified these protections. (interview 21, July 25, 2023)*

Legal recognition is contested not only at the bureaucratic level but also within religious-legal institutions.

Recent rulings by the Federal Sharia Court have contested protections provided by the law, questioning whether legal identity from a state authority can operate when in conflict with a religious authority. This dynamic reveals how state recogni-

tion and the denial of human rights frameworks become moral and political judgments about who counts as deserving of full protection of the law. As one respondent explained:

*The Federal Sharia Court has also issued decisions refusing to recognize [khwaja sira] as human. In fact, they have been denied the right to obtain a national identity card, violating national laws and fundamental human rights recognized by international law. This means that, according to the current perspective of religious scholars, khwaja sira are no longer considered human beings, raising important ethical and legal issues. (interview 19, July 15, 2023)*

Some scholars noted that social safety net programs, such as the Pakistani public benefit program Ehsaas, could help khwaja sira achieve a basic standard of living. However, khwaja sira who are unable to obtain official identification are prevented from accessing these benefits:

*The government started the Ehsaas program, providing 12,000 rupees to poor, daily wage workers, and women. However, nothing specific was done for the khwaja sira community because they often do not have national identity cards. Consequently, they received no assistance from the government. (interview 21, July 25, 2023)*

Some scholars advocated for vocational programs to support the social inclusion and economic independence of khwaja sira, without necessarily challenging traditional religious frameworks. One respondent stated:

*They cannot easily integrate into public spaces, and the government does not provide them with separate residential or housing societies or systems. [Having such systems in place would mean that] the threat to their well-being is reduced and they could also receive financial assistance and psychological support. (interview 10, May 6, 2023)*

While religious discourse may offer a degree of formal recognition, khwaja sira continue to face discrimination in accessing public benefits. One re-

ligious group, Tanzeemi Ittehad-Ulema-e-Ummat Pakistan (also known as Tanzeemi Ittehad-e-Ulamat), took a strong stand on these issues. As a respondent explained:

*The organization known as Tanzeemi Ittehad-Ulema-e-Ummat Pakistan is a group of scholars that has grown to about 500 members. I agree with their recommendation that harassing or persecuting khwaja sira is a crime against Islam. Harassing any individual, committing violence, or oppressing them is a crime in Islam. (interview 17, July 5, 2023)*

Another participant commented on the phenomenon of recognizing the human rights of khwaja sira, noting that refusing to acknowledge their rights conflicted with Islamic notions regarding the equality of humanity:

*As for guarding the rights and dignity of khwaja sira, Islam does not permit oppression, harassment, or looking down upon any individual, including khwaja sira. In Islam, there is equality among all people. No one is superior to another simply because of their gender. Regarding the fatwas issued by the respected scholars and muftis [that approve of transgender marriage], it is evident that they have conducted research before issuing such verdicts. They are knowledgeable scholars who are well-versed in Islamic jurisprudence and have issued these fatwas, based on their expertise and understanding of Islamic teachings. Therefore, I respect their decisions. (interview 16, July 1, 2023)*

This speaker emphasizes the authority of religious scholarship, noting that fatwas issued by scholars and muftis represent a legitimate form of Islamic jurisprudence. Ultimately, as is evident in the narratives of our participants, the positions of religious scholars and leaders can work to either uphold or negate the health needs and human rights of khwaja sira.

## Discussion

The findings from our interviews with religious scholars and leaders in Khyber Pakhtunkhwa demonstrate the ongoing tensions within Muslim

religious circles regarding how gender and sexuality are understood. Our findings demonstrate that the successful recognition of the human rights of khwaja sira in Pakistan depends on both addressing the concerns of religious leaders and amplifying the voices of marginalized communities. Religious authorities in Pakistan often act as gatekeepers in defining the limits of gender expression, thereby influencing how and to whom rights are extended.<sup>20</sup> We found that religious scholars framed the rights of khwaja sira within conditional moral and religious frameworks, granting support only when such rights were perceived to align with Islamic teachings. While tensions remain between embracing human rights discourse and upholding religious doctrine, some religious communities have embraced the need to recognize human rights for khwaja sira. For example, the Lahore-based religious organization Tanzeemi Ittehad-Ulema-e-Ummat Pakistan, led by Chairman Ziaul Haq Naqshband, has taken a notably progressive stance in advocating for the rights of khwaja sira.

In the following sections, we highlight four main implications of our findings: (1) lack of uniformity in Islamic jurisprudence; (2) lack of legal gender recognition; (3) increasing awareness of human rights of khwaja sira; and (4) advocacy for khwaja sira rights.

#### *Lack of uniformity in Islamic jurisprudence*

There are multiple understandings of the human rights of khwaja sira from the perspectives of religious scholars and leaders. Islamic jurisprudence on gender diversity is not uniform but is instead historically layered and deeply contested.<sup>21</sup> As some scholars and institutions reject the recognition of gender-diverse identities and call for rollbacks to the legal recognition of third gender identities, others articulate more inclusive theologies embedded in imperatives of non-harm, justice, and human dignity. Khwaja sira frequently deploy religious discourse as a modality of resilience, claiming a right to live with dignity and to be protected from persecution.

#### *Lack of legal gender recognition*

Our findings illustrate how the denial or delay of legal gender recognition constitutes a significant structural barrier for khwaja sira communities in Pakistan. While the Transgender Persons (Protection of Rights) Act is a progressive shift in social policy, its implementation has been inconsistent, and recent legal challenges have undermined its validity. Khwaja sira communities often remain invisible in policymaking, reinforcing the pattern of conditional empathy, as echoed in the present study.<sup>22</sup>

Within discussions with religious scholars and leaders, there was often a conflation of the identities of being intersex and being transgender. While fiqh does not explicitly condemn individuals who identify as gender non-binary, societal interpretations of Islamic teachings often continue to cast khwaja sira as being homosexual, leading to suspicion and stigma against khwaja sira communities.<sup>23</sup>

Our research also validates findings that demonstrate how khwaja sira experience barriers to obtaining public benefits.<sup>24</sup> Before the passage of the Transgender Persons Act in 2018, the Pakistani government required “medical examinations” to confirm the gender identity of khwaja sira for official documentation, namely being able to register as a third gender person on one’s national identity card, to qualify for state benefits. Such biomedical definitions serve to essentialize gender as an ascribed byproduct of anatomy, rather than an aspect of identity. Despite these legal advancements, institutional practices and societal attitudes have not consistently aligned with the law. Documented cases demonstrate how khwaja sira have still been subjected to medical verification, particularly when inconsistencies or doubts arise in official records.<sup>25</sup>

Experiences of marginalization are also present within the criminal justice system, where many khwaja sira report police harassment and abuse because they lack official identification with their selected gender identity.<sup>26</sup> Taken together, these patterns show that without secure documentation and accompanying forms of legal recognition in state institutions, khwaja sira remain systematically outside of the boundaries of full citizenship.

### *Increasing awareness of human rights for khwaja sira*

Intersectional frameworks are critical to addressing the layered oppression faced by khwaja sira communities.<sup>27</sup> Awareness-raising campaigns led by the government and civil society can play a vital role in dismantling stereotypes and promoting inclusion for khwaja sira. For example, national media campaigns could highlight the lived experiences of khwaja sira to assist in humanizing their struggles.<sup>28</sup>

The gap between law and practice is deepened by a lack of awareness of these rights, resulting in persistent police harassment, corruption, and bureaucratic neglect.<sup>29</sup> Educational initiatives that foster a more nuanced understanding of gender diversity within Islamic contexts are essential for long-term cultural transformation. Professional development workshops for service providers and educators can help address these issues. Programs should be designed to sensitize employers to address structural barriers to well-being, citizenship, and full civic inclusion.<sup>30</sup> Public institutions and health care facilities should introduce anti-discrimination policies, gender-neutral facilities, and equitable hiring practices.<sup>31</sup> Community dialogue with local leaders can further strengthen social acceptance and encourage communities to treat transgender individuals with dignity and respect.

To strengthen enforcement of the Transgender Persons Act, additional investment is needed in training lawyers, government officials, and advocates to handle discrimination claims effectively. Establishing accessible and free/low-cost legal aid services and community-based support networks can empower khwaja sira to assert their rights.<sup>32</sup> By fostering dialogue and emphasizing shared values of justice and compassion, religious leaders can work toward a more inclusive and equitable society that recognizes the human rights of khwaja sira and other gender-diverse people in Pakistan.

### *Advocacy for khwaja sira rights*

While recent policy reform and advocacy efforts offer promise for social change, significant obstacles remain in dismantling the systemic discrimination

faced by khwaja sira. Our findings suggest that sustained advocacy is needed not only to strengthen legal protections for khwaja sira but also to address their social exclusion. Although Pakistan's legal framework has begun to acknowledge the human rights of the khwaja sira community, entrenched social prejudice and institutional bias continue to undermine the effective protection and enforcement of those rights. For example, khwaja sira are often excluded from rites of passage, such as funerals and marriages. In Muslim communities, corpses are traditionally bathed by family members in preparation for their burial through a process known as *ghusl*. With khwaja sira, their own families may refuse to claim their bodies and mosques may refuse to perform their funeral and burial rites. This often leaves khwaja sira in the position of having to bury their dead on their own, without the formal recognition of local Muslim communities of their death rituals. In other spheres, khwaja sira navigate these conditionalities strategically to gain access to essential services and social acceptance.<sup>33</sup> To counter these harms, the state can strengthen protections against hate speech, misgendering, and discrimination in employment.<sup>34</sup>

The khwaja sira community in Khyber Pakhtunkhwa has also continued to resist marginalization through collective action and advocacy.<sup>35</sup> Trans Muslims reclaim spaces of religion, faith, and theology to affirm their non-binary existence, offering counter-narratives that challenge dominant religious interpretations and present alternate readings of Islamic precedence.<sup>36</sup> Local community-based organizations, such as Blue Veins, TransAction, and Gender Interactive Alliance, have played a pivotal role in mobilizing community members and raising awareness. Operating under Pakistan's 1882 Civil Societies Act, these organizations interact with state institutions, collaborate with international donors, and implement structured programs aimed at increasing social welfare and rights-based development.

However, even with the involvement of these organizations, legal recognition of third gender people remains inconsistent. Legal victories are often accompanied by societal backlash, under-

scoring the complexity of gender identity rights in South Asian and Muslim contexts.

Ultimately, discrimination against khwaja sira runs counter to both constitutional guarantees and Islamic ethical principles.<sup>37</sup> Clarifying and strengthening legal safeguards would uphold the dignity of khwaja sira and reduce their vulnerability.<sup>38</sup>

Efforts to support khwaja sira communities must also be grounded in a commitment to social justice and inclusivity. Addressing these challenges requires comprehensive reforms grounded in international human rights law, alongside sustained support for civil society organizations working to protect the dignity, safety, and overall wellbeing of the khwaja sira community. Religious leaders hold a powerful position in shaping moral thinking in Pakistani communities, as imams can play a central role in resolving stigma against these communities.

Religious scholars could advocate for the human rights of khwaja sira in their *khutbahs* (weekly Friday sermons). *Khutbahs* have long been used as a forum for social change and a space for moral reflection. Research on khwaja sira communities in Pakistan has shown how religious exclusion, such as the lack of access to mosques and the denial of burial rites, causes deep emotional injury and systematic social exclusion. When respected religious figures challenge the mocking, misgendering, and abuse of khwaja sira in public forums and through the engagement of religious rites, they publicly acknowledge the human rights of khwaja sira.

## Conclusion

This research contributes to ongoing discussions regarding Islamic perspectives on human rights, as well as existing scholarship that explores how gender-diverse communities engage with religious discourse and moral authority. By engaging religious leaders in meaningful dialogue, we highlight how khwaja sira identities are understood in the context of Islamic teachings and how these rights are met by the state and other nongovernmental organizations. While Pakistan's Transgender Persons (Protection of Rights) Act marks a significant milestone in ensuring these rights, the social ac-

ceptability of this policy is limited by competing religious formulations, cultural resistance, and selective implementation.

Ultimately, we underscore the importance of recognizing the human rights of third gender people in Pakistan and envision khwaja sira as active agents in constructing this recognition.<sup>39</sup>

This research also explores the significance of translating human rights frameworks into local epistemologies, especially in Muslim-majority contexts.<sup>40</sup> Our findings indicate that policy efforts addressing gender diversity in Pakistan could benefit by leveraging religious actors to strengthen human rights recognition.<sup>41</sup> Ultimately, this study demonstrates that although legal recognition of gender diversity exists in Pakistan, the human rights of khwaja sira are not yet fully recognized, as evidenced by the views of religious scholars and community leaders in Khyber Pakhtunkhwa.

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## Ethical considerations

The Fordham University Institutional Review Board approved the study under expedited review in September 2022 under protocol #2193. The study

also received ethical review approval from board members at our research partner organization, SEEK. Following a community-based consultation, the research team and collaborating organization agreed on an incentive of 7,000 PKR per interview (approximately US\$25). All participants provided informed consent after having the risks, benefits, and financial incentives orally reviewed with them. To protect participant confidentiality, we did not collect any personally identifiable information. All interviews were conducted in private, confidential settings.

## References

1. G. Reddy, *With Respect to Sex* (University of Chicago Press, 2005).
2. The Transgender Persons (Protection of Rights) Act (2018).
3. M. Khan, S. Khan, and N. Gul, "Legal Analyses on Rights to Transgenders: A Case Study of Pakistan," *Journal of International Affairs* 4/4 (2021).
4. S. Azhar, M. M. G. Herrera, and I. Ahmad, "'The Hardest and Most Difficult Days of My Life': Mental Health of Khwaja Sira in Swat, Pakistan During the COVID-19 Pandemic," *Journal of Gay and Lesbian Mental Health* 28/4 (2024).
5. I. Awan, M. Brookes, M. Powell, and S. Stanwell, "Understanding the Public Perception and Satisfaction of a UK Police Constabulary," *Police Practice and Research* 20/2 (2019).
6. The Transgender Persons (Protection of Rights) Act (2018).
7. J. A. Redding, "The Pakistan Transgender Persons (Protection of Rights) Act of 2018 and Its Impact on the Law of Gender in Pakistan," *Australian Journal of Asian Law* 20/1 (2019).
8. A. U. Khan, S. N. B. Bukhari, and S. Noreen, "Legal Protection of Trans-Gender's Rights in Pakistan Versus Constitution of Pakistan, 1973: A Critical Analysis," *Al-Āfāq Islamic Research Journal* 2/2 (2022).
9. S. Zaman, "Pakistan's Progressive Transgender Law Faces Opposition 4 Years Later," *Voice of America News* (September 28, 2022), <https://www.voanews.com/a/pakistan-s-progressive-transgender-law-faces-opposition-4-years-later-/6768168.html>.
10. S. Azhar, I. Ahmad, M. M. G. Herrera, et al., "I Would Prefer to Be Dead Than to Live This Way': Lived Experiences of Stigma and Discrimination Against Khwaja Sira in Swat, Pakistan," *Cambridge Prisms: Global Mental Health* 11/e60 (2024).
11. S. Azhar, "Recent Changes in Gender and Sexuality Policy in India: A Postcolonial Analysis," in Proceedings of the 2nd International Conference on Gender Research (Roma Tre University, 2019).
12. A. Sen, "Elements of a Theory of Human Rights," *Philosophy and Public Affairs* 32/4 (2004).
13. J. Donnelly, "Cultural Relativism and Universal Human Rights," *Human Rights Quarterly* 6/4 (1984).
14. A. Sachedina, "Abdullahi Ahmed An-Na'im, Toward an Islamic Reformation: Civil Liberties, Human Rights, and International Law," *International Journal of Middle East Studies* 25/1 (1993).
15. M. H. Kamali, *The Dignity of Man: An Islamic Perspective* (Islamic Texts Society, 2002).
16. A. Ahmad, "Freedom, Equality and Justice in Islam: By Mohammad Hashim Kamali," *American Journal of Islam and Society* 20/3-4 (2002).
17. K. L. Campbell, K. M. Winters-Stone, A. V. Patel, et al., "An Executive Summary of Reports from an International Multidisciplinary Roundtable on Exercise and Cancer: Evidence, Guidelines, and Implementation," *Rehabilitation Oncology* 37/4 (2019).
18. S. Bano, "Transgender Migration and Displacement: The Experience of Khwaja Sira Sex Workers in Lahore," *Culture, Health and Sexuality* 26/5 (2024).
19. S. A. Khan, "Guru-Chela Relationship in Khwajasira Culture of Pakistan: Uncovering the Dynamics of Power and Hegemony Within," *Pakistan Journal of Women's Studies: Alam-e-Niswan* 27/1 (2020).
20. M. H. Kamali, *Freedom, Equality and Justice in Islam* (Islamic Texts Society, 2002).
21. Zaman (see note 9).
22. A. H. Qureshi, A. Saeed, A. Fatima, et al., "Campus Climate and Transgender Inclusion: Rethinking Equity in University Classrooms in Pakistan," *Research Journal of Psychology* 3/4 (2025).
23. H. Jami and A. Kamal, "Measuring Attitudes Toward Hijras in Pakistan: Gender and Religiosity in Perspective," *Pakistan Journal of Psychological Research* 30/1 (2015).
24. Bano (see note 18).
25. H. Hamzaiftikhar, S. H. Salleh, and N. A. M. Yusuf, "Implementation of Self-Perceived Identity for Gender Change: Issues of Policy Coherence and Relevance Towards Transgender Welfare in Pakistan," *Environment-Behaviour Proceedings Journal* 9/SI20 (2024).
26. A. Alamgir, "'We Are Struggling to Seek Justice': A Study of the Criminal Justice System and Transgender Experiences in Pakistan," *International Journal of Transgender Health* 25/2 (2024).
27. K. Crenshaw, "Mapping the Margins: Intersectionality, Identity Politics, and Violence Against Women of Color," in M. A. Fineman (ed), *The Public Nature of Private Violence* (Routledge, 2013).
28. United Nations Development Programme, *Journey-Mapping of Transgender Political Candidates* (2024).

29. International Commission of Jurists, *Pakistan: Transgender Advocacy—Analysis Brief* (2020); National Commission for Human Rights, *Transgender—The Need for Mainstreaming: Interim Report* (2017).
30. A. Alamgir, S. Brown, E. Gray, and P. Kelly, “Exploring Resistance, Resilience, and Refusal Amongst Khawaja Sara and Hijra Communities in Postcolonial Pakistan,” *LGBTQ+ Family: An Interdisciplinary Journal* 21/2 (2024).
31. A. H. Huffman, M. J. Mills, S. S. Howes, and M. D. Albritton, “Workplace Support and Affirming Behaviors: Moving Toward a Transgender, Gender Diverse, and Non-Binary Friendly Workplace,” *International Journal of Transgender Health* 22/3 (2020).
32. A. Rashid and U. Rashid, “Constitutional and Legal Guarantees for Transgender in Pakistan: Reforms and Failures in Law,” in G. Guney, D. Davies, and P-H. Lee (eds), *Towards Gender Equality in Law* (Palgrave Macmillan, 2022).
33. S. A. Khan (see note 19).
34. J. T. Theilen, “Depathologisation of Transgenderism and International Human Rights Law,” *Human Rights Law Review* 14/2 (2014).
35. S. Azhar, I. Ahmad, L. Gaudio, et al., “‘We Are Raising Our Voices’: Coping Strategies Used by Khwaja Sira in Swat, Pakistan,” *International Journal of Psychology* 60/2 (2025).
36. M. Hendricks, “Diversity of Sexuality in Islam: Interview with Imam Muhsin Hendricks,” *CrossCurrents* 61/4 (2011); A. A. M. Zaharin and M. Pallotta-Chiarolli, “Reclaiming Transgender Identity Through Intersectionality and Decoloniality: A Critical Autoethnography of an Academic-Activist Performance,” *Journal of Intercultural Studies* 43/1 (2022).
37. S. Suhail, “The Movement for Transgender Legal Rights in Pakistan,” in A. Roy (ed), *New Gender Politics in South Asia* (Springer Nature, 2026); N. Nawaz and H. Safdar, “Transgender Rights in Pakistan: A Complete Study Under the Constitution and Pakistan Law,” *Pakistan Journal of Humanities and Social Sciences* 11/2 (2023).
38. Nawaz and Safdar (see note 37).
39. F. A. Khan, “Khwaja Sira: Transgender Activism and Transnationality in Pakistan,” in S. S. Wadley (ed), *South Asia in the World: An Introduction* (Routledge, 2014).
40. Donnelly (see note 13); Ahmad (see note 16).
41. Nawaz and Safdar (see note 37); National Commission for Human Rights (see note 29).



# Defending Informed Consent: Civil Society's Victory Against Emergency Research Deregulation in South Korea

YOUNG SU PARK, DORIS SCHROEDER, ORLA DRUMMOND, AND OCK-JOO KIM

## Abstract

Informed consent is both a foundational principle of research ethics and a human right grounded in self-determination and bodily integrity. During the COVID-19 pandemic, legislative attempts were made in South Korea to bypass informed consent and ethics review requirements for research involving patients with infectious diseases. Framed as emergency measures to accelerate biomedical innovation, the proposals sparked resistance from a broad coalition of civil society actors, including human rights advocates, patient organizations, labor unions, medical professionals, and bioethics scholars. This coalition, drawing on international bioethics norms and lessons from past research ethics controversies, mounted a coordinated public response, warning that such deregulation could erode fundamental ethical safeguards and set a concerning precedent. Their efforts helped prevent the proposed legislation from advancing in the parliamentary process. This defense of informed consent must be understood within the context of South Korea's post-authoritarian democratic evolution. Decades of civic struggle—from resistance to military dictatorship to the response to a constitutional crisis triggered by a martial law declaration in 2024—have shaped a politically conscious and ethically engaged public. This case study illustrates how informed consent can function not simply as a technical or procedural requirement but as a hard-won civil right anchored in democratic participation. South Korea's experience offers globally relevant insights into the role of civic vigilance in safeguarding human rights, especially during public health crises and emergency rule.

