The Social Roots of Roma Health Conditions

By Karen Plafker

The World Health Organization defines health as " *a state of complete physical, mental and social well-being* […] *not merely the absence of disease or infirmity* […] *the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition.*"[1]

The Roma peoples of Central and Eastern Europe are in the unique position of suffering the worst health conditions of the industrialized world together with some of the worse health problems associated with the third world. Rates of both infectious and non-communicable diseases are high.[2] The proportion of Roma living in poverty exceeds 75% in countries throughout the region.[3] Unemployment is also high, with reports of total unemployment in certain Roma areas.[4] Access to preventive and curative healthcare services is low.[5]

Perhaps most disturbingly, the health status of Roma is consistently worse than that of populations as a whole.[6] The fact that there is a disparity between Roma and majority communities in virtually every health indicator is not in dispute, nor is the fact that Roma are invariably on the wrong side of that gap. But debate continues on the causes of this gap and the steps that should be taken to close it.

Obstacles to promoting Roma health

Efforts to promote the health of Roma populations often fail to confront the social structures which shape health in the first place: inequity and discrimination in education, employment, and housing; poor access to clean water and sanitation; lack of social integration; minimal political participation; poor access to food; disparities in income distribution; etc.[7] In better cases, this results in well-intentioned, charitable health programs which offer no systemic or sustainable change. In the worst cases, the health needs of Roma communities are deliberately ignored, efforts are focused on the majority population's fears about infectious disease and fertility,[8] or the Roma are simply blamed for their predicament.

The gaps in health status between Roma and majority populations reflect – and are compounded by – official discrimination and marginalization of Roma throughout the countries of Central and Eastern Europe. The conventional wisdom that lifestyle explains the health status of Roma communities fails to take into account the social structures which determine health and create the context in which these lifestyles are taught and learned.

- *Official and popular misconceptions about the determinants of health.*

  To date, much of the national and local-level discussion about the relatively poor health of Roma has focused on a perceived lack of health data and on the poor health behaviour of the Roma. To acknowledge the underlying causes of ill health and inequitable health status within national populations would require acknowledging the inequity inherent in existing political and economic structures that result in the inequitable distribution of resources. Refusal to challenge the *status quo* fuels the limited understanding among politicians, policymakers and the general public of the broad social influences which shape the health of all, including the Roma. This is virtually a defining characteristic of official responses to minority health in the developed world.

Compounding this situation are challenges specific to national governments and Roma communities in Central and Eastern Europe:

- *Weak civil society advocacy skills in Central and Eastern Europe.*

  Civil society skills in promoting health are limited, a fact reflected by the relatively small number of NGOs, Roma or non-Roma, working specifically on health and their limited experience in effecting change in health. Health rights and conceptual frameworks which understand health as a social product – as something more than just sickness and medicine – are not widely shared. In addition, there are few alliances among Roma NGOs, or between Roma groups and non-Roma groups concerned with social justice, which might facilitate an alternative vision of health.

- *Citizenship issues and fear of repression.*

  Meanwhile, the citizenship of many Roma remains unresolved in many countries. This has left many people in Roma communities without some of the basic tools of citizenship and political participation, including voting and standing for political office. The lack of documents also raises specific concerns about the ability of Roma to access health services directly or to secure the insurance or social security documents they need to utilize services. While only a small proportion of what we understand as "health" is attributable to utilization of health services, lack of access to services is the proverbial "canary in a coal mine," a warning sign and, in this case, concrete evidence of the wider discrimination which permeates every aspect of life in many Roma communities. Meanwhile, efforts to secure documents receive a mixed response from Roma communities, including the fear that registering with authorities creates the opportunity for government repression.

- *Inadequate public response to minority health issues.*

  Inadequate official action has virtually created the poor health conditions in which Roma live. Yet there is still an absence of both political will and popular support for needed policy, infrastructure and programmatic change. For example, there are numerous reports of racism on the part of health providers towards Roma. But remedy is available neither in the courts, in the training framework for healthcare providers, nor through any other mechanism. In fact, there is an almost-complete lack of structures for protecting and promoting health-related rights, such as codes of ethics for health professionals, patients' rights charters, complaints mechanisms of any kind, or ombudsman offices concerned with health rights.

  Policies discriminate directly against Roma or affect them disproportionately even as states present them under the guise of other objectives. Examples include fees for documents needed to access health services, or health insurance schemes covering up to three children only. This signals how little contact there is between government and Roma communities and illustrates the lack of Roma participation in government and in healthcare delivery systems.

We may be underestimating the existing opportunities to challenge this reality and place responsibility for disparities in health between Roma and others squarely at the door of government policy and practice. Responses are needed which re-shape the terms of the causality

debate and integrate health into the broader rights-based Roma political, social and economic justice agenda.

Opportunities to promote Roma health

It is time to move beyond frameworks which focus exclusively on individual responsibility, and instead claim the rightful place of Roma health within the broader struggle for human rights and full economic, social and political participation.

