

## EDITORIAL

# The Critical Role of Research in Advancing Romani's Right to Health

JACQUELINE BHABHA, MARGARETA MATACHE, AND TERESA SORDE MARTI

As we finalize this special section on *Romani People and the Right to Health*, a landmark ruling on Roma health rights has just been handed down by the European Committee of Social Rights. On October 16, 2017, the committee accepted as admissible the European Roma Rights Centre's complaint against Bulgaria alleging systemic discrimination against Romani women in maternity wards.<sup>1</sup> The complaint details segregation, substandard and abusive maternity care, and disproportionate barriers in access to health insurance for this part of the Roma population.<sup>2</sup> The committee's finding advances official recognition of the intersectional discrimination affecting Romani women and girls across Europe and perhaps beyond. We use the word "perhaps" advisedly, for conclusive evidence documenting discriminatory and racist practices against Roma living on other continents is lacking, a point underlined in 2016 by Rita Izsak-Ndiaye, the United Nations (UN) Special Rapporteur on minority issues.<sup>3</sup>

Despite its significance, the Bulgarian case is not unique in Europe. A 2014 shadow report submitted to the UN Committee on Economic, Social and Cultural Rights by Romani CRISS, a Romanian Roma Rights organization, also drew attention to "the segregation of Roma patients, especially Roma women, in separate rooms" at Marie Curie Hospital in Bucharest, as well as three other locations in Romania.<sup>4</sup> According to the report, Romani women complained about "unrenovated ... and untidy rooms; [the fact that] the nurses change the sheets very rarely; [and the fact that] babies receive treatment, such as syrups, with [already used] ... unsterilized utensils."<sup>5</sup> A further ex officio investigation by Romani CRISS in partnership with the Equality Body revealed the segregation of Romani children in special wards at the Marie Curie Hospital in Bucharest.

This special section in *Health and Human Rights Journal* brings together a number of respected scholars who document unequal power relations, prejudicial practices, intersectional discrimination, and inequalities, looking at causes and suggesting remedies. While there have already been multiple efforts to document and analyze health-related human rights violations affecting Romani constituencies all over the world, the present collection of articles sheds light on new realities and provides fresh insights into how these violations can be reversed or remedied. Authors analyze anthropological, law, and policy perspectives

JACQUELINE BHABHA is a professor of the practice of health and human rights at the Harvard T. H. Chan School of Public Health and director of research at the Harvard FXB Center for Health and Human Rights.

MARGARETA MATACHE is a Roma rights activist and scholar from Romania, director of the Roma Program at the Harvard FXB Center for Health and Human Rights, and a Harvard instructor.

TERESA SORDE MARTI is Serra Hünter Associate Professor of Sociology at the Universitat Autònoma de Barcelona.

Please address correspondence to Margareta Matache. Email: [mmatache@hsph.harvard.edu](mailto:mmatache@hsph.harvard.edu).

Competing interests: None declared.

Copyright: © 2017 Bhabha, Matache, and Marti. This is an open access article distributed under the terms of the Creative Commons Attribution Non-Commercial License (<http://creativecommons.org/licenses/by-nc/3.0/>), which permits unrestricted non commercial use, distribution, and reproduction in any medium, provided the original author and source are credited.

addressing the right of Roma to health in different geographical contexts, deconstructing some of the underlying assumptions and frameworks. Some contributors examine the racialization of Roma in policy and practice and the health disparities between Roma and majority populations, while others investigate bias in the formulation of policies and their implementation. Yet others explore the tactics and stakeholders involved in health-based initiatives and grassroots and Roma-led efforts geared toward realizing Roma's equal access to health. The methodologies used by contributors vary from large-scale surveys to ethnography and policy analysis.

The papers by Claude Cahn and by Gwendolyn Albert and Marek Szilvasi demonstrate that discrimination has been a triggering cause of ill health for Roma. Both papers look at the intersection of gender and ethnicity in discriminatory policies, examining more than 50 years of policies supporting the forced sterilization of Romani women in the former Czechoslovakia and its successor states. Communist Czechoslovakia carried out sterilization practices starting in 1973, and both the Czech Republic and Slovakia, after they split in 1993, continued this practice until shortly before their entry into the European Union in 2004.<sup>6</sup> These cases involved evident power disparities between non-Roma health personnel and Romani patients along multiple dimensions, including ethnicity, gender, social and professional status, and educational attainment. Profoundly abusive measures were thus executed by paid public personnel. The cases raise awareness of the lack of free and informed consent, as well as how minority and other marginalized groups are protected in the medical context.

These sterilization cases relate to a longer eugenic history aimed at shrinking the size of the Roma population. In Sweden between 1935 and 1976, Romani women were forcibly sterilized, as they were perceived as a "socially inferior element of society."<sup>7</sup> During the Holocaust, the Nazis also targeted Romani women for sterilization experiments on the basis of similar eugenic rationales. The idea of Roma racial inferiority as the underlying justification for these policies continues to exist in Europe

and translates into substantial health discrepancies between Roma and non-Roma populations.