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## Introduction

Informed consent is a cornerstone of ethical research and a pillar of human rights, as affirmed in both the Declaration of Helsinki and the Universal Declaration on Bioethics and Human Rights.<sup>1</sup> Yet in times of public health crisis, it can be among the first ethical safeguards to be called into question.<sup>2</sup> The COVID-19 pandemic saw many countries re-evaluate long-standing protections in the name of urgency, efficiency, and the public good.<sup>3</sup> Among them was South Korea, an internationally praised model for pandemic response that nevertheless struggled with the boundaries of consent and the reach of state authority.<sup>4</sup> The legislative proposals at the center of the South Korean case directly implicated internationally recognized human rights—including the rights to self-determination, bodily integrity, and participation in health-related decision-making—raising important questions about the limits of emergency powers and the obligations of states under international human rights law.

In 2021, a South Korean legislative proposal sought to permit the use of biospecimens collected during infectious disease outbreaks without individual informed consent.<sup>5</sup> The proposal, framed as a pragmatic step to enhance research readiness, sparked an intense and coordinated backlash from bioethicists, civic organizations, and human rights advocates.<sup>6</sup> While the proposed bill lapsed at the end of the parliamentary session and was ultimately never enacted, the opposition it triggered highlighted broader concerns about the erosion of democratic accountability and ethical governance.

This paper examines how South Korean civil society successfully defended informed consent against legislative attempts at deregulation during the COVID-19 pandemic. In this paper, we define “civil society” as a broad constellation of nonstate actors—including professional associations, advocacy organizations, and grassroots groups such as labor unions, women’s groups, health justice advocates, and environmental organizations—engaged in public advocacy and collective action. We argue that the South Korean defense of informed consent occurred at the intersection of research ethics,

human rights, and democratic governance—three domains that are analytically distinct yet deeply interdependent in practice. Informed consent, as the case demonstrates, is simultaneously a procedural safeguard in research ethics, a legal expression of the right to self-determination under international human rights law, and a marker of democratic accountability. South Korea’s civic mobilization in defense of informed consent suggests how these dimensions may converge in practice when a society draws on its history of democratic struggle to defend ethical and human rights norms, even under conditions of national emergency.

## The human rights and ethical stakes of emergency research deregulation

Informed consent is not merely a procedural norm within biomedical research governance—it is a right grounded in international human rights law and constitutional protections. Establishing this legal and normative foundation is essential to understanding why the legislative proposals described below were met with such immediate and organized opposition.

### *International human rights framework*

Free, prior, and informed consent is a human rights norm that derives from the fundamental rights to self-determination and to be free from discrimination guaranteed by the International Covenant on Civil and Political Rights, the International Covenant on Economic, Social and Cultural Rights, and the International Convention on the Elimination of All Forms of Racial Discrimination.<sup>7</sup>

Constructed as a pillar right, self-determination ensures the rights of peoples and nations to be free from coercion of any sort and to live in dignity.<sup>8</sup> Essentially, this entails the right to be fully informed and the freedom to either accept or refuse, without coercion, any offers, plans, projects, programs, or proposals affecting individuals or their resources.<sup>9</sup>

From a global human rights perspective, the pandemic tested the contemporary understanding of the right to the highest attainable standard of

health, enshrined in article 12 of the International Covenant on Economic, Social and Cultural Rights, to which South Korea is a signatory. The Committee on Economic, Social and Cultural Rights had previously noted in General Comment 14 that the right to the highest attainable standard of health explicitly grants both freedoms and entitlements, including the right to control one's health and body and the right to be free from nonconsensual medical treatment and experimentation.<sup>10</sup> There is a further requirement that health services be culturally acceptable to individuals and communities.<sup>11</sup> The World Health Organization similarly identifies informed consent, bodily integrity, and participation in health-related decision-making as core state obligations under the right to health.<sup>12</sup>

It is widely accepted that the rights to self-determination, dignity, and bodily integrity underpin the fundamental aspects of informed consent from a legal perspective. As Antonio Sandu has argued, informed consent constitutes the normative basis for human rights protection in medical and biomedical research, having developed from a narrow civil law concept into an indispensable instrument in human rights protection.<sup>13</sup> Informed consent is presented as a legal expression of autonomy or self-determination, representing an act through which the patient or research participant expresses agreement for a medical intervention or participation in a study—a complex process of communication and deliberation, not merely a procedural formality.<sup>14</sup>

### *South Korea's constitutional protections*

The aforementioned global norms are reinforced by South Korea's constitutional order.<sup>15</sup> Article 36(3) of the South Korean Constitution does not explicitly declare a fundamental right to health, but it has been interpreted by courts and scholars as providing constitutional support for such a right through the state's duty to protect citizens' health.<sup>16</sup> Article 10 clearly sets the legal grounds for the right to self-determination, expressed explicitly around human dignity and values (존엄과 가치)—the exact formulation of the constitutional text.<sup>17</sup> As Chai-hark Hahm has observed, the current South Korean

Constitution of 1987 stands as the culmination of the hard-won fruit of generations of democratic struggle—a testament to the enduring resolve of South Korean citizens who steadfastly endeavored to subordinate state power to constitutional rule.<sup>18</sup>

### *Why the 2021 proposals were perceived as rights-threatening*

Against this backdrop, the 2021 legislative proposals to permit the use of biospecimens collected during infectious disease outbreaks without individual informed consent were not just viewed as technical adjustments to research governance. They were understood as potential infringements on human rights that had been hard-won through democratic mobilization. Allowing the use of biospecimens without consent, or exempting such research from ethics review, appeared to conflict with constitutional values grounded in human rights and with international human rights obligations, as discussed below.

For many civil society actors, the proposals signaled a troubling precedent: that emergency conditions could be used to justify bypassing fundamental protections. This concern—rooted in both legal principle and historical experience—became a central driver of the civic mobilization that followed.

### *The legislative proposals and their ethical implications*

On March 2, 2021, Representative Byun Jae-il and 10 lawmakers introduced two legislative proposals aimed at facilitating infectious disease research in South Korea. The first, an amendment to the Infectious Disease Control and Prevention Act (Bill No. 2108444), would have authorized the Korea Disease Control and Prevention Agency to permit research on pathogens derived from infectious disease patients without written informed consent.<sup>19</sup> The Ministry of Health and Welfare justified the proposal by arguing that obtaining written consent during emergencies is “realistically impossible for frontline healthcare workers,” and cited the United States' Health Insurance Portability and Accountability Act, the European General Data Protection

Regulation, and Japan's Next-Generation Medical Infrastructure Act as examples of systems that allow limited research use of pseudonymized data without consent.

However, these foreign frameworks include strict safeguards—such as proportionality, necessity, anonymization, and independent oversight—that were absent from the Korean proposal. Critics argued that the bill selectively imported the exceptions while omitting the protective mechanisms that give those exceptions ethical and legal legitimacy.<sup>20</sup> Indeed, the US Health Insurance Portability and Accountability Act and the Common Rule permit consent waivers only upon independent ethics review confirming minimal risk, practical necessity, and adequate de-identification protections.<sup>21</sup> The European General Data Protection Regulation similarly conditions research exceptions on proportionality, necessity, data minimization, and independent supervisory oversight.<sup>22</sup> Japan's Next-Generation Medical Infrastructure Act, far from eliminating consent, requires all medical data to be processed by government-certified anonymization agents and covers only anonymized data, not physical biospecimens.<sup>23</sup> The Korean proposal, by contrast, authorized consent-free research on biospecimens without mandatory ethics review, proportionality assessment, or certified anonymization, reproducing the deregulatory outcome of these foreign frameworks while dispensing with the ethical architecture that makes such exceptions internationally defensible.

The second proposal, an amendment to the Act on the Promotion of Collection, Management and Utilization of Pathogenic Resources (Bill No. 2108443), sought to redefine “pathogenic resources” to include specimens such as blood, plasma, serum, saliva, urine, and sputum collected from infectious disease patients.<sup>24</sup> By shifting these materials from the Bioethics and Safety Act to the Pathogenic Resources Act, the amendment would have removed them from the category of “human-derived materials” and thereby exempted related research from ethics review oversight.

Taken together, the two proposals reflected a technocratic logic that prioritized research speed

and administrative efficiency over established ethical safeguards such as the right to self-determination, informed consent, and ethics review. Although framed as temporary crisis measures, they risked normalizing a legal environment in which core protections could be bypassed. The absence of clear limitations, safeguards, and accountability mechanisms raised serious concerns among bioethics scholars, patient advocacy groups, and human rights organizations.

### *Civil society's ethical reasoning and advocacy*

The legislative proposals introduced in early 2021 sparked swift and organized opposition from academic and civic sectors in South Korea. On March 19, four major scholarly societies—the Korean Bioethics Association, the Korean Association of Medical Law, the Korean Society for Medical Ethics, and the Korean Association of Institutional Review Boards—released an exceptional joint statement denouncing the proposed bills.<sup>25</sup> The statement warned that the legislation undermined internationally recognized ethical standards, including standards promoted through the Declaration of Helsinki and South Korea's own Bioethics and Safety Act. In particular, it highlighted article 8 of the 2013 version of the Declaration of Helsinki, which states that while the primary purpose of medical research is to generate new knowledge, “this goal can never take precedence over the rights and interests of individual research subjects.”<sup>26</sup> In the view of the professional organizations, the bypassing of informed consent—even under emergency conditions—represented a dangerous precedent that could erode public trust and institutional integrity.

Just 11 days later, a broad civil society coalition—including disability rights groups, labor unions, health justice advocates, and civil society organizations—issued their own public statement.<sup>27</sup> This coalition emphasized that public health emergencies do not justify the suspension of ethical norms.

Their opposition was grounded in the view that the proposed bills violated core principles of biomedical ethics—particularly informed consent and prior ethics review—as enshrined in interna-

tional standards. The joint statement warned that exempting infectious disease samples from these safeguards could lead to the exploitation of patients who are already in vulnerable situations. Signatory organizations, including those representing infectious disease patients, people with disabilities, low-income groups, and other marginalized populations, stressed that public health emergencies must not be used to justify the erosion of fundamental human rights.

Beyond their legal critiques, the two academic and civil society statements addressed the broader ethical and social implications of the proposed legislation. The statement issued by professional organizations drew on established bioethical and legal standards, emphasizing the importance of informed consent and prior ethics review within internationally recognized frameworks. By contrast, the civil society statement framed its opposition in terms of lived experience, social vulnerability, and the potential consequences of weakening protections for those most at risk.

Taken together, these statements combined formal legal and ethical critique with broader concerns about public accountability and the rights to self-determination and dignity. They highlighted specific risks associated with the proposed legislation, including the normalization of research without informed consent, the disproportionate impact on marginalized populations, and the erosion of trust in public health institutions during a time of crisis.

The statements also referred to South Korea's past experiences with authoritarian governance, during which science and public health policies were implemented without sufficient public consultation. These references served to situate the proposed legislative changes within a wider historical and political context, rather than as purely technical regulatory adjustments.

### *A broad-based coalition beyond the academic sphere*

What made the resistance to the legislative proposals particularly significant was the breadth and diversity of the coalition that emerged. Beyond

academic societies, 29 civil society organizations opposed the deregulation bills. As noted above, this coalition included medical professionals (e.g., the Association of Physicians for Humanism), grassroots health and justice advocates (e.g., the Center for Health and Social Change and the Network for the Right to Health), and groups representing people with disabilities and consumer rights.

The coalition's unified message was that public health emergencies do not justify circumventing informed consent or weakening research oversight. Instead, crisis conditions demand stronger ethical protections, not weaker ones. Drawing from their organizational histories rooted in South Korea's democratization movements, these groups emphasized civic participation, government accountability, and the centrality of human rights in public health governance.

The coalition demonstrated impressive organizational coordination. Joint statements were carefully worded to bridge professional ethics and grassroots human rights concerns. Press releases were published, media coverage followed, and a substantial number of public comments were submitted through official legislative channels. These activities indicate that the issue moved beyond expert debate and entered broader public discussion. This expansive coalition showed that informed consent was not merely a technical safeguard but a symbol of democratic governance. In uniting diverse voices under a common ethical banner, the campaign set a precedent for rights-based civil resistance in the bioethical domain.

The 29 organizations represent a broad spectrum of Korean society, categorized into six types by locus of ethical concern and civic engagement.

First, labor and professional organizations ( $n = 3$ ), including the Korean Confederation of Trade Unions—one of the country's largest and most influential labor unions—demonstrated that concerns about informed consent extended beyond traditional bioethics communities. Their support reflected a broader worker-rights framework that emphasizes human rights and democratic participation in decision-making processes.

Second, organizations representing disabil-

ity, poverty, and marginalized groups (n = 4) brought perspectives rooted in lived experiences of structural exclusion. Organizations such as Solidarity Against Disability Discrimination and Homeless Action have historically challenged medical paternalism and emphasized the importance of informed consent and rights-based service delivery for those whose voices are often disregarded in policymaking.

Third, HIV/AIDS and human rights organizations (n = 9) formed the largest category of signatories. These groups—including KNP+ (the Korean Network of People Living with HIV/AIDS), the Korean Youth Community of People Living with HIV, and Hi-Friends—have long been at the forefront of the struggle for medical rights, privacy, and protection from stigma. Their opposition to the legislative waiver proposals drew on decades of advocacy defending the bodily integrity and autonomy of sexual minorities and people living with HIV/AIDS. The proposed consent waiver was

perceived as a direct threat to people already living with stigmatized infectious conditions, for whom the nonconsensual use of biological samples carried particular historical and personal weight.

Fourth, civic watchdog and participatory policy organizations (n = 3), such as People’s Solidarity for Participatory Democracy and the Korean Progressive Network Jinbonet, framed the issue within a larger critique of state overreach and democratic erosion. These groups emphasized procedural justice and the need for public accountability when revising legal frameworks that affect human rights, particularly in emergencies.

Fifth, consumer and patient rights organizations (n = 3), including the Korea Consumer Federation, highlighted the ethical and legal expectations that citizens hold toward the health care system. Their inclusion signaled that informed consent is not merely a professional guideline but a social contract grounded in trust and transparency between institutions and the public.

TABLE 1. Civil society organizations that signed the 2021 joint statement opposing legislative waivers of informed consent

Category	Organizations
Labor and professional organizations (n = 3)	Korean Confederation of Trade Unions Labor City Solidarity Digital Information Committee of Lawyers for a Democratic Society
Organizations representing disability, poverty, and marginalized groups (n = 4)	Homeless Action Korean People’s Solidarity Against Poverty Our Stories Solidarity Against Disability Discrimination
HIV/AIDS and human rights organizations (n = 9)	Korean Youth Community of People Living with HIV Center for Sexual Rights and Reproductive Justice Different Bodies HIV/AIDS Human Rights Activists Network Human Rights Movement Sarangbang Human Rights Network Baram Gwangju Human Rights Group “Hwaljjak” KNP+ (Korean Network of People Living with HIV/AIDS) Hi-Friends
Civic watchdog and participatory policy groups (n = 3)	Criticism Group Vision Korean Progressive Network Jinbonet People’s Solidarity for Participatory Democracy
Consumer and patient rights organizations (n = 3)	Headquarters of the Movement for Free Medical Care Korea Consumer Federation Welfare State Made by Us
Health and human rights advocacy and research networks (n = 7)	Association of Physicians for Humanism Center for Health and Social Change Health and Medical Policy Network for the Right to Health Korean Pharmacists for a Healthy Society Network for a Healthy World The People’s Health Institute

Finally, health and human rights advocacy and research networks ( $n = 7$ ), such as the Center for Health and Social Change, the Association of Physicians for Humanism, and the Network for the Right to Health, contributed expert knowledge and long-standing commitment to public health ethics. These organizations provided the conceptual and empirical foundation for the joint statement, drawing from both domestic and international standards, including global human rights norms.

Taken together, the diversity and breadth of these organizations show that resistance to the legislative waivers was not limited to academic bioethicists or legal professionals. Rather, it reflected a deeply rooted civic ethic in South Korea—an ethic grounded in lived experience, participatory democracy, and transnational ethical norms.

#### *Public objections and media engagement*

In addition to formal statements by academic and civic organizations, individual citizens also played an active role in opposing the legislative proposals. During the official public comment period on the National Assembly's website (March 3–12, 2021), the two bills attracted strikingly different levels of public response. The proposed amendment to the Infectious Disease Control and Prevention Act (Bill No. 2108444)—which would have permitted research on infectious disease pathogens without written consent—received 2,654 individual objections, an exceptionally high number in the context of South Korean legislative processes. This volume of participation reflected in part the digital organizing capacity of civil society networks, whose coordinated use of the National Assembly's online comment system amplified public opposition at scale.<sup>28</sup>

By contrast, the proposed amendment to the Pathogenic Resources Act (Bill No. 2108443), which concerned ethics review oversight, received only seven comments. This disparity is significant: It reflects the fact that the consent waiver provision was immediately legible to the public as a direct threat to self-determination and bodily integrity, while the ethics review exemption—a more technical governance matter—generated far less public concern.

For communities already living under the stigma of infectious disease, particularly people living with HIV/AIDS, the prospect of nonconsensual use of their biological materials was experienced as an existential threat, not an abstract policy question.

Most bioethics- or health-related bills typically receive only a handful of comments, and it is not uncommon for such amendments to pass without any public input. This unusually high volume of engagement signaled widespread public concern over the ethical implications of the proposed deregulatory changes and reflected a broader consensus that the human right to self-determination must remain nonnegotiable, even in emergencies.

The controversy also drew notable media attention—an uncommon development for technical amendments concerning research governance. National outlets such as *Medipana News* and *Korea Biomedical Review* not only reported the legal details but also highlighted the intensity of civic backlash, framing the issue in both ethical and constitutional terms.<sup>29</sup> Rather than offering uncritical coverage, many articles incorporated civic commentary and ethical critique, thereby helping mobilize public awareness beyond academic and professional spheres.

This convergence of citizen protest and media engagement was rare in South Korea's legislative landscape, where many laws are revised with minimal public scrutiny. In this case, however, the synergy between digital activism, civil society advocacy, and press coverage generated a robust democratic response. Ultimately, both bills failed to reach a committee vote and lapsed automatically at the end of the parliamentary session—a procedural outcome that itself reflected the weight of sustained public and professional opposition. The event serves as a compelling reminder that public ethics and civic agency can meaningfully influence lawmaking, even during a global crisis.

#### Discussion: Historical roots and global implications

The speed, breadth, and effectiveness of South Korea's civic mobilization raises an important

question: What made this response possible? The answer lies not in the specific circumstances of 2021 but in the longer arc of South Korean democratic and ethical development. This section contextualizes the case within South Korea's political history and draws out its implications for global debates on research ethics, human rights, and democratic governance.

### *South Korea's historical path to ethical vigilance and civic resistance*

South Korea's contemporary civic and ethical landscape cannot be understood without considering its turbulent modern history. Prior to Japanese colonization in the early 20th century, the Korean peninsula had been governed by a succession of unified dynasties—including Unified Silla, Goryeo, and Joseon—for over a millennium, fostering a deep sense of cultural and political continuity.<sup>30</sup> From 1910 to 1945, Korea was under Japanese colonial rule, a period marked by severe cultural, political, and institutional suppression. In the aftermath of World War II, the country was forcibly divided along the 38th parallel. This division crystallized into two separate states in 1948, making the Korean peninsula one of the last enduring vestiges of the Cold War.

Shortly after its founding, South Korea was devastated by the Korean War (1950–1953), which left millions dead and the country in ruins. Amid postwar poverty, the country embarked on a rapid process of economic modernization. However, this came at a high cost to civil liberties. From 1961 to 1987, South Korea was ruled by successive military regimes. Under Presidents Park Chung-hee and Chun Doo-hwan, dissent was violently suppressed. The 1980 Gwangju Uprising, in which civilian protesters were massacred under martial law, became a symbol of the brutal cost of authoritarian rule.<sup>31</sup> During this period, many students, labor organizers, and intellectuals were imprisoned, tortured, or disappeared. A generation of South Koreans—including this paper's corresponding author—came of age during this era, witnessing firsthand the fear and repression of a government willing to sacrifice human rights for state power and economic growth.

South Korea's democratic transformation began in earnest with mass protests in 1987, leading to constitutional reforms and the election of a civilian president in 1992. Since then, democratic institutions and civil society organizations have expanded significantly.

The country's ethical governance infrastructure developed more slowly. It was not until the Hwang Woo-Suk scandal of 2005–2006 that South Korea experienced a reckoning with research ethics.<sup>32</sup> Hwang, a nationally celebrated stem cell researcher, was found to have fabricated data in two landmark papers published in *Science*, while also obtaining eggs from female junior researchers under ethically compromised conditions. The scandal—which unraveled despite initial state backing and intense national pride—exposed deep structural failures in research oversight and triggered a public debate about the relationship between scientific ambition, state support, and ethical accountability.

The public's response was profound, reflecting a renewed demand for scientific integrity and the recognition of human rights and contributing to legislative and institutional reforms in bioethics. This shift has been described by Korean scholars as an "ethical modernization."<sup>33</sup> The incident catalyzed the establishment of new oversight bodies and, in 2013, prompted South Korea to amend its Bioethics and Safety Act to bring domestic regulations into closer alignment with internationally recognized bioethical standards, including the principles articulated in the Declaration of Helsinki regarding informed consent. This foundational legal reform would later provide the normative anchor for the academic and civic coalition statements of 2021.<sup>34</sup> The scandal also marked a pivotal moment in public engagement with biomedical ethics and highlighted the role of media and civil society in demanding accountability from the scientific community.

A decade later, the 2015 outbreak of Middle East respiratory syndrome (MERS) provided an additional formative experience that further shaped public expectations regarding ethical governance. The government's initial response was widely criticized for a lack of transparency, particularly

its failure to disclose information about affected hospitals and transmission pathways.<sup>35</sup> This was perceived as prioritizing institutional and political interests over public trust, leading to widespread criticism and a rapid erosion of confidence in public health authorities.<sup>36</sup>

The MERS experience underscored the ethical and political importance of transparency, accountability, and effective risk communication in public health crises. In its aftermath, reforms were introduced to improve information disclosure, public engagement, and participatory governance in epidemic response.<sup>37</sup>

During the COVID-19 pandemic, South Korea's prior experience with MERS initially prompted a transparent and participatory response.<sup>38</sup> The government emphasized open communication and citizen cooperation rather than coercion or lockdowns.<sup>39</sup> This established a high standard of public trust and ethical responsiveness. South Korea's reliance on digital contact tracing and public disclosure of movement data did raise privacy concerns, but these measures were subject to public debate and oversight.<sup>40</sup> The balance struck between technological surveillance and democratic accountability reflected a maturing ethical infrastructure shaped by earlier public health crises and civic engagement.<sup>41</sup>

The layers of historical trauma and civic awakening provide the necessary context to understand the powerful civil society response to the 2021 legislative proposals aimed at waiving informed consent for infectious disease research. The proposed amendments were not merely technical revisions—they triggered historical memory, ethical commitments, and constitutional instincts. South Korea's civil society, forged through decades of struggle against authoritarianism, acted decisively to defend human rights norms, even during a global emergency.<sup>42</sup> Their success underscores the enduring connection between democracy, ethics, and public health.