There *are* opportunities for change. First of all, there is interest in health issues at the community level: Roma women leaders often cite health – along with education – as a top community priority. And there is a growing community of Roma rights organisations. While many of these do not work on health as yet, they may be encouraged to integrate health into their advocacy agenda and to use health data as evidence of discrimination in other areas of public life, including employment, education and delivery of public services, including health care.

Second, although decisions about European Union enlargement often seem to be a foregone conclusion, the EU accession process still offers opportunities to influence official Roma health policies and practice. The EUMAP monitoring project, of which this website is part, is one example of monitoring government compliance with the political criteria for EU membership. The "Roma strategies," which were prepared by the accession country governments as part of the accession process and which make explicit governments' commitments to promote Roma rights in all spheres, offer another opportunity for NGO monitoring and advocacy.

Finally, the international human rights system provides plenty of space for advocating Roma rights to health. The International Covenant on Economic, Social and Cultural Rights (ICESCR) guarantees the right to health, specifically "the highest attainable standard of physical and mental health,"[9] and other human rights instruments contain additional guarantees related to health.[10] What this language actually means and, therefore, what states can be held accountable for continues to evolve. For example, in a General Comment issued in 2000, the UN's Committee on Economic, Social and Cultural Rights noted that:

…'the highest attainable standard of physical and mental health' is not confined to the right to health care. On the contrary, the drafting history and the express wording of article 12.2 [of the ICESCR] acknowledge that the right to health embraces a wide range of socio-economic factors that promote conditions in which people can lead a healthy life, and extends to the underlying determinants of health, such as food and nutrition, housing, access to safe and potable water and adequate sanitation, safe and health working conditions, and a healthy environment."[11]

In other words, despite some lack of clarity about the "content" of the right to health, there is recognition at the international level that health cannot be described or improved in isolation.

The UN treaty monitoring bodies are increasingly interested in health and the ways in which human rights and health intersect. Some have guidelines on health for use by states parties during the reporting process, or in seeking input from non-state parties – intergovernmental and non-governmental organisations – to complement state reports. The "shadow reports" on reproductive health prepared by NGOs for submission to the Committee on the Elimination of Discrimination Against Women (CEDAW)[12] is one example of advocates using the international human rights machinery to advance the right to health, up to and including health care. These efforts should be encouraged and relationships fostered between the treaty-monitoring bodies and Roma NGOs.

Litigating claims of discrimination in the right to health is another mechanism for advancing Roma health. A pilot initiative is underway in one Central European country to assess how anti-discrimination litigation at the national level can contribute to social change around Roma health. Bringing claims to the regional or international human rights commissions remains under-explored

A reconceptualisation of the determinants of health suggests new ways to respond to the disparities between the health status of Roma and majority populations. Defining health as more than disease makes it possible to integrate health into wider Roma rights agendas. Simultaneously, understanding health as a human right opens the door to using enforcement mechanisms related to national, regional and international law to advance Roma health.

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Footnotes

[1] Constitution of the World Health Organization (WHO). The Constitution was adopted by the International Health Conference, New York, 19 June—22 July 1946, signed on 22 July 1946 by the representatives of 61 States (*Off. Rec. Wld Hlth Org*., 2, 100), and entered into force 7 April 1948.

[2] Hajioff, S. and McKee, M., "The health of the Roma people: a review of the published literature", 54 *Journal of Epidemiology and Community Health* 864-9 (2000).

[3] Ringold, D, *Roma and the Transition in Central and Eastern Europe: Trends and Challenges*, Washington, DC: The World Bank, 2000, pp 10-12.

[4] *Ibid*., p. 14.

[5] Zoon, I. *On the Margins: Roma and Public Services in Romania, Bulgaria, and Macedonia*, New York: Open Society Institute, 2001; Zoon, I. *On the Margins: Roma and Public Services in Slovakia*, New York: Open Society Institute, 2001.

[6] Ringold, p. 20.

[7] See, e.g., Marmot, M. and Wilkinson, R.G. (eds.) *Social Determinants of Health*, Oxford: Oxford University Press, 1999; Berkman, L.F. and Kawachi, I. (eds.) *Social Epidemiology*, Oxford: Oxford University Press, 2000.

[8] Hajioff and McKee; Koupilova, I., Epstein, H., Holcik, J., Hajioff, S., McKee, M., "Health needs of the Roma population in the Czech and Slovak Republics", 53 *Social Science & Medicine* 1191-1204 (2001).

[9] ICESCR, Article 12.

[10] International Convention on the Elimination of All Forms of Racial Discrimination (Article 5); International Convention on the Elimination of All Forms of Discrimination Against Women (Articles 10, 12, 16).

[11] Committee on Economic, Social and Cultural Rights, General Comment 14, UN ESCOR, 2000, Doc. No. E/C.12/2000/4.

[12] See, e.g., Center for Reproductive Law and Policy (CRLP), in collaboration with Be Active, Be Emancipated (B.a.B.e.), *Women's Reproductive Rights in Croatia: A Shadow Report*, 2001. Online here. See also Center for

Reproductive Law and Policy (CRLP) and the Family Planning and Sexual Health Association, Vilnius, Lithuania, *Women's Reproductive Rights in Lithuania: A Shadow Report, 2000*. Online here.