Analyses of health-related discrimination against Romani women in the essay by Kristefer Stojanovski, Alaka Holla, Ilir Hoxha, Elizabeth A. Howell, and Teresa Janevic address additional contexts, including access to quality antenatal care in Kosovo. The authors present evidence relating to antenatal care in Kosovo and explore disparities between Roma and non-Roma women. They show that Roma, Ashkali, and Balkan Egyptian women (all placed under the umbrella of the Romani population in Kosovo) receive inferior prenatal care compared to Kosovar Albanian and Serbian women and that women who are recent migrants or displaced refugees receive the worst care.

Other papers explore discrimination against Romani communities living in situations of extreme poverty and marginalization, often in ghettoized settlements on the outskirts of Western metropolises. Four articles focus on individual constituencies, distinguished by subgroup (Romani migrants, *Gens du voyage*, and "badocari"), by country of residence (France, Sweden, and Denmark), and by the particular setting (*villages d'insertion*, settlements, homeless, and caravan sites). Daniel Manson's article touches on the vulnerabilities of Romani people living in *villages d'insertion*, or integration villages, in France. Manson describes the *village d'insertion* as an expression of state power and of the division between "deserving and undeserving" in terms of the rights to health and shelter. Martha F. Davis and Natasha Ryan examine the marginalization of Roma through the denial of water and sanitation facilities in Sweden. Camilla Ida Ravnbøl documents the struggles of the "badocari," a particular group of homeless Romanian Roma living in Copenhagen. She offers a syndemic approach that stresses the links between social injustice, ethnicity, and disease. Finally, Lise Foisneau shows how health-related policies perpetuate the exoticization and exclusion of Roma. Her paper deconstructs political discourse and policies on the *gens du voyage* in France. She shows how areas reserved for the *gens du voyage*, allegedly to facilitate better health outcomes in practice, violate basic human rights pertaining to decent

living conditions and provide a tool for surveillance and intrinsic marginalization.

Despite this predominantly bleak picture, it would not be accurate to characterize all health-related developments concerning Romani populations in Europe as solely negative.<sup>8</sup> Romani nongovernmental organizations have developed programs explicitly targeting health-related discrimination, such as through the introduction of community-based health mediators who are familiar not only with communities' apprehensions but also with the urgent imperative of making mainstream health care more accessible and functional for them. Indeed, for almost two decades now, the emphasis of institutional initiatives on Roma access to health has been, above all, on health mediation. In Romania, for example, the mediation program started by Romani CRISS in 1996 and taken over by the Ministry of Health in 2001 includes among its goals the improvement of communication between Roma and medical personnel and increased Roma access to medical services. Despite good health outcomes in many communities, the mediators have not succeeded in reversing several enduring elements of anti-Roma discrimination.<sup>9</sup> Moreover, the mediators' presence has not neutralized the lack of anti-bias and anti-racist training for health personnel or the broader failures of health institutions to prioritize the elimination of pervasive discrimination in health care provision.

Another positive development with some encouraging results is the use of litigation as a strategy for tackling anti-Roma discrimination in the health sector.<sup>10</sup> Alpha Abdikeeva and Alina Covaci discuss the impact of legal advocacy on Roma's awareness of their health rights, using Macedonia as a case study. They argue that the increasing use of lawsuits has led to some reduction in the prevalence of violations of Roma health rights.

Overall, the articles presented here provide a comprehensive, diverse, and critical reflection on the state of Romani groups' access to health on the European continent. They remind us that this issue is still a major unresolved challenge on the human rights agenda. Racial discrimination, poor living conditions, and forced evictions are among the

many factors that compound the unequal health status of Europe's Roma families and communities.

Research has a significant role to play in documenting health deficits, policy inadequacy, and productive strategies for advancing the enjoyment of health rights by all. We are enthusiastic about contributing to this aim through this special section of *Health and Human Rights Journal*, whose essays add to the knowledge production on Roma rights to health.

## References

1. European Roma Rights Centre v. Bulgaria (European Committee of Social Rights, Complaint No. 151/2017, decision on admissibility, October 16, 2017). Available at <https://rm.coe.int/cc151casedoc1-en-complaint/1680725339>.
2. Ibid.
3. Office of the United Nations High Commissioner for Human Rights, Global study on the human rights situation of Roma worldwide. Available at <http://www.ohchr.org/EN/Issues/Minorities/SRMinorities/Pages/GlobalStudyonRomaworldwide.aspx>.
4. Romani CRISS, NGO Report on the third to fifth periodic reports of Romania concerning the International Covenant on Economic, Social and Cultural Rights (2014). Available at <http://romanicriss.org/PDF/Romani%20CRISS%20report%20for%20Romania%20s%20review%20under%20the%20UN%20Committee%20for%20Economic,%20Social%20and%20Cultural%20Rights.pdf>.
5. Ibid.
6. Gwendolyn Albert, "Forced sterilization and Romani women's resistance in Central Europe," *Different Takes* 71 (2011).
7. Swedish Ministry of Culture, *The dark unknown history: White paper on abuses and rights violations against Roma in the 20th century* (Stockholm: Government of Sweden, 2015).
8. A. Pomykala and S. Holt, *Romani women: A priority for European public health policy* (New York: Open Society Institute, 2009).
9. Open Society Foundations, *Roma health mediators: Successes and challenges* (New York: Open Society Foundations, 2011).
10. L. London, "What is a human-rights based approach to health and does it matter?" *Health and Human Rights Journal* 10/1 (2008), pp. 65–80.

This editorial had a correction made and was updated on 8 May 2022.