### *Governance lessons and global significance*

South Korea's experience also speaks to wider concerns about the relationship between emergency

powers and democratic erosion, in particular the absence of meaningful prior public consultation before the legislative proposals were introduced. In South Korea, as in many democracies, major legislative changes affecting health and research governance are typically subject to stakeholder consultation and parliamentary deliberation. The 2021 bills were introduced without such a process, which itself became a focal point of civil society criticism. The coalition statements explicitly demanded participatory policymaking—not merely the withdrawal of the bills, but a commitment to future co-deliberation.<sup>43</sup> This points to a broader governance lesson: The legitimacy of research ethics frameworks depends not only on their substance but on the process by which they are made.

South Korea's case illuminates the relationship between three analytically distinct but deeply interconnected domains: research ethics, human rights, and democratic governance. Research ethics norms—particularly informed consent and ethics review—provided the immediate grounds for opposition. Human rights law, both international and constitutional, supplied the normative authority that gave those norms legal weight and political force. And democratic governance, forged through decades of civic struggle, provided the institutional capacity and collective will to act.

The 2021 mobilization can be understood as having been effective in part because these three domains converged, enabling civil society actors to simultaneously invoke bioethical standards, human rights obligations, and constitutional principles in a single coherent argument. It is this convergence that distinguishes the South Korean case from technocratic policy debates and gives it broader significance for wider discussions on research governance, democratic resilience, and the protection of human rights during public health emergencies.

At the level of global research governance, the concerns articulated in the South Korean case resonate with broader international efforts to address the ethical challenges of public health emergencies. The 2024 revision of the Declaration of Helsinki, which includes expanded attention to research in

emergency contexts and the role of community engagement, reflects an ongoing attempt to clarify the conditions under which research may proceed without undermining fundamental protections.<sup>44</sup> Similarly, the PREPARED Code: A Global Code of Conduct for Research During Pandemics provides practical guidance for researchers and ethics committees navigating these tensions, including a dedicated chapter on the code's core principles.<sup>45</sup> The analysis presented in this paper contributed to discussions that informed aspects of this broader work, situating the South Korean experience within an evolving global conversation about pandemic ethics.

## Conclusion

Giorgio Agamben's theory of the "state of exception," Michel Foucault's analysis of biopolitics, and Hannah Arendt's warnings about the conditions that give rise to totalitarianism all caution against the instrumental use of insecurity to justify authoritarian measures.<sup>46</sup> As Erich Fromm has observed, fear and instability can lead citizens to relinquish autonomy in exchange for a false sense of protection.<sup>47</sup> The Korean example underscores how even democracies, when gripped by national emergencies, may veer toward exceptionalism, undermining the very ethical and legal safeguards that define open societies.<sup>48</sup> Importantly, South Korea's overall COVID-19 governance had been recognized internationally as a model response, which makes the 2021 legislative proposals all the more striking.<sup>49</sup> The South Korean resistance to deregulatory reforms serves as a reminder that ethical norms must not be suspended but rather reinforced during moments of national vulnerability.

At the domestic level, the events examined in this paper may be understood within a longer trajectory of democratic development and civic engagement in South Korea. Historical experiences of authoritarian governance, together with subsequent processes of democratization, have contributed to a political culture in which public scrutiny and participation play an important role in shaping policy decisions. In this context, the 2021 mobilization can

be interpreted as one instance of a broader pattern of civic vigilance in the face of perceived threats to rights and accountability.

This pattern is further illuminated by two pivotal episodes that bracket the case examined here. In 2016–2017, sustained mass candlelight protests—drawing millions of citizens across South Korea—led to the constitutional impeachment and removal of President Park Geun-hye, demonstrating that institutional accountability mechanisms could be activated through organized civic pressure even in the face of entrenched political power.<sup>50</sup> In December 2024, when the sitting president declared martial law in an attempt to suspend parliamentary governance, citizens and lawmakers once again mobilized with remarkable speed, and the declaration was overturned within hours.<sup>51</sup> These episodes, though distinct in domain—constitutional governance, bioethics, and research regulation—reflect a shared democratic infrastructure: South Korean civil society possesses both the institutional memory and the organizational capacity to recognize, name, and resist perceived violations of rights. The 2021 defense of informed consent is best understood as part of this same tradition of civic vigilance—one in which the protection of rights, whether in the research ethics arena or in the constitutional order, is treated as a nonnegotiable civic obligation.

South Korea's experience offers a set of insights that may be relevant beyond the specific case examined here. It suggests that the resilience of ethical and legal protections during crises depends both on formal regulatory frameworks and on the presence of engaged civil society actors, institutional accountability, and public trust. In this sense, informed consent is not merely a technical requirement but part of a broader normative architecture that supports democratic governance.

In times of crisis, the challenge lies in upholding ethical standards under conditions of uncertainty and urgency. The South Korean case indicates that sustained civic engagement and adherence to internationally recognized ethical principles can help ensure that responses to public health emergencies remain aligned with human rights and democratic values.

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## References

1. World Medical Association, Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects (adopted 1964, last amended 2024); United Nations Educational, Scientific and Cultural Organization, Universal Declaration on Bioethics and Human Rights (2005).
2. World Health Organization, *Ethics in Epidemics, Emergencies and Disasters: Research, Surveillance and Patient Care: Training Manual* (2015), pp. 7–8; Nuffield Council on Bioethics, *Research in Global Health Emergencies: Ethical Issues* (2020), pp. 9–11; National Academies of Sciences, Engineering, and Medicine, *Integrating Clinical Research into Epidemic Response: The Ebola Experience* (National Academies Press, 2017), pp. 3–5.
3. S. A. Zweig, A. J. Zapf, C. Beyrer, et al., “Ensuring Rights While Protecting Health: The Importance of Using a Human Rights Approach in Implementing Public Health Responses to COVID-19,” *Health and Human Rights* 23/2 (2021).
4. D. Lee, K. Heo, Y. Seo, et al., “Flattening the Curve on COVID-19: South Korea’s Measures in Tackling Initial Outbreak of Coronavirus,” *American Journal of Epidemiology* 190/4 (2021); J. Park and E. Chung, “Learning from Past Pandemic Governance: Early Response and Public-Private Partnerships in Testing of COVID-19 in South Korea,” *World Development* 137 (2021); J. Jeon, H. Kim, and K. S. Yu, “The Impact of COVID-19 on Conduct of Clinical Trials for Medical Products in Korea,” *Journal of Korean Medical Science* 35/36 (2020); Y. Park and O. Kim, “Government Initiatives for Research Ethics During COVID-19 Pandemic in Korea,” *Journal of Korean Medical Science* 39/12 (2024).
5. National Assembly of the Republic of Korea, “Partial Amendment to the Infectious Disease Control and Prevention Act,” Bill No. 2108444, sponsored by Representative Byun Jae-il et al. (March 2, 2021) (Korean-language source).
6. People’s Solidarity for Participatory Democracy et al., “Joint Civil Society Statement Opposing Legislative Efforts to Undermine Bioethical Standards during Public Health Crises” (March 30, 2021) (Korean-language source).
7. Human Rights Council, Free, Prior and Informed Consent: A Human Rights-Based Approach, UN Doc. A/HRC/39/62 (2018).
8. Ibid.
9. Ibid.
10. Committee on Economic, Social and Cultural Rights, General Comment No. 14, UN Doc. E/C.12/2000/4 (2000), paras. 12–13, 43(a).
11. Ibid.
12. World Health Organization, “Human Rights,” <https://www.who.int/health-topics/human-rights>.
13. A. Sandu, “Ethical and Legal Perspectives on Informed Consent in the Context of International Human Rights Law,” *Logos Universality Mentality Education Novelty: Law* 13/1 (2025).
14. Ibid.
15. Constitution of the Republic of Korea (1987).
16. S. Jeon, “Public Health and Constitutional Rights During the COVID-19 Pandemic,” *Journal of Korean Law* 20/2 (2021).
17. M. Kim, “Enhancing Professional Awareness of Informed Consent: Safeguarding the Rights of Patients and Practitioners,” *Journal of Korean Neurosurgical Society* 67/6 (2024).
18. C. Hahm, *The Constitution of South Korea: A Contextual Analysis* (Hart Publishing, 2024).
19. National Assembly of the Republic of Korea, Bill No. 2108444 (see note 5).
20. Korean Bioethics Association et al., Joint Statement Opposing Legal Amendments That Undermine Informed Consent and Ethical Standards in Infectious Disease Research (March 19, 2021) (Korean-language source).
21. United States, 45 Code of Federal Regulations (CFR) §164.512(i)(2)(ii); 45 CFR §46.116(f)(3).
22. European Union, General Data Protection Regulation Article 89, Regulation (EU) 2016/679 (2016); European Data Protection Board, Guidelines 03/2020 on the Processing of Data Concerning Health for the Purpose of Scientific Research in the Context of the COVID-19 Outbreak (2020); C. Staunton, S. Slokenberga, A. Parziale, and D. Mascalzoni, “Appropriate Safeguards and Article 89 of the GDPR: Considerations for Biobank, Databank and Genetic Research,” *Frontiers in Genetics* 13/719317 (2022).
23. Y. Wakabayashi, H. Asai, T. Horimatsu, et al., “Next-Generation Medical Infrastructure Law in Japan: Appropriate Use of Individual Medical Information,” DIA Global Forum (2023), <https://globalforum.diaglobal.org/issue/february-2023/next-generation-medical-infrastructure-law-in-japan>.
24. National Assembly of the Republic of Korea, “Partial Amendment to the Act on the Promotion of Collection, Management and Utilization of Pathogenic Resources,” Bill

- No. 2108443, sponsored by Representative Byun Jae-il et al. (March 2, 2021) (Korean-language source).
25. Korean Bioethics Association et al. (see note 20).
  26. World Medical Association, Declaration of Helsinki (2013), art. 8.
  27. People's Solidarity for Participatory Democracy et al. (see note 6).
  28. National Assembly of the Republic of Korea, Bill No. 2108444 (see note 5); H. Lee and J. Oh (eds), *Digital Media, Online Activism, and Social Movements in Korea* (Lexington Books, 2021).
  29. *Medipana News* (March 23, 2021); *Korea Biomedical Review* (March 23, 2021); *Daily Medi* (March 17, 2021); *Doctor's News* (March 23, 2021); *Hankyung Medical* (March 23, 2021); *Health Korea News* (March 23, 2021); *Korea Medical Times* (March 23, 2021) (Korean-language sources).
  30. B. Cumings, *Korea's Place in the Sun: A Modern History* (W. W. Norton & Company, 2005), chs. 1–3.
  31. *Ibid.*; B. Cumings, *The Korean War: A History* (Modern Library, 2010).
  32. T. Kim, "How Could a Scientist Become a National Celebrity?," *East Asian Science, Technology and Society* 2/1 (2008); H. Gottweis and B. Kim, "Explaining Hwang-Gate," *Science, Technology and Human Values* 35/4 (2010).
  33. J. Kim and K. Park, "Ethical Modernization: Research Misconduct and Research Ethics Reforms in Korea Following the Hwang Affair," *Science and Engineering Ethics* 19/2 (2013).
  34. O. Kim, "Bioethics and Research Ethics in Korea After the Hwang Woo-Suk Scandal," in *The Hwang Woo-Suk Scandal 10 Years Ago from the Present Perspective* (Park Young-Sa, 2018) (Korean-language source).
  35. S. Lee, "Costly Lessons from the 2015 MERS Coronavirus Outbreak in Korea," *Journal of Preventive Medicine and Public Health* 48/6 (2015).
  36. O. Kim, "Ethical Perspectives on the Middle East Respiratory Syndrome Coronavirus Epidemic in Korea," *Journal of Preventive Medicine and Public Health* 49/1 (2016).
  37. Lee, "Costly Lessons" (see note 35); Kim, "Ethical Perspectives" (see note 36).
  38. Lee, "Costly Lessons" (see note 35); Kim, "Ethical Perspectives" (see note 36).
  39. Park and Kim (see note 4).
  40. M. Ryan, "In Defence of Digital Contact-Tracing: Human Rights, South Korea and COVID-19," *International Journal of Pervasive Computing and Communications* 16/4 (2020).
  41. M. Moon, "Fighting COVID-19 with Agility, Transparency, and Participation: Wicked Policy Problems and New Governance Challenges," *Public Administration Review* 80/4 (2020).
  42. Cumings (2005, see note 30), ch. 7.
  43. People's Solidarity for Participatory Democracy et al. (see note 6).
  44. Y. Park, D. Schroeder, and O. Kim, "Research Ethics Challenges in Pandemic Korea and Their Implications for the Revised 2024 Declaration of Helsinki," *Journal of Korean Medical Science* 40/42 (2025).
  45. PREPARED, "The PREPARED Code: A Global Code of Conduct for Research During Pandemics," <https://www.globalcodeofconduct.org/prepared-code/>; K. Chatfield and M. Singh (eds), *Research Ethics and Integrity During Pandemics: Developing the PREPARED Code* (Springer, 2025).
  46. G. Agamben, *State of Exception* (University of Chicago Press, 2005); M. Foucault, *Society Must Be Defended: Lectures at the Collège de France, 1975–1976* (Picador, 2003); H. Arendt, *The Origins of Totalitarianism* (Harcourt, 1951).
  47. E. Fromm, *Escape from Freedom* (Holt Paperbacks, 1994).
  48. A. J. London and J. Kimmelman, "Against Pandemic Research Exceptionalism," *Science* 368/6490 (2020).
  49. S. Lee and T. Kim, "South Korea's Combating COVID-19 Under the Rule of Law," *Verfassungsblog* (April 8, 2021).
  50. W. Kang, "Determinants of Unaffiliated Citizen Protests: The Korean Candlelight Protests of 2016–2017," *Korea Journal* 59/1 (2019).
  51. B. A. Engel, "Making Sense of South Korea's Senseless Martial Law Declaration," *Asia Pacific Journal: Japan Focus* 22/12 (2024).

# Governing Difference: Traditional Peoples' Rights and the Institutionalization of Traditional Medicine in South America

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## Abstract

Since the 1970s, the World Health Organization (WHO) has advanced “traditional medicine” as a global policy category for culturally grounded health care. In South America, this framework has encountered a distinct political landscape in which traditional peoples have emerged as collective subjects mobilizing around rights, territorial claims, and expanding conceptions of citizenship. This paper examines how the codification of “tradition” from an identity category into a health regulatory term reconfigures the conditions under which difference can be expressed, claimed, and sustained. Drawing on archival research across 10 South American countries, as well as WHO and United Nations documentation, the study traces how the global framework has been incorporated, requalified, or displaced across distinct national contexts. The analysis reveals a spectrum of regulatory arrangements in which institutional incorporation and the political force of collective difference are not commensurate, ranging from frameworks that engage with the political projects through which traditional peoples have sought to reshape citizenship to those in which “tradition” operates as a market authorization criterion detached from the subjects who sustain it. The codification of tradition into governable categories does not simply extend recognition to those who bear it; it reconfigures the terms under which they can act as political subjects.

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## Introduction

In a 2009 interview reflecting on Indigenous participation in Brazil's 1988 National Constituent Assembly, Ailton Krenak compared the state to a beast: "one of those beasts that can be restrained but, from time to time, still devours someone."<sup>1</sup> The comparison was made without metaphor. The Krenak people were, at the time of that interview, facing the imminent risk of being devoured themselves. In that same year, 2009, while two decades of constitutionally recognized Indigenous rights in Brazil were being celebrated, the Brazilian Supreme Court was considering the possibility of summarily retracting them.<sup>2</sup> Far from hyperbolic, Ailton Krenak's image served as a reminder that, for certain identities, the distance between being devoured and almost being devoured remains perilously narrow. Recognizing that a restrained beast never ceases to be a beast is, therefore, a prudent way to avert danger.

Although constantly aware of such threats, the Krenak people in Brazil, like the Aymara in Peru, the Kichwa in Colombia, the Montubio in Ecuador, and other groups engaged in struggles for life and territory against latifundia and biopiracy, witnessed a regional shift as many South American states began to incorporate cultural difference into their legal and institutional frameworks. While not without ambiguity, this shift signaled a new political moment in the region in which the long-standing pressure to dissolve difference into a homogenized nation-state gave way to its formal recognition as a constitutional principle and the basis for collective rights.<sup>3</sup>

In much of South America, this reconfiguration was articulated through the idea of "tradition" (or "traditionality"). Despite its diffuse conceptualization, the term proved politically productive precisely because of its openness, allowing heterogeneous groups to organize their distinct projects of autonomy under a shared political front. Encompassing Indigenous, Afro-diasporic, mestizo, peasant, and other local communities, the category of "traditional people" became a key marker of identity from the 1980s onward, enabling historically marginalized groups to assert themselves

as political subjects within the national political arena.

During this same period, the World Health Organization (WHO) intensified its framing of "traditional medicine" as a strategic concept for achieving culturally grounded health care. The encounter between WHO's conceptualization and South American traditional peoples' agenda became a key vector in public debates, linking processes of citizenship pluralization to the incorporation of medical pluralism into public policies.

Previous studies have shown that the reframing of "tradition" within global health governance tends to displace its political and relational dimensions.<sup>4</sup> The South American context calls for closer attention to this dynamic. In the region, the notion of "tradition" is deeply embedded in long-standing struggles over the very terms of citizenship—struggles that have produced constitutional transformations, collective rights instruments, and expanding arenas of political participation.

This paper examines how the institutionalization of WHO's concept of traditional medicine across 10 South American countries intersects with broader processes of citizenship pluralization in the region, and what that intersection does to the political projects through which traditional peoples have sought to reshape the terms of belonging.

## Tracing the institutional life of "traditional medicine": Sources, scope, and analytical approach

This study focuses on South American countries that explicitly reference "traditional medicine" in their public health policies, encompassing both highly institutionalized frameworks (Bolivia, Brazil, Chile, Colombia, Ecuador, Peru, and Venezuela) and more circumscribed regulatory approaches (Argentina, Paraguay, and Uruguay).

Through archival research, we selected public policies, health programs and regulations, and development plans and government reports. The selection prioritized documents that reflect the institutional consolidation of traditional medicine

within public policy, including legislation and other instruments that make this consolidation observable. Particular attention was given to documents that reveal how regulatory forms intersect with the operationalization of rights and the participation of traditional peoples.

We identified documents using the term “traditional medicine” as endorsed by WHO, alongside regionally specific terminologies such as “ancestral medicine,” “Andean medicine,” “Indigenous medicine,” “traditional knowledge,” and “traditional practices.” To address terminological variation, the study assumes equivalence not at the level of meaning but at the level of policy function: Since all countries in the corpus engage with the WHO category—whether by adopting, requalifying, or displacing it—the term functions less as a fixed referent than as a site where the relationship between global regulatory frameworks and nationally situated political projects becomes legible. The variation in how countries mobilize, reframe, or depart from WHO’s formulation is part of what the analysis seeks to trace.

We conducted online searches in Portuguese, Spanish, and English, using official government portals and other relevant digital platforms. Among the 249 documents identified, we paid particular attention to a subset of 87 documents published between the 1990s and 2010s. This period captures the moment when the international consolidation of traditional medicine as a policy category became most pronounced, coinciding with the democratic reopening and the simultaneous intensification of neoliberal reforms across South America—what Evelina Dagnino has described as a “perverse confluence.” In this context, the adoption of the WHO framework produced its most consequential and ambivalent effects on the processes through which traditional peoples were asserting themselves as political subjects.<sup>5</sup> Documents published after 2010 were incorporated where relevant to trace subsequent regulatory developments and their implications for the relationship between therapeutic institutionalization and citizenship pluralization.

The analysis follows a twofold orientation. It examines how the WHO framework travels

downward into national policies and whether the regional innovations in traditional peoples’ rights find upward resonance within global health governance or remain marginal to it.

Analytically, the study addresses “traditional medicine” as a political category whose effects are not fixed but emerge from the contexts in which it is mobilized. The analysis therefore examines how traditional medicine operates within institutional frameworks to frame the recognition of culturally differentiated subjects and their citizenship claims. The central move is to track how groups for whom “traditional” is a self-ascribed marker of identity are positioned within these frameworks—as beneficiaries, providers, rights holders, or sources of evidence—and what that stance does to the conditions under which they can act as political subjects.

Contributing to studies on citizenship and pluralism, this paper argues that the codification of “tradition” into a governable policy category does not simply extend recognition to those who bear it; it reconfigures the conditions under which difference can be expressed, claimed, and sustained.<sup>6</sup> Although these effects vary according to the social configurations and national frameworks of each country, they consistently operate across a spectrum of possibilities in which greater institutional incorporation does not necessarily preserve, and may actively reconfigure, the political force of those who sustain these practices.<sup>7</sup> What is at stake, ultimately, is not whether recognition occurs but under what conditions, and whether those conditions allow difference to remain a living political force or instead render it governable at the cost of its own dynamism.

