

FOREWORD

Romani Global Diaspora: Implementation of the Right to Health

RITA IZSÁK-NDIAYE

It has long been obvious that the general health status of Roma is much worse than that of non-Roma. Surveys have found that European Roma are disproportionately unvaccinated, have poorer-than-average nutrition, and experience higher rates of infant mortality and tuberculosis. Estimates in 12 European Union (EU) member states suggest that Roma live 7–20 fewer years than non-Roma.¹

However, the lack of standardized and systematic disaggregated data prevents us from knowing what factors are rendering Roma more vulnerable to various specific diseases and sicknesses and what exact barriers they face when trying to access health care services. This is not the case in countries such as the United States, the United Kingdom, India, and Brazil, where disaggregated national data-collection schemes broken down by age, ethnicity, race, income, gender, and other variables highlight existing disparities in health status and access to health care. Thanks to such health statistics in the United States, for example, we know the differences between various racial groups regarding live births, smoking habits, obesity, hypertension, health insurance coverage, mortality, leading causes of death, and many other areas, which enables the formulation of appropriate legal and policy responses for the various population groups.²

Health care has always been one of the four main pillars of Roma rights advocacy, together with education, employment, and housing. For instance, it was part of the Decade of Roma Inclusion 2005–2015. In addition, the EU Framework on National Roma Integration Strategies—adopted by the EU Employment, Social Policy, Health and Consumer Affairs Council in 2011—invited member states to focus on access to health care, with particular emphasis on quality health care, including preventive health care and health education. However, this area was and remains the least researched, understood, and strategized field of work given the sensitive and closed nature of health data and health care services. Roma in general often feel mistreated by public authorities, who approach them with suspicion, prejudice, and even hostility. But when it comes to administrative procedures at municipal offices, employment bureaus, and educational institutions, much can be seen and overheard by the public at large, which might positively influence attitudes and behaviors. However, this is not the case in the health arena, where treatments happen behind closed doors and where public knowledge on the subject matters and on patients' rights in general is limited. Health care facilities are usually difficult places for everyone. Anyone who has ever been hospitalized due to sickness

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or childbirth can probably recall feelings of fear, stress, uncertainty, and vulnerability during their treatment. Such feelings are further exacerbated for minorities, who often sense a larger cultural and social distance from health care institutions and their personnel, where the underrepresentation of Roma workers can be acute.

This special section of the journal is therefore an important step forward in documenting existing problems and challenges for Roma in health care and suggesting steps that can be taken to improve their health status, remedy past violations, and empower them to claim their rights.

One of the gravest human rights violations ever committed against Roma and Romani women is the practice of coercive, forced, and involuntary sterilization. Authors in this special section explore current conceptual, legal, political, and social obstacles and their antecedents in 20th century notions of population control. Some also argue that an administrative mechanism is needed to provide financial compensation to victims because the road to remedy via the courts is effectively blocked.

Indeed, courts and judges need to be sensitized to have a better understanding of and approach toward Roma rights cases. I was in a courtroom in Hungary in 2003, when Ms. Sz. A., a Hungarian Roma woman, testified about a coercive sterilization performed on her in 2001. She was asked to explain what it meant in her community for a woman not to be able to bear a child anymore. She felt humiliated and ashamed to talk about this sensitive issue in front of a group of complete strangers in a cold and unfriendly courtroom, and silently sobbed instead of responding. It was a heartrending moment. In the end, although the appellate court found that the doctors had acted negligently in failing to provide her with detailed information, it turned down the appeal on the ground that the plaintiff had failed to prove a lasting handicap as a result of the hospital's conduct. Fortunately, her case ended up at the United Nations Committee on the Elimination of Discrimination against Women in 2006, which issued a positive ruling recommending that Hungary compensate the victim and take measures to ensure that health officials provide adequate information

to patients and obtain their informed consent. Consequently, in 2008, Hungary amended its Public Health Act to ensure that women receive proper information regarding sterilization procedures, and in 2009, the Ministry of Social Affairs and Labour announced that it would compensate Ms. Sz. A. in line with the committee's recommendations. This clearly demonstrates that lawyers and judges at the national level should familiarize themselves with Romani culture and understand the issues of Roma women better so that they can establish a more welcoming and encouraging atmosphere for the discussion of such delicate matters and so that judges are enabled to deliver better rulings.

There are several studies across Europe that show that Roma are more reluctant to access health care services due to factors such as language and literacy barriers, limited knowledge of the health system, discrimination, a lack of trust, a lack of identification cards or insurance, and physical barriers.³ The most likely encounter with health care facilities happens during pregnancy and childbirth. Many years ago, I led a research project on forced sterilization and discrimination against Romani women in the health care system. We conducted 131 interviews with Hungarian Roma women, documenting the existence of segregated maternity wards, negligent treatment of Romani women by medical professionals, verbal abuse, the provision of substandard health care services, and the requirement of payment when treatment was supposed to be free.⁴

Stereotyping and discrimination against Roma often happen because of the stigma associated with them. They are often labeled as dirty, smelly, and unclean, while at the same time being denied access to water and sanitation, which highlights one of the insidious qualities of stigma: it has a self-fulfilling and circular nature.⁵ Although the United Nations General Assembly has confirmed the right to safe and clean drinking water and sanitation as a human right that is essential for the full enjoyment of life and all human rights, Roma lack even rudimentary access to water and sanitation in countries where non-Roma communities have universal access to them.⁶ Unfortunately, this leads

not only to heightened barriers in accessing health care services but also to eviction. According to international human rights standards, access to water services and protection from forced eviction should not be made conditional on a person's land tenure status, such as living in an informal settlement.⁷

The dire situation of Roma is not limited to the European continent. In 2014, at the invitation of the Human Rights Council, I carried out a comprehensive study of the human rights situation of Roma worldwide, with a particular focus on the phenomenon of anti-Gypsyism.⁸ My research found that Roma face similar challenges outside of Europe as well. For example, living conditions in Roma villages in central and southern Iraq are reportedly among the most deplorable in the country. Many Roma live in windowless mud houses without electricity, clean water, health care, or adequate food, and are cut off from social security services. And in Brazil, many Roma settlements reportedly have no electricity, safe drinking water, or sanitation, despite the fact that some of these settlements have been in existence for over 20 years. In general, for Roma around the world, poverty, a lack of identification documents, and a lack of transportation options from remote areas to health-care facilities all contribute to negative health impacts, which are compounded by poor living conditions, such as living near garbage dumps or polluted rivers. Factors precluding Roma access to health care include being refused medical treatment, having no access to emergency services, being subjected to verbal abuse, and being segregated in hospital facilities. Furthermore, lack of access to health care may result from indirect discriminatory practices, such as when Roma are required to provide identity or residency documents in order to register and qualify for health care benefits.

As the articles in this special section show, the tasks ahead of us are many, and they require a coordinated multisectoral approach. Measures addressing the socioeconomic vulnerability, including the poorer health status, of Roma must involve efforts not only to tackle poverty and marginalization but also to end widespread prejudice and discrimination toward Roma. Therefore,

awareness-raising among the Roma population and civil society on health rights is essential.

These papers will further educate and inspire us to continue our struggle to ensure that appropriate laws, policies, programs, and projects are established to finally achieve equality for Roma both in rights and in dignity so that they become more aware, more empowered, and just as likely to live as long and as healthily as their non-Roma neighbors.

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