### Forging a global path

In its earliest formulations, developed between the 1960s and the late 1970s, WHO’s category of “traditional medicine” referred to a heterogeneous set of locally embedded health practices and knowledge systems.<sup>8</sup> Particularly attentive to the multiethnic configurations that had emerged from colonial rule in Southeast Asia and Sub-Saharan Africa, WHO approached cultural difference as both an obstacle

and a strategic resource.<sup>9</sup> Within this framework, the term “traditional” pointed to difference from Western medicine, while “medicine” functioned as an aggregating category, gathering diverse care regimes defined less by their distinctions than by their pragmatic convergence.<sup>10</sup>

The conceptualization remained openly unsettled—traditional medicine was variously described as “the sum total of all the knowledge and practices, whether explicable or not, used in diagnosis and prevention,” as “a solid amalgamation of dynamic medical know-how and ancestral experience,” or as “the sum total of practices, measures, ingredients, and procedures of all kinds”—yet WHO advanced a resolute assertion that “the essential differences among the various systems of medicine arise not from differences in their goals or effects, but from the cultures of the people who practice them.”<sup>11</sup> Aligned with the internationalist ethos of the United Nations, this formulation located medical difference in the populations who sustain it, while framing such diversity as compatible with integrated health governance. Within the horizon of the Global Strategy for Health for All by the Year 2000, traditional medicine was conceived as a pathway to universalize health coverage.<sup>12</sup>

From the 1990s onward, WHO increasingly rearticulated traditional medicine as a domain capable of policy integration and transnational circulation. This process reached its clearest expression in the Traditional Medicine Strategy 2002–2005, in which WHO reformulated the category as “a comprehensive term used to refer both to traditional medicine systems such as traditional Chinese medicine, Indian Ayurveda and Arabic Unani medicine, and to various forms of Indigenous medicine.”<sup>13</sup> Here, the place of difference was simultaneously redefined. No longer anchored in the subjects who sustained these practices, “tradition” was recast as a resource to be integrated into national health systems and emerging therapeutic markets. This redefinition was not only about who sustains the tradition being referred to but also about where the term is applied: “‘traditional medicine’ is used when referring to Africa, Latin America, South-East Asia, and/or the Western

Pacific, whereas ‘complementary and alternative medicine’ is used when referring to Europe and/or North America (and Australia).”<sup>14</sup> That geography is not incidental; it maps a distinction about how recognition claims could be made, where, and by whom, quietly displacing the broader disputes over political belonging that had driven the mobilization of “tradition” in its earliest global formulations.

From the mid-2010s onward, this trajectory culminated in a further inflection of the category itself. Rather than stabilizing the distinction between “traditional” and “complementary and alternative” medicine established in the 2002 strategy, subsequent WHO publications progressively blurred it, producing a proliferating polysemy: “complementary and alternative medicine,” “traditional and complementary medicine,” “traditional medicine/complementary and alternative medicine,” and “traditional and complementary medicine” co-exist across WHO documentation without stable definitional boundaries.<sup>15</sup> Far from a merely terminological question, this drift reflects a gradual repositioning of the term “traditional” within a broader regulatory horizon.

The consolidation of this trajectory became particularly visible in the First Traditional Medicine Global Summit, convened by WHO in 2023 in Gandhinagar, India. The summit revealed how major powers are now projecting the category onto a shifting geopolitical landscape in which the global governance of health is itself being reconfigured by emerging stakeholders. India and China showcased distinct yet convergent models: China promotes a state-sanctioned “tradition” centered on Han medicine within a framework of health commodification, while India reframes Ayurveda within a Hindu-nationalist agenda. Despite their differences, both models expand the global circulation of their medical systems through the export of educational frameworks, regulatory models, and pharmaceutical products.<sup>16</sup>

Thus, the mediating role of regional institutions acquires particular significance at this juncture, where global health governance progressively redefines tradition as a strategic category detached from the subjects who sustain it.

## PAHO and WHO: A distant embrace

In South America, the Pan American Health Organization (PAHO) functions as the primary institutional bridge between WHO's global agenda and the region's own political configurations.<sup>17</sup> Repeatedly caught between the political demands of traditional peoples whose claims have become increasingly present in the region's institutional arena and the global regulatory frameworks within which it operates, the organization has rarely fully aligned with either. The Health of the Indigenous Peoples Initiative offers a particularly illustrative case of this pattern.

From 1993 to 1997, two PAHO resolutions—CD37.R5 and CD40.R6—formally recognized the structural inequities shaping Indigenous peoples' access to health care and committed member states to addressing them. More than instruments for expanding service coverage, they stood out for their political framing, affirming Indigenous peoples' right to self-determination, calling for the recognition of their distinct therapeutics, and requiring governments to establish mechanisms for Indigenous representation in the design of health care systems.<sup>18</sup> In the years that followed, this political momentum found initial institutional expression in a work plan developed for 2000–2001, which still maintained the specificity of its agenda, positioning so-called Indigenous medicine as a distinct area of engagement alongside (but not subsumed within) the broader category of “traditional, complementary and alternative medicine,” each carrying its own questions and constituencies.<sup>19</sup>

That specificity, however, proved difficult to sustain. As the hybridized concept of traditional, complementary, and alternative medicine gained increasing institutional density, expanding into national departments, international frameworks, and dedicated policy instruments, Indigenous medicine has remained largely confined to its own domain. This compartmentalization has had a specific consequence. The political claims that had originally shaped the Indigenous agenda—benefit-sharing, prior informed consent, and collective rights over knowledge—have never been systematically extended to the very regulatory domains where they

are most at stake. Traditional, complementary, and alternative medicine frameworks—herbal medicine above all—have advanced without engaging these claims, even as they draw extensively on the knowledge systems of the peoples whose rights they leave unaddressed.

In a context where the particular dimensions of Indigenous claims had lost institutional traction, interculturality emerged from the turn of the millennium as a bridging concept that carried the promise of a mutually valorizing encounter between distinct therapeutic traditions.<sup>20</sup> In practice, however, it has operated in a way that deepens rather than resolves the existing compartmentalization. By framing traditional medicine primarily as a space of convergence between therapeutic systems, interculturality has progressively disconnected it from the collective subjects and the rights most directly associated with traditional peoples—claims that have been increasingly confined to the domain of Indigenous medicine, while non-Indigenous traditional peoples have been largely left outside both formulations. What had been a terrain where recognition, belonging, and rights could be contested has been recast as an approach to the administration of cultural difference, with traditional medicine repositioned as a therapeutic category rendered compatible with the expanding frameworks of complementary and alternative medicine.<sup>21</sup> Institutional recognition of difference thus proceeds on terms that constrain its political scope, gradually requiring a certain dispossession of alterity as the price of legibility within the health system.

This dynamic has produced what may be described as a double distancing. PAHO's progressive alignment with global regulatory logics has moved the organization away from the demands of traditional peoples, who had mobilized traditional medicine as a site of political struggle. At the same time, the region's distinctive political innovations have found little resonance within WHO's global architecture, where PAHO's limited influence has constrained their upward circulation.<sup>22</sup> South American demands have remained distant from PAHO, just as PAHO has remained distant from WHO, reproducing at each level the conceptual

divergences that have hindered effective strategic alignment between the two agendas.<sup>23</sup>

At this intersection, one can observe how global regulatory logics do not simply absorb locally grounded demands; they reconfigure the terms under which those demands can be expressed. How national governments across South America have navigated this double distancing, and with what consequences for the relationship between medical pluralism and the broader political projects of citizenship pluralization unfolding in the region, is the question to which the analysis now turns.

### Traditional peoples' rights and the institutionalization of traditional medicine in South America

From the 1980s onward, South American countries progressively responded to WHO's call to develop national policies addressing traditional medicine. Although this agenda was widely adopted across the region, its implementation followed divergent timings and trajectories that cannot be understood apart from the broader institutional transformations unfolding during the same period, particularly those associated with democratic reopening and the progressive consolidation of difference as an organizing principle of citizenship pluralization across the region.

Ecuador, Bolivia, and Colombia represent the cases where constitutional transformation went furthest, and it is precisely in these cases that traditional medicine has been most deeply articulated with broader political projects of citizenship pluralization, yet through distinct institutional pathways.<sup>24</sup>

In Ecuador, whose 2008 Constitution established plurinationality as a foundational principle of the state, institutionalization proceeded through hybridization. The National Directorate of Intercultural Health and Equity incorporated *hombres y mujeres de sabiduría* into the Ministry of Public Health under a dedicated ethical code that reframed biomedical categories, such as "medicine," "ethics," "diagnosis," and "specialization," recasting them through concepts and distinctions drawn from

Indigenous cosmologies.<sup>25</sup> This process conferred significant institutional legitimacy upon these subjects through a logic that was, at its core, one of translation—and translation, as Viveiros de Castro argues in discussing the asymmetries of intercultural encounters, is always a form of betrayal.<sup>26</sup> The ethical code itself acknowledges that in adopting this denomination—*código de ética*—its authors are translating their practice into terms legible to the surrounding Ecuadorian society, while insisting that the document expresses something that cannot adequately be rendered in Castilian. In this case, the categories through which difference is recognized belong to one of the two worlds being bridged, and the bridge runs in one direction. Difference is acknowledged, but on terms that make it fully administrable, a recognition secured through the internal reconfiguration of the very practices it claims to recognize.

Bolivia's trajectory suggests a different institutional logic. Its 2009 Constitution, the first in the region to establish the state as explicitly plurinational and to constitutionalize Indigenous self-government as a foundational right rather than a policy concession, created the normative conditions under which traditional medicine could be institutionalized on different terms.

The Law on Bolivian Ancestral Traditional Medicine (Law 459 of 2013) did not simply incorporate traditional practitioners into the national health system; it created devices that attempted to preserve the relational conditions under which these practices make sense. Remuneration, for instance, was regulated in accordance with "the mode that makes sense for each nation," explicitly accommodating non-monetary forms of exchange rather than converting reciprocity into a wage relation. Similarly, accreditation was structured as a community process. It is the community, not the state, that validates the practitioner.

Yet the critical notes within Bolivia's own institutional documents regarding the incorporation of traditional practitioners into national health settings highlight the political limitations of this framework. The 2016–2020 Strategic Plan, aimed at operationalizing the Plurinational Constitution

and consolidating health concerns raised since the pre-constituent assemblies, acknowledged plainly that the health sector had consistently failed to assume traditional medicine as an operative part of its structure—and that, in practice, traditional medicine remained separate from official services, with the attendant risk of becoming little more than the defense of corporate interests.<sup>27</sup> Even where normative devices attempt to preserve relational logics, their encounter with biomedical infrastructure produces reconfigurations that the framework itself acknowledges as problematic.<sup>28</sup>

Notably, Bolivia and Ecuador are also among the countries whose policy arguments make least reference to the WHO framework, constructing instead a normative repertoire more directly tied to the constitutional transformations that redefined citizenship in both countries.

Colombia occupies an analytically distinct position. Its 1991 Constitution recognized the multiethnic nature of the state and established collective rights, producing a constitutionalism in which alterity is recognized within the state rather than becoming partially constitutive of it. This distinction is legible from the outset in the institutional architecture of health policy.

With Resolution 5078 of 1992, Colombia's Ministry of Health separated "traditional medical cultures" from "alternative therapeutics," inscribing cultural difference as a criterion of recognition irreducible to the logic of professional certification.<sup>29</sup> This opening created a space of expanding citizenship, in which new collective actors were incorporated into state provision. The case of Afro-Pacific midwifery regulation illustrates both the reach and the limits of this incorporation.<sup>30</sup> Its recognition as cultural heritage induced a displacement from the field of health, where specific categories for traditional practices had advanced without inscribing their practitioners within a system of autonomous collective rights, toward a framework in which the link between knowledge and the rights of those who hold it as a community could be formally established. As this case suggests, alterity is recognized on its own terms only insofar as the available instruments permit, and not as far

as the recognized subjects might claim.

In Brazil and Argentina, traditional medicine has been inscribed within institutional arrangements structured primarily by a universalizing logic of rights that creates openings for the inclusion of difference without producing the conditions for alterity to operate as a self-sustaining political force.

In Brazil, the 1988 Constitution established health as a universal right, producing the institutional architecture of the Unified Health System and, within it, a logic of inclusion that tends to absorb difference as a variant of the universal rather than recognize it on its own terms. This is most visible in the institutional separation between two distinct policy trajectories. Complementary and alternative medicine—nationally designated as *práticas integrativas e complementares em saúde*—was institutionalized through a 2006 national policy and has since expanded to make Brazil the country with the largest number of institutionalized complementary and alternative medicines among WHO member states, incorporating globally circulating practices such as Ayurveda and acupuncture and 26 others through the universalist logic of access.

Indigenous health, by contrast, was constituted as a separate subsystem—SasiSUS, established in 1999—structurally centered on biomedical care adapted to Indigenous contexts, within which Indigenous therapeutic and diagnostic systems remain without formal recognition as constituent parts of the subsystem and without dedicated state support. This separation is not merely organizational. It reflects a configuration in which the most globally mobile therapeutic practices are absorbed into the universal right to health, while practices most directly tied to collective identity and territorial belonging are lateralized within it.<sup>31</sup>

Argentina's 1994 Constitution recognized the ethnic and cultural preexistence of Indigenous peoples and established collective rights as a foundational principle. The country has no specific framework concerning traditional medicine; instead, its regulatory architecture is limited to herbal medicine. The National Administration of Drugs,

Food and Medical Devices' 2015 phytotherapeutic regulation, strongly influenced by the European Medicines Agency framework, introduced the criterion of "long tradition of use" as the basis for herbal drug registration without clinical evidence, a formulation that reveals how the universalizing logic through which traditional knowledge enters the national regulatory field is shaped by evidentiary standards produced entirely outside the communities whose practices they purport to govern.<sup>32</sup>

Taken together, these cases suggest that the relationship between institutionalization and political agency is neither linear nor uniform. Where institutionalization was grounded in constitutional transformations that repositioned traditional peoples as collective subjects of rights, and where those peoples sustained organized forms of agency capable of shaping the terms of recognition, the encounter between traditional medicine and state frameworks produced configurations in which difference retained, at least partially, its capacity to operate as a living political force. Where institutionalization proceeded through the adoption of globally circulating regulatory frameworks, disconnected from collective rights instruments and from the political struggles that had produced them, recognition tended to operate as accommodation, extending institutional space to difference while constraining the conditions under which it could be claimed and sustained. What varies across these cases is not whether recognition occurs but the degree to which its terms remain open to contestation by those who bear it.

### The political imagination of legal subjects

The redemocratization processes that reshaped South American political life coincided with a significant expansion of international binding agreements that progressively extended the political horizon of citizenship. The near-simultaneous adherence of all countries examined here to the Convention on Biological Diversity throughout the 1990s, and to the Nagoya Protocol in the following

decades, consolidated within the regional juridical architecture concepts such as traditional knowledge, prior informed consent, community sovereignty over biological resources, and benefit-sharing arrangements. These concepts were not merely extensions of existing human rights frameworks but carried within them a different understanding of the subjects of rights, one more compatible with the non-Western cosmologies that modern legal tradition had historically rendered invisible.<sup>33</sup>

Several countries went further than environmental protection, constitutionalizing collective subjects as inseparable from the territorial and ecological relations in which they are embedded.<sup>34</sup> The political imagination behind this original formulation was one in which citizenship is grounded in ecological relations.<sup>35</sup> From this, the subject of rights is not abstracted from the territory that sustains it, and health cannot be governed as though detached from the conditions of collective life. Yet even where this imagination was constitutionalized with greatest depth, it remained bounded. The broader regulatory frameworks governing traditional medicine did not incorporate this body-territory nexus, and the constitutional vision did not migrate into the general regulatory architecture. What was recognized in one register was contained in another, granted a bounded institutional space that left the dominant ordering of the health system undisturbed.

Nothing in the available juridical architecture made this outcome necessary. The international instruments ratified during the same period—International Labour Organization (ILO) Convention 169 (1989), the Convention on Biological Diversity (1992), the Declaration on the Rights of Indigenous Peoples (2008), and the Nagoya Protocol (2010)—offered a juridical language through which the regulation of traditional medicine could have been coordinated with the territorial and ecological frameworks that the region's constitutions were simultaneously constructing. During the same decades in which South American countries were ratifying instruments that recognized collective subjects as sovereign over their biological resour-

es and traditional knowledge, WHO's traditional medicine agenda was consolidating in a direction that systematically bypassed these frameworks. Tellingly, ILO Convention 169 is absent from WHO programmatic documents on traditional medicine, and the Declaration on the Rights of Indigenous Peoples appears only marginally in the most recent WHO report.<sup>36</sup> Global health governance and the international legal instruments governing collective rights for traditional peoples developed in parallel, without sustained articulation, and this disjunction has reproduced itself regionally.

The Peruvian case documents this reproduction with particular precision, since it allows the disjunction to be traced as a historical process with a visible turning point. In 2008, the National Health Institute convened the First Forum on Research and Biotrading in Traditionally Used Medicinal and Food Plants, gathering the Ministry of Health, the Ministry of Commerce, the National Biocommerce Program, and the National Commission Against Biopiracy. The commission's representative grounded his intervention explicitly in the Convention on Biological Diversity, describing it as the instrument that had "changed the global paradigm" by recognizing state sovereignty over genetic resources and affirming that "traditional knowledge belongs to the peoples who developed it."<sup>37</sup>

What the consolidated regulatory framework retained from that encounter was the product, not the subject. The registration system distinguished between unprocessed plant materials, which could circulate without sanitary authorization provided they carried no therapeutic indication, and processed natural health products, which required registration and proof of pharmacological activity. For the latter, a 2000 decree introduced a further provision. Products lacking clinical studies could be commercialized bearing the label "traditionally used for," a formulation that translates traditional knowledge into a regulatory threshold, detached from any reference to the communities that hold it.<sup>38</sup>

In the following decades, the binding international instruments continued to deepen traditional peoples' rights in other domains of Peruvian state

action: the creation of the Intercultural Affairs Ministry in 2010, charged with promoting compliance with ILO Convention 169 and implementing the right to prior consultation, and the approval in 2026 of the National Policy for Indigenous and Native Peoples to 2040, structured around the Convention on Biological Diversity statements, tracing a trajectory of progressive recognition that has never reached the regulated pharmaceutical sector. The registration system has developed according to its own logic, insulated from the democratic innovations reshaping other areas of state recognition.

This pattern has not been confined to Peru. Across the region, the binding instruments that reshaped the juridical horizon of citizenship in other domains have left the regulated pharmaceutical sector structurally untouched—one grounding tradition in collective rights, the other converting it into a privately certifiable good. The result is not contradiction but compartmentalization, and it is in that compartmentalization that the political force of difference is most consistently contained.

## Recognition and its limits

South American citizenship pluralization also unfolds through disputes over the status, ownership, and circulation of knowledge. In this context, the regulation of traditional medicine becomes a key site where competing frameworks define what counts as "tradition" and which institutional actors are entitled to authorize its use.

The regulatory model governing traditional herbal products, first established by the European Medicines Agency and subsequently reinforced by WHO for its member states, introduced an alternative route for pharmaceutical registration in which "documented traditional use" substitutes for clinical evidence.<sup>39</sup> In this framework, "tradition" is no longer anchored in the communities that sustain it but in the temporal continuity of a practice as established through documentary records. The terminological displacement is telling: from "medicine" to "product," from collective knowledge to certifiable property, and from lived practice to doc-

umentary record, raising the prior question of who holds access to such archives and who is recognized as their legitimate author.<sup>40</sup> What disappears in this process is precisely what the binding international instruments sought to protect: the collective subject as sovereign over its own knowledge and the territorial relations that give that knowledge meaning.

In Brazil and Uruguay, this regulatory recodification operated more immediately, aligning national regulatory frameworks with the European model and dissociating the therapeutic product from the rights and recognition of the communities that generated it. Yet this alignment was not achieved without contestation. In Brazil, traditional peoples and their organizations sought throughout the first decade of the 21st century to articulate health regulation with the expanding citizenship that had been under construction since redemocratization, bringing that demand into institutional spaces of representation and political participation.<sup>41</sup> That coordination was never achieved. While traditional peoples and their organizations pressed for the inclusion of their demands within the regulatory framework, the national health surveillance authority moved in a parallel and contrary direction, deepening its alignment with international regulatory harmonization spaces, progressively constraining the regional particularities that those disputes sought to introduce.<sup>42</sup>

In countries where constitutional recognition of collective subjects went further, the operation is more complex. The Ecuadorian case illustrates this with particular clarity. Its plurinational constitutional framework, established in 2008, did not merely recognize cultural diversity within a pre-given state order; it subjected the foundations of that order to renegotiation. Yet even within such a framework, the regulatory architecture governing pharmaceuticals followed a more limited trajectory. The framework concerning herbal medicine aligned with the logic of industrially simplified registration based on documented traditional use, extending sanitary authorization to products whose therapeutic legitimacy rested on bibliographic records of local practices, requiring these medicines to be registered and commercialized under health

authority surveillance.<sup>43</sup> Even in earlier versions of this regulatory framework—more closely aligned with the international harmonization that consolidated around the standard established by the European Medicines Agency in 2004—rather than constructing a direct link between this registration system and the collective subjects who generated the knowledge it drew upon, the Ecuadorian state established itself as co-owner of any herbal medicine patent, entitled to receive the corresponding royalties.<sup>44</sup>

This provision was explicitly framed as a response to the threat of international biopiracy, consistent with Andean Community Decision 391, a regional instrument concerning access to genetic resources registered within the framework of the World Intellectual Property Organization. Yet in both cases, by positioning the state and market rather than the traditional peoples themselves as the effective holders of co-ownership rights, it constructs a chain of institutional mediations between the knowledge and its generators, enacting at the regulatory level the dynamic that marks citizenship pluralization across the region, where the admission of difference and the containment of its political force are one and the same operation.

What these cases reveal, taken together, is a specific mode of incorporating difference that liberal frameworks of recognition tend to obscure. Ghassan Hage has argued that multicultural recognition does not redistribute power but confirms it.<sup>45</sup> The subject who recognizes remains at the center, while the recognized is positioned at the periphery of a structure the recognizer controls. What is at stake is not whether recognition occurs but what kind of political subject it produces. Across the region, traditional medicine has been admitted into the institutional architecture of health governance, but on terms that fix the “traditional” in a given position rather than allowing its presence to reconfigure the conditions of its own recognition.<sup>46</sup> Citizenship has pluralized; the regulatory frameworks through which that pluralization has been institutionalized have not followed. What has expanded is not the capacity of traditional peoples to define the terms of their own participation but

the capacity of existing structures to accommodate their presence without being transformed by it.

## Conclusion

The institutionalization of traditional medicine in South America has unfolded at the intersection of two processes that do not move together: the expansion of citizenship to encompass collective difference, and the progressive codification of “tradition” into regulatory categories shaped by global health governance.

This paper has traced, across national frameworks and international institutions, not simply a gap between rights and regulation but the specific ways in which that codification reconfigures the terms under which difference can be expressed, claimed, and sustained.

The spectrum of configurations documented here—from normative architectures that attempt to preserve the relational conditions of traditional practices to frameworks in which “tradition” operates exclusively as a market authorization criterion—reveals that what is at stake is not the recognition of difference but the conditions under which difference can remain a living force within the broader political projects through which traditional peoples have sought to reshape the terms of citizenship in the region.

## References

1. M. A. T. Coelho and A. Krenak, “Genocídio e resgate dos ‘Botocudo’, São Paulo,” *Estudos Avançados* 23/65 (2009).
2. A. Sheps, “The Dispute over the Raposa Serra do Sol Reserve Demarcation: A Matter of Indigenous Constitutional Rights or National Sovereignty?,” *Anuario Mexicano de Derecho Internacional* 10 (2010).
3. R. Merino, “Reimagining the Nation-State: Indigenous Peoples and the Making of Plurinationalism in Latin America,” *Leiden Journal of International Law* 31/4 (2018).
4. M. Ashworth and E. Cloatre, “Enacting a Depoliticised Alterity: Law and Traditional Medicine at the World Health Organization,” *International Journal of Law in Context* 18/4 (2022).
5. E. Dagnino, “Sociedade civil, participação e cidadania: De que estamos falando?,” in D. Mato (ed), *Políticas de ciudadanía y sociedad civil en tiempos de globalización* (Universidad Central de Venezuela, 2004).
6. P. Wade, *Race and Ethnicity in Latin America*, 2nd edition (Pluto Press, 2010).
7. N. G. Postero, *Now We Are Citizens: Indigenous Politics in Postmulticultural Bolivia* (Stanford University Press, 2007).
8. World Health Organization, Eleventh Session EM/RC11/16, Regional Committee for the Eastern Mediterranean (1961).
9. World Health Organization, “Health Development in South-East Asia,” WHO Regional Publications, South-East Asia Series No. 7 (1978).
10. P. C. Carlessi, “Instituting Traditional Medicine: Changes to Identity and Legitimacy in Global Health,” *Social Theory and Health* 22/4 (2024).
11. *Ibid.*, p. 9.
12. H. Mahler, “Health for All by the Year 2000,” *World Health* (February–March 1981), <https://iris.who.int/server/api/core/bitstreams/b977d535-7a53-4d16-8f13-a86addc50f41/content>.
13. World Health Organization, *Traditional Medicine Strategy 2002–2005* (2002), p. 1.
14. *Ibid.*, p. 8.
15. World Health Organization, *WHO Global Report on Traditional and Complementary Medicine 2019* (2019); World Health Organization, *WHO Traditional Medicine Strategy 2014–2023* (2013).
16. M. Rong, “A Han vs. Minorities Dual Structure of Chinese Society,” *China: An International Journal* 11/2 (2013); A. Mazumdar, “India’s Soft Power Diplomacy Under the Modi Administration: Buddhism, Diaspora and Yoga,” *Asian Affairs* 49/3 (2018).
17. M. Cueto and S. Palmer, *Medicine and Public Health in Latin America: A History* (Cambridge University Press, 2014).
18. J. K. Cowan, “Culture and Rights After Culture and Rights,” *American Anthropologist* 108 (2006).
19. Pan American Health Organization, *Traditional, Complementary and Alternative Medicines and Therapies: Evaluation Plan of Work 2000–2001 and Plan of Work 2002–2003* (2002), <https://iris.paho.org/server/api/core/bitstreams/bdd305aa-ee8e-4b3f-906e-b88dfffb0d87/content>.
20. Pan American Health Organization, Development and Strengthening the Implementation of Local Health Systems: Resolution V; Health of Indigenous People (1993), <https://iris.paho.org/items/caoobe12-69f7-44d9-a221-odf468abcaod>.
21. Pan American Health Organization and World Health Organization, *Traditional, Complementary and Alternative Medicine and Therapies in the Americas: Policies, Plans and Programs* (2002).
22. B. M. Meier and A. S. Ayala, “The Pan American Health Organization and the Mainstreaming of Human Rights in Regional Health Governance,” *Journal of Law, Medicine and Ethics* 42/3 (2014); A. Perez-Brumer, D. Hill,

and R. Parker, "Latin America at the Margins? Implications of the Geographic and Epistemic Narrowing of 'Global Health,'" *Global Public Health* 19/1 (2024).

23. O. Feo Istúriz, C. Feo Acevedo, and P. Jiménez, "Pensamiento contrahegemónico en salud," *Revista Cubana de Salud Pública* 38/4 (2012).

24. D. J. Yashar, *Contesting Citizenship in Latin America: The Rise of Indigenous Movements and the Postliberal Challenge* (Cambridge University Press, 2005).

25. Ministry of Health (Ecuador), *Código de ética de los hombres y mujeres de sabiduría de la medicina ancestral-tradicional de las nacionalidades y pueblos del Ecuador: Nuestra manera de pensar, sentir, conocer y hacer medicina* (2021).

26. E. V. de Castro, "Exchanging Perspectives: The Transformation of Objects into Subjects in Amerindian Ontologies," *Common Knowledge* 10/3 (2004).

27. Ministry of Health (Bolivia), *Plan estratégico institucional 2016–2020* (2017).

28. G. E. Morales, *Decolonizing Medicine: Indigenous Politics and the Practice of Care in Bolivia* (Stanford University Press, 2025).

29. Ministry of Health (Colombia), Resolución 5078: Por la cual se adoptan normas técnico-administrativas en materia de medicinas tradicionales y terapéuticas alternativas y se crea el Consejo Asesor para la conservación y el desarrollo de las mismas (1992), pp. 1–3.

30. Ministry of Culture (Colombia), Resolución 1077: Por la cual se incluye la manifestación "saberes asociados a la partería afro del Pacífico" en la Lista Representativa de Patrimonio Cultural Inmaterial del ámbito nacional (2017), [https://normograma.mincultura.gov.co/compilacion/docs/resolucion\\_mincultura\\_1077\\_2017.htm](https://normograma.mincultura.gov.co/compilacion/docs/resolucion_mincultura_1077_2017.htm).

31. E. J. Langdon and L. Garnelo, "Articulation Between Health Services and 'Indigenous Medicine': Anthropological Reflections on Policies and Reality in Brazil," *Salud Colectiva* 13 (2017).

32. National Administration of Drugs, Food and Medical Devices (Argentina), Disposición 5418/2015: Drogas vegetales (2015), <https://www.argentina.gob.ar/normativa/nacional/disposici%C3%B3n-5418-2015-249127/texto>.

33. A. Escobar, "Whose Knowledge, Whose Nature? Biodiversity, Conservation, and the Political Ecology of Social Movements," *Journal of Political Ecology* 5/1 (1998).

34. C. G. Barié, *Pueblos Indígenas y derechos constitucionales en América Latina: Un panorama*, 2nd edition (Instituto Indigenista Interamericano, Comisión Nacional para el Desarrollo de los Pueblos Indígenas y Editorial Abya-Yala, 2003).

35. M. C. Garrido and A. M. Alarcón, "The Commoditization of Ecosystems Within Chile's Mapuche Territory: A Violation of the Human Right to Health," *Health and Human Rights* 25/1 (2023).

36. World Health Organization, *Global Traditional Med-*

*icine Strategy 2025–2034* (2025).

37. National Institute of Health (Peru), *I Foro: Investigación y biocomercio en plantas medicinales y alimenticias de uso tradicional en el Perú* (2010), <https://repositorio.ins.gob.pe/bitstream/handle/20.500.14196/172/CENSI-0001.pdf>, p. 46.

38. Ministry of Health (Peru), Decreto supremo 004-2000-SA: Modifican el reglamento para el registro, control y vigilancia sanitaria de productos farmacéuticos y afines (2000).

39. European Parliament, Directive 2004/24/EC Amending, as Regards Traditional Herbal Medicinal Products, Directive 2001/83/EC on the Community Code Relating to Medicinal Products for Human Use (2004).

40. M. Strathern, M. Carneiro da Cunha, P. Descola, et al., "Exploitable Knowledge Belongs to the Creators of It: A Debate," *Social Anthropology* 6 (1998).

41. P. Carlessi and J. R. Ayres, "Neo-Traditional Medicines: Ethnographic Contributions to Conceptual Definition," *Canadian Bulletin of Medical History* 38/S1 (2021).

42. A. C. B. Carvalho, J. P. S. Perfeito, W. B. Vidal Filho, and D. Silveira, "A Decade Retrospective and Future Prospects: How European Regulatory Alignment Shapes Brazil's Herbal Medicine Market," *Journal of Ethnopharmacology* 353 (2025).

43. National Agency for Sanitary Regulation, Control and Surveillance (Ecuador), Resolución ARCSA-DE-023-2016-YMIH: Normativa técnica sanitaria sustitutiva para la obtención del registro sanitario y control de productos naturales procesados de uso medicinal (2016), [https://www.gob.ec/sites/default/files/regulations/2018-11/Documento\\_ARCSA-DE-023-2016-YMIH\\_normativa-tecnica-sanitaria-sustitutiva-obtencion-registro-sanitario-control-productos-naturales-procesados-de-uso-medicinal.pdf](https://www.gob.ec/sites/default/files/regulations/2018-11/Documento_ARCSA-DE-023-2016-YMIH_normativa-tecnica-sanitaria-sustitutiva-obtencion-registro-sanitario-control-productos-naturales-procesados-de-uso-medicinal.pdf).

44. Ministry of Public Health (Ecuador), Acuerdo Ministerial 244: Reglamento y control de productos naturales de uso medicinal (2006), <https://www.controlsanitario.gob.ec/wp-content/uploads/downloads/2014/07/Reglamento-y-Control-de-Productos-Naturales-de-Uso-Medicinal-Decreto-Ejecutivo-1395.pdf>.

45. G. Hage, *Alter-Politics: Critical Anthropology and the Radical Imagination* (Melbourne University Publishing, 2015).

46. G. Boccara and P. Ayala, "Patrimonializar al indígena: Imaginación del multiculturalismo neoliberal en Chile," *Cahiers des Amériques Latines* 67/1 (2011).

# Political Contestation of the Right to Health in the United States: Eighty Years of Conservative Opposition to Health and Human Rights

BENJAMIN MASON MEIER AND DARBY MCBRIDE

## Abstract

The United States stands apart from other nations in opposing the right to health under international law, with longstanding conservative opposition to a human right to health holding back policy efforts to realize health care and underlying determinants of health—at home and throughout the world. Over the past 80 years, American conservative ideology has presented persistent political obstacles to the advancement of health as a human right, challenging who is entitled to rights and what those rights entail. This ideological opposition has reframed health as a narrow privilege for some rather than an expansive right for all. Examining the historical evolution of the right to health since the end of World War II, this paper analyzes how shifting conservative opposition over the years has undermined human rights in health policy and culminated in existential challenges for health systems. The paper concludes that the guarantee of health as a human right must be codified as a defining principle of American democracy, enshrining constitutive commitments to health as a foundation for a healthier future under law.

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## Introduction

The advancement of health as a human right has long been challenged in the United States by conservative ideologies, which have sought to limit the right to health in domestic policy and global governance. While the justifications for this opposition have shifted over time and across political parties—alternatively grounded in individualism, neoliberalism, and nationalism—US conservative opposition has persisted through the years, presenting recurring obstacles to the development and implementation of the right to health. This enduring ideological opposition to the right to health in US policy has expanded in scope and impact with the rise of right-wing populist nationalism, as the US government is now taking rapid steps to limit health and human rights in domestic and global health policy, presenting an existential challenge to the foundational notion of health as a human right. To understand these current retrogressive measures, it is imperative to examine historical American opposition to the right to health, with past failures to progressively realize human rights in health policy offering lessons to shape future advocacy to ensure health as a human right.

The right to health encompasses interconnected freedoms and entitlements that support the realization of health care and underlying determinants of health. These government responsibilities for health have come to be codified under international law, shifting the public health debate from political aspiration to binding obligation. Through the evolving development of the right to health under international law, the US government has worked with other states under the United Nations (UN) to establish a common global vision for public health. Yet, in stark contrast to the progressive trajectory of other high-income nations, this US advancement of the right to health has faced continuing conservative opposition over *who* is entitled to rights and *what* rights should be upheld by the state—with this opposition framing health as a privilege of wealth rather than a fundamental right for all. Such ideological opposition has repeatedly limited health advancements in US policy, reflecting an American interpretation of human rights

that has constrained the notion of health as a universal human right and an essential government responsibility. This selective US conceptualization of rights holders and state obligations in health has shaped conservative opposition over the past 80 years, with past obstacles to the right to health now presenting new challenges: for the US public health system, in foreign health assistance, and through global health governance.

This paper analyzes the long evolution of the right to health in US policy, examining the persistent opposition of American conservative ideology that has laid the foundation for the current US abandonment of human rights in domestic and global health policy. Beginning in the aftermath of World War II, the first section frames early US efforts to establish human rights and public health as central to a new international order. However, in contrast with the health policy trajectory in other high-income nations, this postwar vision for health and human rights faced early challenges from American conservatives, with the second section detailing this opposition amid Cold War tensions. The third section examines the increasing politicization of health in the United States, beginning in the 1980s amid a surge of Republican Party support for neoliberal economic policies and conservative religious ideologies and giving rise to new Republican attacks on Democratic health initiatives and global health governance. The 21st century reshaped this Republican attack on the right to health, with the fourth section investigating how the securitization of health amid the US “War on Terror” reframed global health engagement as either a security imperative or religious charity.

Despite an unprecedented expansion of domestic health care access under the 2010 Affordable Care Act, this Democratic effort to progressively realize access to health coverage reignited sweeping Republican attacks on health policy, leading into the 2016 election of President Trump. The fifth section traces the populist policies of the first Trump administration, considering the lasting implications of the US rejection of the right to health amid the COVID-19 response. Despite subsequent efforts to address determinants of health under the Biden

administration, President Trump would return to office following the 2024 election, with this right-wing populist governance now threatening public health science, human rights protections, and global health institutions. These ongoing populist attacks on health and human rights, a culmination of past conservative opposition, will outlast this administration. In responding to these longstanding political obstacles to the right to health, threatening universal rights and health entitlements, this paper concludes that ideological constraints on the right to health will endure in US conservatism until health is reconceptualized under US law as a fundamental human right and a central foundation of American democracy.

### Roosevelt's dream of health for all as a human right

The initial conceptualization of a right to health under international law arose in the context of World War II, as the United States positioned itself in the allied fight against tyrannical governments as a beacon for the advancement of individual freedoms, international institutions, and health protections.<sup>1</sup> However, postwar efforts to codify health and human rights were stymied by conservative attacks on health-related human rights and opposition to universal health care systems.

#### *From “four freedoms” to human rights*

Even before the United States entered World War II, US President Franklin Delano Roosevelt proclaimed to the world in January 1941 that the postwar era would be founded on four “essential human freedoms”: freedom of speech, freedom of religion, freedom from fear, and freedom from want.<sup>2</sup> The last of these “Four Freedoms”—freedom from want—heralded a state obligation to provide for the health of its peoples. As the Great Depression and ensuing World War transformed the United States, Roosevelt cited this “freedom from want” as central to a “Second Bill of Rights,” looking to uphold economic and social rights as central to a “New Deal” under US law, with the understanding that “a necessitous man is not a free

man.”<sup>3</sup> Roosevelt intended this Second Bill of Rights to serve as a constitutive commitment—rather than a constitutional amendment—embedding new responsibilities into American institutions and values.<sup>4</sup> While proclaiming such values as universal, extending across all nations, Roosevelt sought to ensure these rights in the United States, calling on Congress in his 1944 State of the Union address to enshrine “the right to adequate medical care and the opportunity to achieve and enjoy good health.”<sup>5</sup> Drawing from this conceptualization of social and economic guarantees, the United States worked with allied nations to establish human rights as a foundation of global governance.<sup>6</sup>

#### *Developing human rights to advance health*

The Charter of the United Nations—signed by nations in June 1945, just after the passing of President Roosevelt—would be the first international treaty to codify human rights, with human rights serving as one of the central pillars of UN governance.<sup>7</sup> Framing health among these human rights, states sought to develop a specialized health agency under the UN. The United States would host the final International Health Conference to establish this new UN health agency, with US President Harry Truman echoing Roosevelt and imploring representatives in his opening message to see health as a right:

*The right to adequate medical care and the opportunity to achieve and enjoy good health should be available to all people. For this objective I can assure you is in the interest and the support of the United States.*<sup>8</sup>

Through the unprecedented declaration that “the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being,” the July 1946 Constitution of the World Health Organization established the mandate of the World Health Organization (WHO) as the “directing and coordinating authority on international health work.”<sup>9</sup> The founding states of WHO envisioned an expansive role for human rights in realizing “a state of complete physical, mental and social well-being and not merely the

absence of disease of infirmity.”<sup>10</sup>

In advancing these rights through the UN, former US First Lady Eleanor Roosevelt was instrumental in shaping the postwar human rights framework through the 1948 Universal Declaration of Human Rights (UDHR). Following the death of her husband, President Truman appointed Eleanor Roosevelt as a delegate to the newly established UN, where she was elected chair of the Human Rights Commission in 1946—and came to be known as the “First Lady of the World.”<sup>11</sup> Roosevelt led delegates in developing the UDHR, which framed a human right to “a standard of living” adequate for health, encompassing both a right to medical care and underlying determinants of health.<sup>12</sup>

However, Roosevelt’s rights-based vision was not embraced throughout the US government.<sup>13</sup> Conservative politicians across political parties opposed efforts to expand international human rights law beyond civil and political rights, as the comprehensive vision of rights in the UDHR was seen as a threat to US institutions of racial segregation and a ploy for the international advancement of communist ideals.<sup>14</sup> These conservative critics attacked Roosevelt as a “menace to liberty” and an “un-American communist,” and the electoral

impact of these attacks shifted US policies in ways that limited the realization of the right to health.<sup>15</sup>

### *Abandoning universal health care*

Even as President Truman became the first US president to propose a comprehensive national health plan—outlining in 1945 a five-point program to advance medical education, health insurance, and public health services—this effort to realize universal health care for all Americans was abandoned amid rising conservative opposition. Nations across the Western world were rapidly rebuilding from the destruction of World War II through the development of national health systems, as seen in the British establishment of the National Health Service to provide free care to all “ordinarily residents” (British citizens and permanent residents, with specific provisions for visitors, refugees, and asylum seekers).<sup>16</sup> However, without US congressional support for universal guarantees of health, the United States instead pursued incremental efforts to expand segregated health care systems through the 1946 Hospital Survey and Construction Act, funding hospitals in underserved communities in exchange for the provision of free emergency care.<sup>17</sup> With the US Congress shifting to Republican con-

FIGURE 1. Eleanor Roosevelt at the Third Session of UN Human Rights Commission in 1948 (Franklin D. Roosevelt Presidential Library and Museum)



trol in the 1946 midterm elections, breaking up the “New Deal coalition” that sought to protect social security for the working classes over the previous decade, the United States abandoned comprehensive health insurance efforts similar to those of postwar European nations.<sup>18</sup> This solidifying conservative opposition to universal health care found support from medical practitioners in the American Medical Association, which feared a loss of physician profits under “fee-for-service” care.<sup>19</sup>

The American Medical Association developed nationwide campaigns against universal health care, equating health insurance subsidies and government health insurance with “socialized medicine.” This coordinated conservative opposition undermined health reform efforts and challenged the right to health at home and abroad.<sup>20</sup>

### Conservative opposition to “socialized medicine”

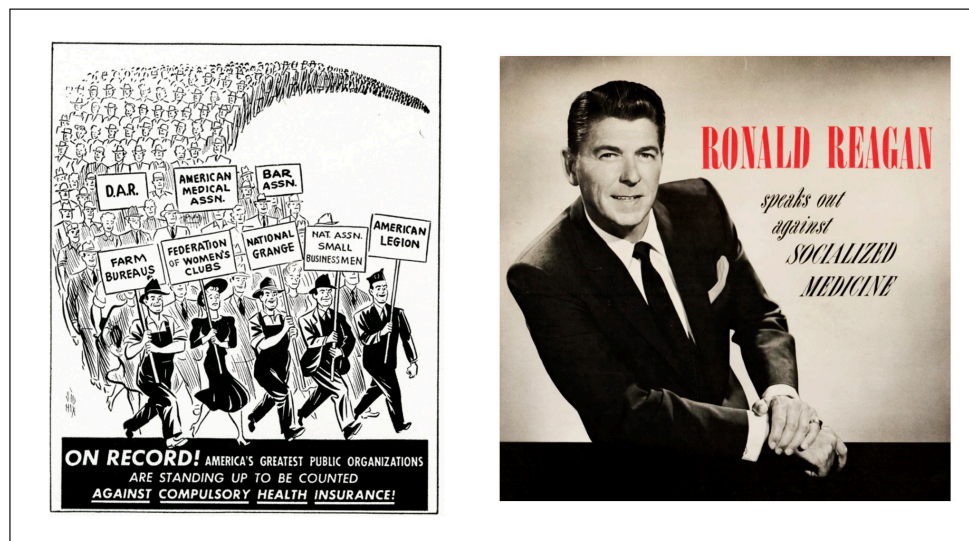
Attacks against “socialized medicine” became a hallmark of US health policy. Undercutting the UDHR’s promise of universal human rights, the international development of health-related rights would be challenged by Cold War divisions between Western capitalist democracies and Soviet

communist regimes, with the US government looking to prevent the rise of “health rights” as a basis to contain the spread of communism.<sup>21</sup> Following the 1952 election of Republican President Dwight D. Eisenhower, the United States withdrew from the development of international human rights treaties, abandoning UN cooperation to codify international standards in order to prioritize ideological conflict amid the Cold War.<sup>22</sup> These Cold War divisions impacted both the conceptualization of the right to health under international law and the implementation of human rights in US health policy.<sup>23</sup>

### *Cold War politics*

Soviet criticism of US health inequalities fueled conservative challenges to the very idea of health as a universal entitlement to be progressively realized through government action. Questioning whether health was a genuine human right or merely a political aspiration, the United States pushed for the codification of international legal obligations only for civil and political rights, individual freedoms from government intrusion that were long protected by the US Constitution.<sup>24</sup> This US rejection of health-related rights contributed to the temporary withdrawal of Soviet states from WHO, with the

FIGURE 2. American Medical Association political cartoon (Sid Hix, 1949) and record jacket for a radio announcement opposing universal health care (American Medical Association, 1961)



Soviet Union arguing in February 1949 that its withdrawal was forced by WHO's lack of focus on the underlying economic and social determinants of health.<sup>25</sup> Without Soviet engagement, international efforts to address social determinants of health would have no voice in World Health Assembly debates, shifting WHO toward disease eradication initiatives and limiting efforts to examine public health under a rights-based framework.<sup>26</sup>

Even as Soviet states returned to WHO, the United States sought to contain the influence of communist (so-called “red”) health initiatives—through both bilateral assistance to advance public health and multilateral influence to limit the right to health. With the United States pursuing bilateral health assistance to undermine the influence of “communist health initiatives,” Democratic President John F. Kennedy's establishment of the United States Agency for International Development (USAID) in 1961 galvanized US foreign assistance for public health in low-income nations.<sup>27</sup> However, the rise of USAID was met by conservative opposition, as conservatives in Congress rapidly called for a “retrenchment in aid,” framing USAID as a waste of taxpayer resources to “placate ungrateful nations.”<sup>28</sup> Facing political opposition at home to advancing health abroad, the United States

pushed WHO to abandon UN negotiations to codify the right to health under international law. Such US opposition to expansive Soviet proposals resulted in a constrained individual right to the “highest attainable standard of health” under the 1966 International Covenant on Economic, Social and Cultural Rights.<sup>29</sup> Challenged by US political pressure, WHO's repeated proclamations of the “non-political” nature of public health and its attempts to avoid political debates on human rights limited multilateral efforts to achieve universal health care throughout the world.<sup>30</sup>

### *Opposition to universal health care*

By the mid-1960s, worldwide attention was again focused on health inequalities as a violation of human rights. The fight for human rights in the United States became intertwined with the struggle for racial equality, with Black Americans systematically denied a wide range of rights, including social and economic rights to education, housing, and health.<sup>31</sup> Seeking to address rising inequities through health care reforms, Democratic Presidents Kennedy and then Lyndon B. Johnson made universal health care a political priority in US policy.<sup>32</sup> Conservative members of Congress, however, sought to limit these universal care initiatives,

FIGURE 3. Maintenance staff clean graffiti from the outside of the WHO Regional Office for the Americas, the Pan American Health Organization, Washington, DC (Associated Press, 1961)



condemning efforts to establish a “welfare state” as the first step in the spread of communism to all aspects of life and reducing the health policy debate from public health to medical coverage.<sup>33</sup> This opposition, often couched in implicitly racist terms, led President Johnson to abandon universal health care reforms and focus instead on narrower health programs for specific vulnerable populations, with interconnected 1965 legislation providing for the rights of the elderly through Medicare and the rights of the impoverished through Medicaid.<sup>34</sup> The American Medical Association supported this proposed government medical assistance for the elderly but actively opposed any expansion of assistance to other populations, framing efforts to ensure health care for all as compromising the control of physicians and insurance companies in setting fees.<sup>35</sup> While the final creation of Medicaid provided federal funding to state governments to facilitate medical coverage for impoverished Americans, compromises in congressional negotiations resulted in inadequate financing for care and state discretion on coverage, allowing health inequities and racial discrimination to persist.<sup>36</sup>

These divisive conservative attacks on health equity initiatives, pushing Southern white voters toward the Republican Party and leading to the narrow 1968 election of Republican President Richard Nixon, would frustrate efforts to expand welfare guarantees under the US Constitution, as US health care reform debates shifted toward the expansion of private health insurance.<sup>37</sup> As domestic health policy became stymied by partisan divisions, these conservative attacks extended globally, with American conservatives turning against international health policy developments under WHO governance.<sup>38</sup>

### *A “new international health order”*

Following the election of a new WHO Director-General in 1973, the WHO Secretariat looked to human rights to advance public health for impoverished populations throughout the world. WHO sought to navigate tensions between the Cold War superpowers while also addressing the concerns of “developing countries,” as these long marginalized

states came together to restructure international development cooperation in the pursuit of a “new international economic order.”<sup>39</sup> With these developing countries voting together in the World Health Assembly to advance health as a universal human right, the WHO leadership held out human rights as central to a political campaign for public health, extolling international legal obligations as a clarion call for the realization of primary health care. This renewed rights-based vision for health would shape WHO’s 1978 International Conference on Primary Health Care, in Alma-Ata, USSR. Drawing from the united advocacy of low- and middle-income countries, the resulting Declaration of Alma-Ata detailed a multisectoral imperative to address underlying determinants of public health, delineating government obligations to promote health as a human right.<sup>40</sup>

WHO leaders saw this moment as the “onset of the health revolution,” with scholars examining the Declaration of Alma-Ata as heralding a “new international health order.”<sup>41</sup> This new order for international health found early support in a renewed US commitment to human rights and global governance, with Democratic President Jimmy Carter inaugurating his presidency in 1977 under the commitment to “guarantee the basic right of every human being to be free from poverty and hunger and disease and political oppression.”<sup>42</sup> While the Carter administration continued to advance the right to health under WHO, amid broader US support for economic and social rights in the late 1970s, the 1980 election of Republican President Ronald Reagan—and with it, renewed conservative opposition to WHO’s regulatory activities—closed any opportunity to implement the Declaration of Alma-Ata and realize primary health care throughout the world.<sup>43</sup>

### Republican attacks against public health and “global” health

The Reagan administration saw the ascendance of the “New Right” in the Republican Party, which brought together two opposing ideological tenets of conservatism: “neoliberalism,” an economic con-

servatism that sought freedom from government intervention, and “moralism,” a social conservatism that advanced government authority to further traditional moral and social values.<sup>44</sup> These contradictory conservative ideals led to inconsistencies across health policy, as US policies simultaneously liberalized the market for privatized health services and imposed right-wing religious ideologies to attack sexual and reproductive rights and LGBTQ+ populations.

### *Challenging WHO governance and US welfare policy*

As health care became increasingly privatized under the neoliberal economic model—prioritizing free market liberalization with minimal government intervention—the Reagan administration presented new obstacles to health, treating health services as a transactional commodity rather than a fundamental right. This economic model for health, advanced forcefully by the Heritage Foundation, a conservative nongovernmental think-tank, was integrated across the US health system, as corporations gained greater control over health determinants and the government stepped back from public health, disregarding structural

barriers to health for marginalized populations.<sup>45</sup> Although these policy shifts purported to promote economic efficiency, the subordination of human rights to market forces served to undermine primary health care, developing-nation health systems, and WHO governance.<sup>46</sup>

Impacting health throughout the world, the Reagan administration first pushed back against WHO regulation of commercial determinants of health, with the United States standing alone in opposition to the 1981 WHO International Code of Marketing of Breastmilk Substitutes, which aimed to regulate transnational formula corporations in order to prevent infant death.<sup>47</sup> Thereafter cutting back US financial support for WHO, the Reagan administration threatened the stability of WHO financing, criticizing the organization for its alleged limitations of free markets and shifting US financial commitments away from general budget support and toward targeted funding for US priorities.<sup>48</sup>

In applying this neoliberal model to the US health system, the “Reagan Revolution” sought the privatization and decentralization of government health programs: the US Department of Health and Human Services faced large budget cuts, the federal government provided grants directly to states for

FIGURE 4. Democratic US Senator Edward Kennedy with WHO Director-General Halfdan Mahler, Alma-Ata, USSR (World Health Organization, 1978)



health programming, and Medicare and Medicaid eligibility were sharply reduced.<sup>49</sup> These neoliberal cost-cutting measures shrank the federal government's share of the nation's health budget, cutting Medicaid by more than 10% and welfare spending by more than 17%, at the expense of rights-based conceptions of health, with the government singling out specific groups as "unworthy" of health entitlements.<sup>50</sup> The Reagan administration often justified these cuts to the "welfare state" in racialized terms, repeatedly demonizing impoverished Black women as "welfare queens" who were seeking to abuse the welfare system and take from "hardworking Americans."<sup>51</sup> Framing poverty as a personal moral failure rather than a foundational government responsibility, the administration narrowed the definition of health to focus only on medical care, increased barriers for impoverished Americans, and disregarded underlying determinants of health.

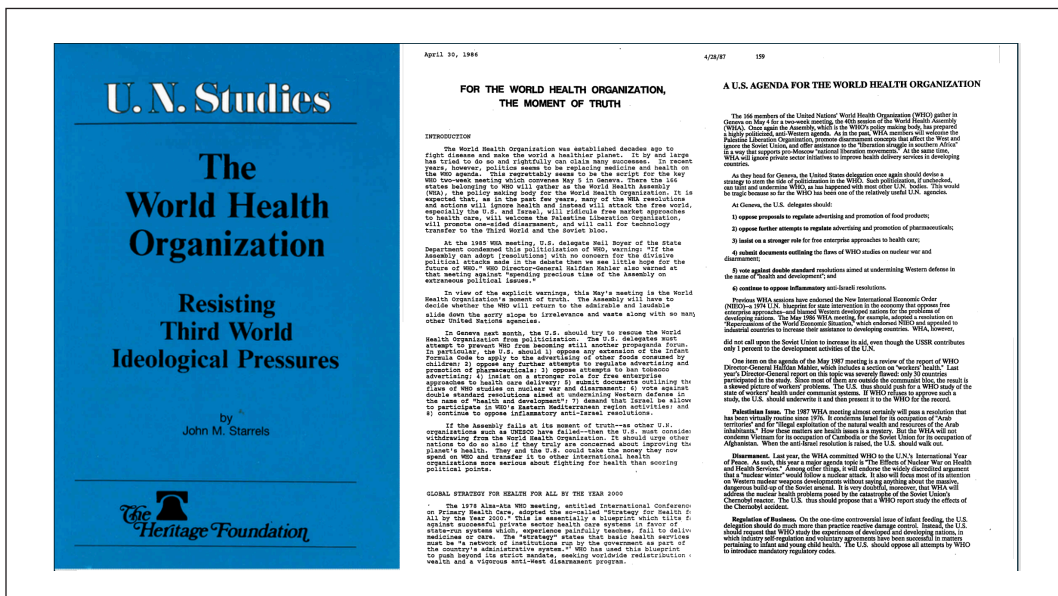
looked to conservative social values to attack sexual and reproductive rights, seeking to constrain the expansion of women's rights and reimpose traditional gender roles. Invoking conservative religious ideologies that opposed gender equality, contraception, and abortion, the administration abandoned domestic family planning programs and raised new obstacles to abortion access.<sup>52</sup> Such attacks on reproductive rights, responding to the 1973 US Supreme Court decision in *Roe v. Wade* and supported by a "moral majority" movement, were seen as central to a larger social conservative battle to protect the traditional, heterosexual "nuclear family" and preserve the patriarchal, male-dominated familial dynamic.<sup>53</sup> This politicization of women's rights impacted health throughout the world, as the United States sought to block foreign assistance to any organization that performed, promoted, or discussed abortions in any country. Announcing this policy shift at the 1984 International Conference on Population in Mexico City, the so-called Mexico City Policy (or Global Gag Rule) constrained family planning programs throughout the world and expanded the administration's attacks on reproductive rights globally.<sup>54</sup>

With these attacks extending to sexual rights,

### Religious attacks on sexual and reproductive rights

These limitations on health extended to reproduction and sexuality, as the Reagan administration

FIGURE 5. Heritage Foundation studies from 1985, 1986, and 1987 seeking to reshape US engagement with WHO governance (Heritage Foundation)



the Reagan administration's inaction in the early days of the HIV/AIDS response reflected an explicit rejection of the rights of gay, bisexual, and transgender populations that were disproportionately impacted by the disease.<sup>55</sup> The administration saw these populations as morally "sinful" and, through this right-wing religious lens, rejected the equal dignity and rights of affected populations—stigmatizing vulnerable communities, denying timely information, and neglecting the right to health.<sup>56</sup> Six years after the first cases were identified, WHO was rallying the world to develop a rights-based Global Strategy for the Prevention and Control of AIDS, but—with more than 20,000 Americans already dead—President Reagan still had not publicly said the word "AIDS."<sup>57</sup> Despite repeated pleas from affected populations asserting a human right to government support, the administration continued to attribute the disease to a "gay lifestyle," denying necessary research, care, and support amid the rapid rise of a pandemic threat.<sup>58</sup> This targeted health neglect at home was extended by neoliberal development policies that exacerbated health inequities globally.

### *Neoliberal health reforms amid structural adjustment programs*

Shifts under the Reagan administration furthered the "neoliberal era" in economic development policy, as US-led international financial institutions exacerbated health disparities within and between countries. This "Washington Consensus" of neoliberal policies—seeking to liberalize the economies of developing countries through deregulation, marketization, privatization, and decentralization—decimated fragile health and social infrastructures throughout the world.<sup>59</sup> Pushing these neoliberal reforms on fragile governments in return for loan-based debt assistance, the International Monetary Fund demanded that low-income countries adopt "structural adjustments" that rapidly reduced government expenditures, scaling back the public health systems necessary to respond to rising health burdens. These market-oriented conservative policy reforms, undertaken to service debt without regard for human rights, limited government action to

ensure basic needs.<sup>60</sup> Under such "structural adjustment programs," the International Monetary Fund was able to "demand cuts in government expenditure, including axing or abolishing programmes for education, health, housing and public sector development, like sewage disposal and public housing."<sup>61</sup> Even as these programs failed to stoke economic growth, the dramatic scaling back of government commitments to uphold public health left in its wake weakened national public health infrastructures unable to bear the burden of rising health challenges.<sup>62</sup>

The end of the Cold War at the start of the 1990s, followed by the election of Democratic President Bill Clinton in 1992, offered the promise of ending US opposition to human rights in global health. Declaring a new post-Cold War consensus on human rights, delegates at the 1993 World Conference on Human Rights sought to bridge the divide between civil and political rights and economic, social, and cultural rights. The resulting Vienna Declaration and Programme of Action declared that all human rights are "universal, indivisible and interdependent and interrelated" and should be treated "on the same footing, and with the same emphasis."<sup>63</sup> The Clinton administration, seeking to establish a "Third Way" movement at the center of the political spectrum, looked in this moment of sweeping global change to renew US leadership in multilateral health governance: playing a leading role in advancing the HIV/AIDS response through the 1994 creation of the Joint United Nations Programme on HIV/AIDS (UNAIDS); spearheading the UN's Fourth World Conference on Women in 1995 and strengthening the United Nations Population Fund (UNFPA); and supporting a united international front against climate change through the 1997 Kyoto Protocol.<sup>64</sup>

Yet despite this renewed leadership and financial support, the conservative legacy of the neoliberal approach to health persisted across US political parties. When the Clinton administration sought to reform health care at home, it proposed only an incremental, market-oriented approach to universal care, prioritizing efficiencies in private health insurance coverage while conspicuously avoiding the language of human rights.<sup>65</sup> As Republican lawmakers and interest groups scaled back their support for

the individual elements of this reform package, the comprehensive bill failed, and in the wake of this failure, Congress passed the 1997 State Children's Health Insurance Program to provide health coverage to uninsured children whose family income was too high to qualify for Medicaid.<sup>66</sup> Throughout the world, the US government continued to address health as a means to economic development rather than as a right—an end unto itself. This neoliberal “health for growth” model elevated health, nutrition, and population funding under the World Bank while strengthening pharmaceutical patent protections under the World Trade Organization.<sup>67</sup> As authority in global health governance continued to shift from WHO to international financial institutions, the WHO Secretariat sought to reorient itself—from the unquestioned leader to a necessary coordinator in a crowded global health governance landscape.<sup>68</sup>

### Global health security: “Compassionate conservatism” abandoned

Amid this leadership vacuum in global health governance, the global health architecture in the 21st century shifted toward greater US hegemony in global health policy, with commentators increasingly noting that “the US domestic agenda is

driving the global agenda” in health.<sup>69</sup> Terrorist attacks against the United States realigned this rising US engagement in global health, refocusing public health through the lens of national security even as Republican President George W. Bush sought to expand lifesaving treatments abroad as a religious imperative. Yet despite this increasing Republican attention to global health, subsequent Democratic Party efforts to expand health care access in the United States would be attacked relentlessly by conservatives as a “threat to freedom,” giving rise to a new anti-government populist movement that opposed the right to health and prevailed in the 2016 US elections.

### *Terrorist attacks and the securitization of public health*

The attacks of September 11, 2001, redefined US interests in public health, as Al-Qaeda terrorist attacks against the United States (alongside a bio-terrorist “anthrax scare” in the days that followed) upended global health engagement under the Bush Administration, reframing public health as a national security imperative.<sup>70</sup> Although President George W. Bush had presented his administration as the foundation of a new “compassionate conservatism,” advancing social conservative values

FIGURE 6. US First Lady Hillary Clinton addresses delegates at the 1995 World Conference on Women in Beijing (Sharon Farmer, Clinton Presidential Library)



alongside government assistance to those in need, these attacks reshaped foreign policy amid a self-declared “War on Terror,” in which public health was redefined to address the fear of bioterrorism and disease “invasion.”<sup>71</sup> The Bush administration rapidly responded to this rising fear by developing the Model State Emergency Health Powers Act, a federal template for state public health law reforms, which was seen to prioritize the state’s police powers to protect “health security” at the expense of individual autonomy, civil liberties, and human rights.<sup>72</sup> The resulting state public health policy debates under this model act demonized immigrants and minority populations—especially Arab and Middle Eastern populations—as Islamic terrorist sympathizers, carriers of disease, and national security threats.<sup>73</sup> The War on Terror would lead to widespread violations of human rights at home and abroad, as the securitization of health was seen to require human rights limitations to protect public health, even as the United States sought to reshape foreign assistance through an unprecedented bipartisan commitment to HIV treatment.

#### *A religious imperative for HIV treatment*

The Bush administration remained eager to advance global health as a religious imperative, but

it was unwilling to delegate substantive health authority to international organizations.<sup>74</sup> Moving away from international institutions as mechanisms for distributing lifesaving treatments, the United States bypassed these multilateral organizations in pursuing an ambitious expansion of its foreign health assistance, increasingly making US bilateral assistance a singular force in global health governance. As the G8 established the Global Fund to Fight AIDS, Tuberculosis and Malaria in 2001, the US government was rapidly moving to create new health institutions outside of the UN system, over which it would have greater control.<sup>75</sup> This bilateral approach to humanitarian assistance found bipartisan support in 2003 through the President’s Emergency Plan for AIDS Relief (PEPFAR), which would become a principal mechanism of US global health funding.

The launch of PEPFAR represented an unprecedented Republican commitment to scaling up programs for the care and treatment of HIV. Although PEPFAR was not presented as a basis to realize the right to health, bipartisan support for this initiative increased US government spending on a scale that rivaled any other American effort in global health, serving as the largest commitment by any nation to fight a single disease.<sup>76</sup>

FIGURE 7. President Bush shakes hands with then-Senator Joseph Biden following the PEPFAR reauthorization (Getty, 2008)



### *The Democratic dream of universal health care gives rise to right-wing populism*

The election of President Barack Obama presented the opportunity to achieve a longstanding Democratic Party goal: universal health care for all Americans. Revitalizing debates on the “moral commitment” of government to secure the health of every American, the 2010 Patient Protection and Affordable Care Act (ACA) advanced the realization of health as a human right, marking the most expansive reform of the US health care system in decades.<sup>77</sup> Yet while the ACA offered an unprecedented expansion of access to health care services, drawing from progressive rights-based health reforms across US states, it did not stray from the neoliberal market-based approach, working through private health insurance systems to expand access to health coverage.<sup>78</sup> Despite this market-based approach, with roots in past Republican proposals, the Republican Party nevertheless attacked the “Obamacare” legislation as a threat to freedom and a violation of the US Constitution.<sup>79</sup> Even though the Obama administration intentionally avoided justifying its policy reforms through a commitment to rights and freedoms, never invoking human rights to frame congressional debates, the ACA reflected a comprehensive effort to rein in insurance costs and improve equitable health outcomes, bringing the United States closer to other nations in realizing a right to health care.<sup>80</sup>

Following the passage of the ACA, President Obama harkened back to President Roosevelt in speaking before the UN General Assembly, declaring explicitly that “freedom from want is a basic human right,” as the 2011 US report to the UN’s Universal Periodic Review heralded the enactment of the ACA as a reflection of America’s commitment to progressively realize the right to health.<sup>81</sup> Beyond this advancement of government responsibility for health care at home, human rights became a renewed focus of US policy to advance health throughout the world, as President Obama strengthened global health policy through a coordinated strategy for US engagement with global health security.<sup>82</sup> This proclaimed commitment to human rights offered a moral justification for

US bilateral leadership in building the capacity of African health institutions and for US multilateral support in developing global resolutions to advance universal health coverage, sexual and reproductive health, and climate change mitigation.<sup>83</sup> Human rights had become a foundation for renewed US leadership in public health; however, these health policy advancements galvanized populist opposition, as conservative activists, under the banner of a “Tea Party” revolution, relentlessly attacked government efforts to expand access to health as a fundamental threat to freedom.<sup>84</sup> The Trump presidential campaign adopted this populist rhetoric in attacking the ACA, riding a right-wing populist wave to capture the Republican nomination, with the 2016 US election turning on opposition to health care reforms and leading to profound transitions in public health policy.<sup>85</sup>

### *The populist threat to public health*

The first Trump administration threatened the human rights that underlie public health, in the United States and throughout the world. Rejecting the fundamental notion that all people are equal in dignity, the administration rapidly pursued discriminatory policies that targeted marginalized populations, denied health services, and redefined “unalienable rights.”<sup>86</sup> The administration also attacked the foundations of health policy, pursuing cuts in health research, prioritization of corporate deregulation, and withdrawal from global initiatives.<sup>87</sup> These violations of human rights, challenges to public health, and isolationism in international affairs undermined the US government’s response to the COVID-19 pandemic. The failures of the pandemic response shaped the 2020 election, after which the Biden administration sought to renew US leadership in global health and human rights. Yet the 2024 elections again presented an existential crossroads for the United States, offering divergent paths for continuing US engagement with health and human rights.

*Violating human rights, undermining health science, and rejecting global governance*

With populist leadership dividing the United States, the first Trump administration threatened universal human rights and weakened public health protections.<sup>88</sup> President Trump opened his presidency in January 2017 by issuing an executive order to establish a “Muslim ban” that restricted refugees and immigrants from seven Muslim-majority countries, and these political attacks on immigrants would expand in the years that followed, as the government prosecuted migrants, separated families, and uprooted lives.<sup>89</sup> Undermining domestic public health systems, the administration pre-empted state public health laws while reducing the power of federal health agencies to prevent disease and promote health.<sup>90</sup> This populist threat to human rights and public health extended globally through isolationist policies, with the Trump administration reducing foreign assistance, flouting international norms, abandoning international partnerships, and weakening international organizations.<sup>91</sup> As seen in attacks on sexual and reproductive health and rights, President Trump expanded the “Global Gag Rule” to restrict American reproductive health assistance, closed US programs addressing HIV/AIDS, maternal and child health, and LGBTQ+ health, and withheld funding to UNFPA.<sup>92</sup> Advancing an “America First” foreign policy, the administration rejected a range of international policies and organizations, as the United States withdrew from several UN agencies and abandoned global efforts to address the cataclysmic threat of climate change under the Paris Agreement.<sup>93</sup> These attacks on human rights, public health, and global governance proved catastrophic in responding to the COVID-19 pandemic.

### *Challenging international human rights amid a public health emergency*

When faced with this new threat, the administration reacted with division and discrimination. The president referred to COVID-19 as the “Chinese virus” (in ways that stoked attacks against Asian Americans), dismissed public health data and expertise (initially denying the severity of the disease before rejecting prevention measures, promoting unproven treatments, and attacking health offi-

cial), and undermined international collaboration through global governance (initially halting WHO funding before calling for US withdrawal from WHO).<sup>94</sup> Abandoning global health governance in responding to a shared health crisis, the Trump administration rejected WHO public health guidance, instituted international travel bans, and blocked health data sharing in the pandemic response.<sup>95</sup> Isolated in facing this public health emergency, the administration pursued repressive measures in ways that undercut democratic guarantees, neglected vulnerable populations, and exacerbated health inequities in violation of human rights obligations.<sup>96</sup> In an effort to redefine rights to reflect administration priorities, the US government’s newly established Commission on Unalienable Rights released a 2020 report that sought to delimit human rights to a narrow conceptualization of rights rooted in a Christian interpretation of natural law, disregarding subsequent advancements of rights under international law (that protect women, children, and minorities), promoting religious freedom as a paramount right, and refuting the human rights that underlie health.<sup>97</sup> Advancing this redefinition of rights globally, the administration in 2020 introduced the Geneva Consensus Declaration as a basis to form an international coalition of conservative countries that would work together to reorient women’s health around conservative values, explicitly rejecting abortion as a human right.<sup>98</sup> These compounding policies weakened US influence in international affairs, constrained the global response to the COVID-19 pandemic, and threatened the international vision of human rights, with the future of health and human rights hanging in the balance.

### *A fleeting moment of renewed leadership*

The 2020 election of President Joseph Biden provided a brief opening to reinstate US leadership as a basis for human rights, public health, and global solidarity. Following a contentious presidential campaign amid a catastrophic pandemic response—a response that had already seen millions of lives lost and left the United States dangerously disconnected from its past international leadership—the public

health and human rights communities sought to support the rebuilding task ahead.<sup>99</sup> Yet even as President Biden looked to reshape US leadership under the right to health, the United States continued to be impacted by health inequities driven by the COVID-19 pandemic.<sup>100</sup> The Biden administration immediately sought to reintegrate human rights into public health through value-based care, prioritizing scientific integrity, health equity, and evidence-based policymaking.<sup>101</sup> Advancing health globally, the administration reversed the US withdrawal from WHO, repealed the Global Gag Rule, reauthorized PEPFAR, rejoined the Paris Climate Agreement, and took unprecedented steps to mitigate the climate threat through the Inflation Reduction Act of 2022.<sup>102</sup> Given the detrimental global health impacts of COVID-19, the US government increased bilateral foreign assistance for health and joined with other WHO member states to strengthen pandemic preparedness multilaterally through 2024 amendments to the International Health Regulations and negotiations that led to the 2025 WHO Pandemic Agreement.<sup>103</sup>

However, health and human rights continued to face systematic obstacles as the 2024 US elections approached, with the Trump campaign explicitly threatening to confront the public health scientists, human rights protections, and global governance institutions that underlie health in the United States and throughout the world.<sup>104</sup> This destructive vision for a second Trump administration was laid out in detail by the Heritage Foundation in its “Project 2025” manifesto, which presented a detailed path to consolidate right-wing power in the US government by reshaping democratic principles, reducing the government workforce, and withdrawing from global governance in ways that would threaten health and human rights.<sup>105</sup> That vision is now rapidly being carried out in US policy.

## Conclusion

Eighty years of conservative opposition to the notion of health as a human right, challenging who is entitled to rights and what those rights include, have led to this uncertain moment, as the Trump

administration attacks public health science, fundamental human rights, and global health governance. These attacks are not an aberration but a culmination, extending past conservative opposition to its ultimate policy solution: the end of health as a human right. Rather than reframing or reducing existing institutions of health and human rights, as seen in past conservative administrations, this administration now seeks to destroy the very institutions that shape the realization of the right to health, eviscerating scientific research structures, persecuting human rights defenders, and abandoning global health engagement.<sup>106</sup> In the absence of congressional action, the administration’s rapid reshaping of US health policy—through the rejection of health expertise, defunding of scientific research, deregulation of harmful industries, privatization of health services, abandonment of foreign assistance, and withdrawal from global governance—will exacerbate health challenges in the United States and threaten millions throughout the world.<sup>107</sup> This decline of US leadership to promote health and human rights will outlive the present administration, undermining health outcomes for generations and widening health inequities at home and abroad.

These attacks on the right to health should be seen as undermining core American values, where health is a foundational underpinning of rights enshrined in the US Constitution and Bill of Rights. While not explicitly enumerated in the nation’s founding documents, principles of individual freedom, a core American value, cannot exist without public health.<sup>108</sup> Presidents have recognized this before. Facing the twin challenges of the Great Depression and World War II, President Roosevelt explicitly proclaimed that the “land of the free” cannot ensure freedom when people live in want.<sup>109</sup> The US government serves to uphold that freedom from want by ensuring the conditions essential for public health. The right to health must be seen not just as an international obligation but as a foundation of American democracy. Supporting this foundation in 1944, Roosevelt called for a Second Bill of Rights, not to challenge the original Bill of Rights but to build on its foundations by guaranteeing the opportunity to achieve good health.

Ensuring this equality of opportunity today will require a social minimum for all individuals and a rights-based allocation of resources for health.<sup>110</sup>

It will be necessary for the United States to enshrine the right to health as central to American democracy, looking to both federal and state laws to unite the nation to realize the highest attainable standard of health. With more than 110 countries already guaranteeing specific rights for the progressive realization of health, the right to health is widely codified as a core value, explicit right, or fundamental entitlement in national constitutions and foundational documents across the world.<sup>111</sup> Within the United States, a rising number of states have already developed constitutional and legislative entitlements to ensure health-related rights for those whose rights are not protected by the federal government.<sup>112</sup> This evolving recognition of the right to health has raised a nationwide imperative, learning from past opposition, to recognize the right to health as a core government commitment. Such constitutive commitments under domestic law will be necessary to make the right to health a reality in the United States, building on past movements to overcome continuing conservative opposition.<sup>113</sup> In this rising American movement to ensure the right to health, there is a crucial role for the political engagement of public health leaders, building a national campaign to ensure that health for all can become a unifying vision to define America's future.

## References

1. L. Henkin, *The Age of Rights* (Columbia University Press, 1990).
2. S. I. Rosenman (ed), *The Public Papers and Addresses of Franklin D. Roosevelt: 1940* (Macmillan, 1941), p. 672.
3. M. R. DiNunzio, *Franklin D. Roosevelt and the Third American Revolution* (Bloomsbury, 2011).
4. C. Sunstein, *The Second Bill of Rights* (Basic Books, 2009).
5. F. D. Roosevelt, "Message on the State of the Union," *Congressional Records* 55/57 (1944).
6. D. J. Whelan and J. Donnelly, "The West, Economic and Social Rights, and the Global Human Rights Regime: Setting the Record Straight," *Human Rights Quarterly* 29/908 (2007).
7. E. R. Stettinius, "Human Rights in the United Nations Charter," *Annals of the American Academy of Political and Social Science* 243/1 (1946).
8. *Official Records of the World Health Organization No. 2: Proceedings and Final Acts of the International Health Conference Held in New York from 19 June to 22 July 1946* (1948), p. 31 (emphasis in original).
9. Constitution of the World Health Organization (1946).
10. *Ibid.*, preamble.
11. M. A. Glendon, *A World Made New: Eleanor Roosevelt and the Universal Declaration of Human Rights* (Random House, 2001).
12. *These Rights and Freedoms* (United Nations Department of Public Information, 1950).
13. A. M. Black, "Eleanor Roosevelt and the Universal Declaration of Human Rights," *OAH Magazine of History* 22/28 (2008).
14. C. Eagleton, "The United States and the United Nations," in *Annual Survey of American Law* (1952).
15. C. Anderson, *Eyes off the Prize: The United Nations and the African American Struggle for Human Rights* (Cambridge University Press, 2009).
16. *Social Insurance and Allied Services: Report by Sir William Beveridge* (Inter-Departmental Commission on Social Insurance and Allied Services, 1942).
17. G. W. Bachman and L. Meriam, *The Issue of Compulsory Health Insurance: A Study Prepared at the Request of Senator H. Alexander Smith, Chairman of the Subcommittee on Health of the Senate Committee on Labor and Public Welfare* (Brookings Institution, 1948).
18. New York Academy of Medicine, *Medicine in the Changing Order* (Commonwealth Fund, 1947).
19. M. M. Peon, *Harry S. Truman Versus the Medical Lobby* (University of Missouri Press, 1979).
20. "The American Medical Association: Power, Purpose, and Politics in Organized Medicine," *Yale Law Journal* 63/937 (1954).
21. A. E. Birn, "Health and Human Rights: Historical Perspectives and Political Challenges," *Journal of Public Health Policy* 29/1 (2008).
22. L. Henkin, "The United Nations and Human Rights," *International Organization* 19/3 (1965).
23. A. E. Yamin, "The Right to Health Under International Law and Its Relevance to the United States," *American Journal of Public Health* 95/7 (2005).
24. P. Alston, "The United Nations' Specialized Agencies and Implementation of the International Covenant on Economic, Social and Cultural Rights," *Columbia Journal of Transnational Law* 18/79 (1979).
25. C. E. Allen, "World Health and World Politics," *Intelligence Organization* 27/41 (1950).
26. C. Osakwe, *Participation of the Soviet Union in Universal International Organizations: A Political and Legal Analysis of Soviet Strategies and Aspirations Inside ILO*,

UNESCO and WHO (Sijthoff, 1972).

27. Statement by Henry R. Labouisse, Head of the Task Force on June 21, 1961, before the Senate Hearings on the International Development and Security Act of 1961 (US Government Printing Office, 1961).

28. U. Mahajani, "Kennedy and the Strategy of Aid: The Clay Report and After," *Western Political Quarterly* 18/3 (1965).

29. B. M. Meier and L. M. Mori, "The Highest Attainable Standard: Advancing a Collective Human Right to Public Health," *Columbia Human Rights Law Review* 37/1 (2005).

30. B. M. Meier, "Global Health Governance and the Contentious Politics of Human Rights: Mainstreaming the Right to Health for Public Health Advancement," *Stanford Journal of International Law* 46/1 (2010).

31. Anderson (see note 15).

32. M. F. Davis, *Brutal Need: Lawyers and the Welfare Rights Movement, 1960-1973* (Yale University Press, 1995).

33. T. Marmor, "The Politics of U.S. Health System Reform," *Conference Series-Federal Reserve Bank of Boston* (1969).

34. R. Stevens, "History and Health Policy in the United States: The Making of a Health Care Industry, 1948-2008," *Social History of Medicine* 21/461 (2008).

35. E. R. Annis, "Government Health Care: First the Aged, Then Everyone," *Current History* 45/104 (1963).

36. K. Davis, "Achievements and Problems of Medicaid," *Public Health Reports* 91/4 (1976).

37. B. Hoffman, *Health Care for Some: Rights and Rationing in the United States Since 1930* (University of Chicago Press, 2012).

38. F. Quimby, *The Politics of Global Health: Prepared for the Subcommittee on National Security Policy and Scientific Developments of the Committee on Foreign Affairs, U.S. House of Representatives* (US Government Printing Office, 1971).

39. N. Chorev, *The World Health Organization Between North and South* (Cornell University Press, 2012).

40. S. Litsios, "The Long and Difficult Road to Alma-Ata: A Personal Reflection," *International Journal of Health Services* 32/4 (2002).

41. T. Lambo, "Towards Justice in Health," *World Health* 4 (1979); C. Pannenberg, *A New International Health Order: An Inquiry into the International Relations of World Health and Medical Care* (Sijthoff and Noordhoff, 1979).

42. "Inaugural Address of Jimmy Carter," Avalon Project, [https://avalon.law.yale.edu/20th\\_century/carter.asp](https://avalon.law.yale.edu/20th_century/carter.asp).

43. P. Bourne, *New Directions in International Health Cooperation: A Report to the President* (US Government Printing Office, 1978); K. Mingst, "The United States and the World Health Organization," in M. P. Karns and K. A. Mingst (eds), *The United States and Multilateral Institutions: Patterns of Changing Instrumentality and Influence* (Routledge, 1990).

44. W. P. Brandon, "Two Kinds of Conservatism in US Health Policy: The Reagan Record," in C. Altenstetter and S. C. Haywood (eds), *Comparative Health Policy and the New Right* (Palgrave Macmillan, 1991).

45. L. J. McAndrews, *The Presidents and the Poor: America Battles Poverty* (University Press of Kansas, 2018).

46. J. Starrels, *The World Health Organization: Resisting Third World Ideological Pressures* (Heritage Foundation, 1985).

47. K. Sikkink, "Codes of Conduct for Transnational Corporations: The Case of the WHO/UNICEF Code," *International Organization* 40/815 (1986).

48. M. Cueto, T. Brown, and E. Fee, *The World Health Organization: A History* (Cambridge University Press, 2019).

49. L. D. Brown, *Health Policy in the Reagan Administration: A Critical Appraisal* (Brookings, 1984).

50. S. Danziger and R. Haveman, "The Reagan Administration's Budget Cuts: Their Impact on the Poor," *IRP Reprint* 24 (1981).

51. K. Stallard, B. Ehrenreich, and H. Sklar, *Poverty in the American Dream* (South End Press, 1983).

52. J. L. Finkle and B. B. Crane, "Ideology and Politics at Mexico City: The United States at the 1984 International Conference on Population," *Population and Development Review* 11/1 (1985).

53. R. P. Petchesky, "Antiabortion, Antifeminism, and the Rise of the New Right," *Feminist Studies* 7/206 (1981).

54. "The International Conference on Population, 1984," *Population and Development Review* 10/755 (1984).

55. L. O. Gostin and Z. Lazzarini, *Human Rights and Public Health in the AIDS Pandemic* (Oxford University Press, 1997).

56. J. Mann and D. Tarantola, "Responding to HIV/AIDS: A Historical Perspective," *Health and Human Rights* 2/5 (1998).

57. N. Krieger and R. Appleman, "The Politics of AIDS" in *AIDS: The Politics of Survival* (Baywood Publishing Company, 1994).

58. D. Altman, "HIV, Homophobia, and Human Rights," *Health and Human Rights* 2/4 (1998).

59. J. Yong, J. V. Millen, A. Irwin, and J. Gershman, *Dying for Growth: Global Inequality and the Health of the Poor* (Common Courage Press, 2000).

60. R. Falk, "Interpreting the Interaction of Global Markets and Human Right," in A. Brysk (ed), *Globalization and Human Rights* (University of California Press, 2002).

61. T. Evans, "A Human Right to Health," *Third World Quarterly* 23/2 (2002).

62. D. P. Fidler, *International Law and Infectious Diseases* (Oxford University Press, 1999).

63. World Conference on Human Rights, Vienna Declaration and Programme of Action, UN Doc. A/CONF.157/23 (1993).

64. C. Campbell and B. A. Rockman, "Third Way Leadership, Old Way Government: Blair, Clinton and the Power

to Govern,” *British Journal of Politics and International Relations* 3/1 (2001); Board on International Health, Institute of Medicine, *America’s Vital Interest in Global Health: Protecting Our People, Enhancing Our Economy, and Advancing Our International Interests* (National Academy Press, 1997).

65. A. R. Chapman, *Health Care Reform: A Human Rights Approach* (Georgetown University Press, 1994).

66. E. D. Kinney, “Recognition of the International Human Rights to Health and Health Care in the United States,” *Rutgers Law Review* 60/335 (2007).

67. World Health Organization, *Macroeconomics and Health: Investing in Health for Economic Development* (2001), <https://www.who.int/publications/i/item/924154550X>; R. P. Petchesky, *Global Prescriptions: Gendering Health and Human Rights* (Zed Books, 2003); L. Forman, “Trade Rules, Intellectual Property, and the Right to Health,” *Ethics and International Affairs* 21/3 (2007).

68. M. Koivusalo and E. Ollila, *Making a Healthy World: Agencies, Actors and Policies in International Health* (Zed Books, 1997); T. M. Brown, M. Cueto, and E. Fee, “The World Health Organization and the Transition from ‘International’ to ‘Global’ Public Health,” *American Journal of Public Health* 96/62 (2006).

69. I. Kickbusch, “Influence and Opportunity: Reflections on the US role in Global Public Health,” *Health Affairs* 21/131 (2002).

70. J. M. Hughes and J. L. Gerberding, “Anthrax Bioterrorism: Lessons Learned and Future Directions,” *CDC Emerging Infectious Diseases* 8/10 (2002); A. S. Khan, “Public Health Preparedness and Response in the USA Since 9/11: A National Health Security Imperative,” *Lancet* 378/1460 (2011).

71. L. O. Gostin, “Public Health Law in an Age of Terrorism: Rethinking Individual Rights and Common Goods,” *Health Affairs* 21/79 (2002).

72. G. J. Annas, “Bioterrorism, Public Health, and Civil Liberties,” *New England Journal of Medicine* 346/1337 (2002).

73. N. B. King, “The Influence of Anxiety: September 11, Bioterrorism, and American Public Health,” *Journal of the History of Medicine and Allied Sciences* 58/4 (2003).

74. J. Kassalow, *Why Health Is Important to U.S. Foreign Policy* (Council on Foreign Relations, 2001).

75. Brown et al. (see note 68).

76. E. J. Emanuel, “PEPFAR and Maximizing the Effects of Global Health Assistance,” *JAMA* 307/20 (2012).

77. A. Rudiger and B. M. Meier, “A Rights-Based Approach to Health Care Reform,” in E. Beracochea, C. Weinstein, and D. P. Evans (eds), *Rights-Based Approaches to Public Health* (Springer, 2011).

78. G. MacNaughton, M. McGill, A. Jakubec, et al., “Engaging Human Rights Norms to Realize Universal Health Care in Massachusetts, USA,” *Health and Human Rights* 20/2 (2018).

79. S. Butler, “Don’t Blame Heritage for ObamaCare

Mandate,” Heritage Foundation (February 6, 2012), <https://www.heritage.org/health-care-reform/commentary/dont-blame-heritage-obamacare-mandate>.

80. C. Ho, *Normalizing an American Right to Health* (Oxford University Press, 2023).

81. B. M. Meier and L. Gable, “US Efforts to Realise the Right to Health Through the Patient Protection and Affordable Care Act,” *Human Rights Law Review* 13/1 (2013).

82. C. McInnes, A. Kamradt-Scott, K. Lee, et al., *The Transformation of Global Health Governance* (Palgrave Macmillan, 2014).

83. L. O. Gostin and E. Friedman, “A Retrospective and Prospective Analysis of the West African Ebola Virus Disease Epidemic: Robust National Health Systems at the Foundation and an Empowered WHO at the Apex,” *Lancet* 385/9980 (2015).

84. K. Arceneaux and S. P. Nicholson, “Who Wants to Have a Tea Party? The Who, What, and Why of the Tea Party Movement,” *Political Science and Politics* 45/4 (2012).

85. J. Geyman, “Crisis in U.S. Health Care: Corporate Power Still Blocks Reform,” *International Journal of Health Services* 48/1 (2017).

86. M. Rise, “On American Values, Unalienable Rights, and Human Rights: Some Reflections on the Pompeo Commission,” *Ethics and International Affairs* 34/1 (2020).

87. J. M. Sharfstein, “Science and the Trump Administration,” *JAMA* 318/14 (2017).

88. D. W. Drezner, “Present at the Destruction: The Trump Administration and the Foreign Policy Bureaucracy,” *Journal of Politics* 81/2 (2019).

89. The White House, “Executive Order Protecting the Nation from Foreign Terrorist Entry into the United States,” (2017), <https://trumpwhitehouse.archives.gov/presidential-actions/executive-order-protecting-nation-foreign-terrorist-entry-united-states-2/>; S. Woolhandler, D. U. Himmelstein, S. Ahmed, et al., “Public Policy and Health in the Trump Era,” *Lancet* 397/10275 (2021).

90. J. G. Hodge, M. Morcelle, S. Wetter, et al., “Public Health Preemption: Constitutional Affronts to Public Health Innovations,” *Ohio State Law Journal* 79/4 (2018).

91. F. Quigley, “Trump-Pence Attack on Healthcare Challenged at Its Roots,” *Health and Human Rights* (October 8, 2019), <https://www.hhrjournal.org/2019/10/08/trump-pence-attack-on-healthcare-challenged-at-its-roots/>.

92. A. Ahmed and T. McGovern, “Sexual and Reproductive Health and Rights: Advancing Human Rights to Protect Bodily Autonomy and Sexuality,” in L. O. Gostin and B. M. Meier (eds), *Global Health Law and Policy: Ensuring Justice for a Healthier World* (Oxford University Press, 2023).

93. The White House, “President Donald J. Trump at the United Nations General Assembly: Outlining an America First Foreign Policy” (September 20, 2017), <https://trumpwhitehouse.archives.gov/briefings-statements/president-donald-j-trump-united-nations-general-assem->

bly-outlining-america-first-foreign-policy/; C. Amirfar and A. Singh, "The Trump Administration and the 'Unmaking' of International Agreements," *Harvard International Law Journal* 59/443 (2018).

94. C. R. Williams, J. G. Kestenbaum, and B. M. Meier, "Populist Nationalism Threatens Health and Human Rights in the COVID-19 Response," *American Journal Public Health* 110/12 (2020).

95. S. Sekalala, L. Forman, R. Habibi, et al., "Health and Human Rights Are Inextricably Linked in the COVID-19 Response," *BMJ Global Health* 5 (2020).

96. L. O. Gostin, A. Constantin, and B. M. Meier, "Global Health and Human Rights in the Age of Populism," in L. O. Gostin and B. M. Meier (eds), *Foundations of Global Health and Human Rights* (Oxford University Press, 2020).

97. "Report of the Commission of Unalienable Rights," (2020) <https://www.state.gov/wp-content/uploads/2020/07/Draft-Report-of-the-Commission-on-Unalienable-Rights.pdf>.

98. L. Morgan, "Anti-Abortion Strategizing and the Afterlife of the Geneva Consensus Declaration," *Developing World Bioethics* 23 (2023).

99. B. M. Meier, L. Hango, V. Matus, et al., "Health and Human Rights in the New American Administration," *Health and Human Rights* (December 20, 2020), <https://www.hhrjournal.org/2020/12/20/health-and-human-rights-in-the-new-american-administration/>.

100. B. J. Stark, "Inequality, COVID-19, and International Human Rights: Whose Lives Matter?," *Journal of International and Comparative Law* 27/2 (2021).

101. R. L. Haffajee and B. D. Sommers, "Evidence-Based Health Policy in the Biden-Harris Administration," *JAMA Health Forum* 2/7 (2021).

102. X. Becerra, "U.S. HHS Secretary Becerra: Remarks at the 74th World Health Assembly," US Mission to International Organizations in Geneva (2021).

103. L. Pace and S. C. Kim, "Strengthening Global Health Security Under the Biden-Harris Administration," *Journal of Law, Medicine and Ethics* 53/1 (2025).

104. B. M. Meier, A. E. L. Palmquist, M. Dockery, et al., "The 2024 U.S. Elections: Global Health Policy at a Crossroads," *Journal of Law, Medicine and Ethics* 52/498 (2024).

105. Heritage Foundation, *Project 2025 Presidential Transition Project* (2023); C. Piroddi, L. Gilby, M. Koivusalo, et al., "The Hegemony of Far-Right Populism, Project 2025, and the Dangers Ahead for Science and Public Health," *International Journal of Social Determinants of Health and Health Services* (2025).

106. J. J. Amon, "Free Speech, the Right to Health, and Genocide," *Health and Human Rights* 27/1 (2025).

107. U.S. Department of State, *America First Global Health Strategy* (2025), <https://www.state.gov/america-first-global-health-strategy/>; J. S. Morrison and L. O. Gostin, "Promise and Gaps in America First Strategy for Global Health," *BMJ*

391 (2025); S. Halabi, L. O. Gostin, K. Wontumi, et al., "Science and Public Health in the Trump Era: The Dismantling of Evidence and Institutions, and Proposals for Reconstruction," *Journal of Health Politics, Policy and Law* 51/2 (2026).

108. W. Parmet, *Constitutional Contagion: COVID, the Courts, and Public Health* (Cambridge University Press, 2023).

109. Sunstein (see note 4).

110. S. Moyn, *Not Enough: Human Rights in an Unequal World* (Harvard University Press, 2018).

111. J. Heymann, A. Cassola, A. Raub, and L. Mishi, "Constitutional Rights to Health, Public Health and Medical Care: The Status of Health Protections in 191 Countries," *International Journal for Research, Policy and Practice* 8/6 (2013).

112. G. MacNaughton, F. Haigh, M. McGill, et al. "The Impact of Human Rights on Universalizing Health Care in Vermont, USA," *Health and Human Rights* 17/2 (2015); A. Rudiger, "Human Rights and the Political Economy of Universal Health Care," *Health and Human Rights* 18/2 (2016).

113. L. O. Gostin, T. Daniely, H. E. Huffstetler, et al., "The Shibboleth of Human Rights in Public Health," *Lancet Public Health* 5/471 (2020).



## BOOK REVIEW

# Social Injustice, Public Health, and Human Rights

AUDREY R. CHAPMAN

*Social Injustice and Public Health*, fourth edition  
edited by Barry S. Levy (Oxford University Press, 2026)

*Social Injustice and Public Health* is a comprehensive collection of 31 essays, each written by leading experts in public health and medicine, that document the profound impacts of social injustice on public health. The volume is edited by Barry Levy—a former director of the American Public Health Association, editor of numerous textbooks, and author of *From Horror to Hope: Recognizing and Preventing the Health Impacts of War*—who also contributed several chapters.<sup>1</sup> The goals of the volume, according to Levy, are to provide a better understanding of the roots of social injustice and its impacts on public health, to promote education and research on this important issue, and to stimulate action to reduce social injustice and minimize its health consequences. It is the fourth edition of a text first published in 2005 and includes several new chapters.

As conceptualized in the volume, social injustice “is the denial or violation of economic, sociocultural, political, civil, or human rights of specific population groups in society based on the erroneous perception of their inferiority by those with more power or influence” (pp. 3–4). Alternatively, the book offers a second definition of social injustice based on the US Institute of Medicine’s conceptualization of public health as what we do as a society collectively to assure the conditions in which people can be healthy. Social injustice, then, refers to policies or actions that adversely affect the conditions that enable people to be healthy. The book explains that while social injustice is often community-wide or even global, its effects fall disproportionately on the groups identified in the first definition above, such as people living in poverty, people of color, women, and older people. As Levy points out, social injustice creates conditions that prevent individuals and groups from having their basic needs met and that, in the process of doing so, violate human rights (p. 4).

*Social Injustice and Public Health* is organized into four parts. The first part comprises an introduction by Levy on the nature of social injustice and its impact on public health, as described above.

The second part examines how social injustice impacts the health of ten population groups. The chapter by Michael Marmot and Ruth Bell explores the impact of social injustice on socioeconomically disadvantaged populations and assesses the root causes and underlying factors of socioeconomic disad-

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vantage. In considering what needs to be done, the authors draw on recommendations from *The Marmot Review Ten Years On*, including those aimed at giving every child the best start in life (pp. 33–34). The remaining chapters explore how social injustice affects the health of people of color (Carol Easley Allen and Cheryl Easley), women (Gina Maranto), children (Luz Claudio and Juan Antonio Ortega-Garcia), older people (Carroll Estes et al.), lesbian, gay, bisexual, transgender, and queer or questioning people (Emilia Lombardi and Talia Mae Bettcher), people with disabilities (Nora Ellen Groce), incarcerated people (David Cloud), people experiencing homelessness (Howard Padwa et al.), and forced migrants (Michael Toole). Many of these chapters not only profile the impacts of social injustice on these communities and examine their causes but also identify what needs to be done now.

The third part addresses how social injustice affects specific aspects of public health, including medical care (Oliver Fein), communicable diseases (Joia Mukherjee), nutrition (J. Larry Brown), non-communicable diseases (Mariachiara Di Cesare et al.), violence (Colleen Ray et al.), war (Barry Levy), mental health (Carles Muntaner et al.), environmental health (Barry Levy), occupational health and safety (Linda Rae Murray), oral health (Myron Allukian et al.), and global health (Barry Levy). Some chapters are US oriented, while others are international in scope. As in the second part, these chapters both discuss the underlying causes and offer recommendations for action.

The fourth part sets out an agenda for action. It features contributions addressing social justice in a human rights context (Sofia Gruskin and Paula Braveman), promoting social justice through public health policy (Kathleen Rest et al.), promoting social justice through public health practice (Joshua Sharfstein et al.), strengthening communities and the roles of individuals in building community life (Robert Aronson et al.), promoting social justice through education in public health (Robert Lawrence), developing a critical research agenda for social justice and public health (Nancy Krieger), protecting human rights through international and national law (Henry Freedman and Martha Davis),

learning from the social movements of the 1960s (Oliver Fein and Charlotte Phillips), and promoting health with equitable and sustainable human development (Richard Jolly and Mark Sidel).

As indicated above, this volume is not explicitly about human rights and health. In the introduction, Levy acknowledges that social justice is closely linked to human rights and specifically identifies three foundational human rights documents—the Universal Declaration of Human Rights, the International Covenant Civil and Political Rights, and the International Covenant on Economic, Social and Cultural Rights—as the basis for identifying the rights to which all people are entitled (p. 6). However, this theme is not then expressed in the contents of the book. Only two of the volume’s 31 chapters focus on human rights, and both appear to be written primarily for public health specialists unfamiliar with human rights. A third chapter advocates for incorporating human rights into public health and medical curricula.

The chapter by Sofia Gruskin and Paula Braveman on addressing social injustice in a human rights context (chapter 23) considers the relevance of human rights to public health in three major spheres: as legal standards and obligations of governments, as a conceptual framework for analysis and advocacy, and as guiding principles for designing and implementing policies and programs. It describes what human rights are and, more specifically, conceptualizes the right to health. Perhaps the most helpful section of the chapter, especially for public health specialists, is the section that explores how human rights principles and standards can be used to promote social justice. As the authors note, most public health actions are intended to benefit entire populations, which means that poor or marginalized populations may benefit too little, even from the best-intentioned initiatives. They therefore argue that using human rights norms along with the routine assessment of potential health implications should become standard practice at all stages of public policy formation, including its design, implementation, and evaluation (pp. 542–543). They conclude that “health workers should be aware that human rights principles, norms, standards, laws,

and accountability mechanisms are relevant tools to help achieve social justice in health ... Human rights principles provide a framework that can guide health workers and others in pursuing social justice in health” (p. 546).

The second chapter with a human rights theme (chapter 29), written by Henry Freedman and Martha Davis, examines the protection of human rights through international and national law. It describes the United Nations Charter as the taproot of a tree, the Universal Declaration of Human Rights as the trunk, and the various covenants based on the Universal Declaration as branches addressing a range of individual rights (p. 653). It provides descriptive information on how the system functions, presumably for health care professionals unfamiliar with the international human rights system. Various sections of the chapter illustrate how US national and state laws can be used to reduce social injustice. The chapter also provides a human rights and legal agenda and identifies some resources for advancing social justice. The authors conclude that when the domestic rule of law is under stress, as is currently the case in the United States, human rights law becomes even more important as a bulwark against injustice. They go on to observe that establishing enforceable social, economic, and cultural rights represents the only sure defense against social injustice. They recommend that “lawyers must go to court, targets of social injustice and their supporters must take to the streets to demonstrate nonviolently, and activists must lobby their elected representatives” (p. 671). Hopefully that will occur.

The chapter by Robert Lawrence on promoting social justice through education in public health (chapter 27) also stresses the importance of incorporating human rights into the curricula of schools of public health, medical schools, nursing schools, and departments of community and preventive medicine. Lawrence identifies human rights as one of the two major developments in the past eight decades relevant to the development and implementation of a social justice curriculum for public health students. The second is the significant progress that has been made in qualitative and quantitative analyses of the social determinants of

health. According to Lawrence, these two developments provide the foundation for education that places social justice at the heart of the public health curriculum (p. 611). However, the chapter does not offer details about how or which human rights should be integrated into the various curricula.

Beyond these chapters, the volume is broadly relevant to the pursuit of health and human rights in several ways. Both the public health community and the human rights community are committed to overcoming social injustice and achieving greater fairness and equity. Both acknowledge that the lack of justice, fairness, and equity results from social structures and discriminatory policies that harm individuals and groups. I think that greater collaboration between these two communities would strengthen each in advancing its commitments and goals. I write this as a human rights specialist in a public health academic department.

Over the past 25 years, the human rights community has become increasingly aware of the importance of the social determinants of health for health outcomes. The United Nations Committee on Economic, Social and Cultural Rights’ General Comment 14 interprets the right to health as an inclusive right extending not only to timely and appropriate health care but also to the underlying determinants of health. Providing these underlying determinants to everyone is identified as a core obligation of state parties that is immediately realizable and not dependent on the availability of resources.<sup>2</sup> For this reason, rights-based approaches to health need to engage in a meaningful way with the growing body of public health research that shows the significant impact of health inequalities and the social determinants of health on health status. *Social Injustice and Public Health* provides a valuable resource for that purpose.

Additionally, one of the hallmarks of a human rights approach is a commitment to protecting the rights and well-being of vulnerable and disadvantaged groups. To that end, the need to protect the rights and needs of these communities has been a recurrent theme in the work of the United Nations human rights oversight committees. It finds expression, for example, in the work of the Com-

mittee on Economic, Social and Cultural Rights, whose General Comment 14 interpreting the right to health identifies the special obligations of states to provide for the satisfaction of the health needs of individuals and groups whose poverty, disabilities, or background make them vulnerable. The text specifically highlights duties to women, children and adolescents, older persons, persons with disabilities, and Indigenous people.<sup>3</sup> This concern is also reflected in the work of other United Nations human rights committees focused on the rights of several of these communities, including their health rights and status and general well-being. These include the Committee on the Rights of the Child, the Committee on the Elimination of Racial Discrimination, the Committee on the Elimination of Discrimination Against Women, and the Committee on the Rights of Persons with Disabilities.

The impact of the COVID-19 pandemic has made it even more important for the human rights community to address the situation of disadvantaged and vulnerable communities. As I have noted elsewhere, during the pandemic, individuals and communities that were already disadvantaged and vulnerable frequently experienced a disproportionate burden of illness, death, and social and economic dislocation. The measures imposed to reduce exposure to COVID-19, such as lockdowns and school closures, also tended to impose a greater burden on already disadvantaged groups.<sup>4</sup>

Many of the groups highlighted in the volume are communities that have been of continuing concern to the human rights community. The chapters exploring how social injustice affects various disadvantaged and vulnerable groups can thus provide a valuable foundation for human rights analysis and policy recommendations.

## References

1. Barry S. Levy, *From Horror to Hope: Recognizing and Preventing the Health Impacts of War* (Oxford University Press, 2022).
2. Committee on Economic, Social and Cultural Rights, General Comment 14, UN Doc. E/C.12/2000/4 (2000), see especially paras. 11, 43.
3. *Ibid.*, see especially paras. 22, 25, 26, 27.

4. Audrey R. Chapman, *The Unequal Pandemic: The Impact of the Pandemic on Vulnerable and Disadvantaged Communities* (Cambridge University Press, forthcoming).

## BOOK REVIEW

# *Jekhipe* Beyond the Nation-State: Collective Life in Matache's *The Permanence of Anti-Roma Racism*

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*The Permanence of Anti-Roma Racism: (Un)uttered Sentences,*  
by Margareta Matache (Routledge, 2026)

While Margareta Matache's *The Permanence of Anti-Roma Racism: (Un)uttered Sentences* is many things—genealogy, theoretical intervention, historical archive, and ethical call—a central argument gives it a special urgency: Matache demonstrates that anti-Roma racism is not a marginal feature of European modernity but one of its constitutive logics, with profound implications for health, rights, sovereignty, and decolonial futures. Beyond its specificity to Roma and Romani peoples, the book offers one of the most important recent analyses of racialization, structural violence, and dehumanization in Europe and beyond. One of the book's great strengths is Matache's ability to welcome readers from adjacent fields while simultaneously challenging foundational assumptions about race, colonialism, enslavement, and humanity itself.

*The Permanence of Anti-Roma Racism* is especially powerful in its treatment of racial formation. Matache constructs a genealogy of Roma racialization while also offering a broader framework for understanding race as a sociohistorical and political technology and process rather than an essential biological category. One of the recurring pedagogical challenges in teaching race and colonialism is conveying what is meant by race's "social construction." Matache answers this challenge not through abstraction but through historical demonstration. Drawing on Frantz Fanon, she shows anti-Roma racism to be not simply irrational prejudice but a historically contingent system tied to extraction, enslavement, labor exploitation, spatial control, and political ordering. While readers will find resonance with critical race and decolonial scholarship more broadly, Matache's intervention is distinct precisely because Roma experiences have remained peripheral to dominant theories of race and coloniality.

Importantly, Matache refuses reductive explanations. While foregrounding the materiality of Roma enslavement and exploitation, she also attends to the narrative, phenomenological, and epistemic dimensions of racism and its purposes. Racialization emerges not only as a mechanism for capital accumulation

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and domination but also for controlling “power, prestige, and symbolic resources and relations” (p. 54). By remaining attentive to race’s functions, Matache demonstrates how anti-Roma racism became naturalized through law, science, discourse, and everyday social relations, producing forms of violence that are simultaneously economic, political, cultural, and ontological.

Spanning enslavement, scientific racism, eugenics, the Holocaust, and contemporary segregation, the book nevertheless retains a remarkable sense of presence. There is throughout the feeling of a life’s vocation: deeply researched, deeply lived, and deeply committed to the survival and flourishing of Roma people. It is an extraordinary feat, and it represents work that, at many times, must have been excruciating given the subject matter and Matache’s own social positioning as a Roma woman and descendant of enslaved people.

Beyond its treatment of race, one of the book’s most important theoretical contributions is its expansion of prevailing theories of colonialism. Matache complicates simplified understandings of European coloniality by demonstrating how imperial and racial logics operated intra-continently as well as externally. Echoing and extending Aimé Césaire’s “imperial boomerang” thesis, she shows how Europe’s treatment of Roma and Jewish populations formed part of the broader architecture of racial modernity, even before and alongside overseas colonial expansion. She also remains attentive to distinctions within Europe itself, particularly between the forms of exclusion and segregation characteristic of core regions and the enslavement regimes of Eastern Europe.

Yet beyond its diagnosis of racial violence, the book’s most generative contribution may be ontological. Crucially, Matache does not reduce Roma existence to victimhood: Alongside the histories of enslavement, expulsion, forced sterilization, segregation, and extermination, she insists on Roma continuity, survivance, and collective worldmaking.<sup>1</sup>

Her discussion of *jekhipe*, or collectiveness, is especially striking. Matache describes a diasporic people who have maintained linguistic, cultural,

and relational continuities across borders without grounding identity in territorial sovereignty, ethnonational domination, or the possessive logics of the modern nation-state. In doing so, the book gestures toward forms of collective life that exceed dominant political imaginaries of liberation, nationhood, and even survival. Matache notes that this approach “might transcend—or perhaps has historically transcended—the biocentric and theocentric feudal notion of land ownership and humanity and the exploitative practices of the in-place multi-hierarchical capitalism concerning soil and other common resources, as well as questioning the restrictive frameworks of borders and nationalism imposed by the nation-state” (p. 35).

In this respect, Matache’s account recalls other suppressed diasporic political traditions—such as the Jewish Labor Bund’s notion of *doikayt* (“hereness”), which imagined collective flourishing in place through cultural continuity, mutuality, and solidarity rather than through territorial nationalism or state sovereignty.<sup>2</sup> Without collapsing distinct histories or political conditions, these resonances illuminate alternative responses to racial violence and persecution that refuse exclusionary nationalism as the necessary horizon of emancipation.

In a moment marked by intensifying ethnonationalism, border violence, ecological crisis, genocide, and displacement, Matache offers not merely a critique of anti-Roma racism but a profoundly generative political and ethical vision: one organized around relationality, collectiveness, and coexistence rather than domination, exclusion, and possession. Indeed, her reflections raise profound questions about what emancipatory futures could look like outside the logics of racial capitalism and settler sovereignty.

These ontological and political questions carry profound implications for health and human rights scholarship. The book repeatedly demonstrates how anti-Roma racism functions not merely as prejudice but as a structural determinant of health, shaping housing, education, labor, environmental exposure, mobility, political recognition, and access to care. Ongoing regimes of segregation across

Europe represent not simply a social failure but an ongoing human rights crisis sustained by institutions, policies, and narratives that continue to treat Roma lives as lesser, as disposable.

Matache's analysis also exposes some of the limitations of liberal human rights discourse. Formal inclusion and recognition have not dismantled the deeper structures of apartness, dehumanization, and racial hierarchy that organize anti-Roma conditions across Europe. The book therefore challenges readers not only to defend human rights frameworks but to interrogate how those frameworks can become constrained when detached from struggles against structural racism, colonialism, and material inequality.

The chapters on resistance are equally critical. Matache reminds readers that Roma people have never been passive recipients of violence. Resistance appears throughout the text: in slave revolts, in cultural preservation, in linguistic continuity, in self-ascription, and in refusals of assimilation into *gadjikane* norms and hierarchies. These struggles resonate strongly with Indigenous and anticolonial movements elsewhere, particularly in their opposition to bureaucratic and epistemic forms of erasure.

The enduring question that remains after reading the book is strategic as much as moral: How can anti-Roma racism be materially dismantled? Matache surveys numerous institutional and structural sites requiring transformation, from education and health systems to legal regimes and public discourse. Yet the scale and persistence of anti-Roma violence also raise pressing questions about prioritization, reparations, political mobilization, and the possibilities—and limits—of reform within *gadjo*-controlled institutions.

Still, the book resists despair. Despite its devastating historical detail, it remains animated by an uncompromising commitment to solidarity, collectiveness, and liberation. The closing sections, including Matache's moving letter to her nephew echoing James Baldwin, leave readers not with closure but with urgency. In this light, the book's title, which might on first glance be read as defeatist, conceals another possibility. While Matache documents the permanence of anti-Roma racism with

devastating clarity, the book simultaneously insists that racial formations and their material drivers are historically produced, and thus ultimately transformable. That tension, and Matache's insistence on the possibility of a radical Roma futurism, may be one of the text's greatest gifts—not only to Roma studies but to contemporary struggles toward decolonization, liberation, and collective survival.

## References

1. G. R. Vizenor, *Survivance: Narratives of Native Presence* (University of Nebraska Press, 2008).
2. M. Crabapple, "Here Where We Live Is Our Country: The Story of the Jewish Labor Bund," *Critical Research on Religion* 13/2 (2025).