

# Romani Women - A Priority for European Public Health Policy

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The poor health status of Roma [1] generally and the inadequate access to healthcare experienced by many Romani communities across Europe require urgent attention and action. [2] The links between good health and overall welfare, including improved living conditions, employment and other opportunities, are well established. For Roma, the effects of inadequate healthcare often impact disproportionately on *women*, who frequently bear principal responsibility for family healthcare and provide the point of contact between Romani communities and public health services. Romani women are often overlooked in policies devised on behalf of Roma. Improving access to healthcare for Romani women is therefore integral to improving the health and overall welfare of entire Romani communities; greater attention should be given to their social, economic and political integration.

These issues are particularly pressing in those post-communist societies which have shifted towards privatisation of public services and the promotion of a free market economy. Several countries are in the process of reforming their healthcare systems. In this climate, care is required to ensure that the most disadvantaged and vulnerable in society are given the same opportunities in these developments as other members of the population. They must not be allowed slip through the net of social protection. At the same time, exclusion of Roma women from adequate healthcare provision remains a pressing issue in Western Europe too, where barriers to accessing healthcare also exist. As in Central and Eastern Europe, the underlying causes go deeper and are often ingrained in prejudice and discrimination.

The development of targeted and effective policies aimed at overcoming the effects of discrimination in relation to access to healthcare for Roma, and particularly Roma women, is a necessary precondition for improving the overall situation of Roma throughout Europe. For moral and practical reasons it is in the public interest that the good health of everyone, including members of minority populations, is assured.

In response to these concerns, a number of inter-governmental organizations have cooperated in a research initiative with a view to contributing analysis and policy options to states for improved access to public healthcare for Roma women and their communities throughout Europe. [3] While the conclusions and recommendations have yet to be finalized, some preliminary findings are

described in this article. The forthcoming report will include examples of good practice in the areas discussed below, for consideration as working models for other States or communities to adopt.

## 1. Discrimination in Accessing Healthcare

The physical, economic and information-based barriers to healthcare that many Roma confront result from complex and inter-related effects of poverty, discrimination, and unfamiliarity with government institutions generally, and healthcare services in particular. The forms of discrimination that Roma experience are multifarious, depending on a variety of factors including whether a community is urban or geographically isolated or whether Roma populations are sedentary or nomadic.

Roma may experience direct discrimination in, for example, the refusal of physicians or healthcare institutions to treat them. They may be the targets of verbal abuse and degrading treatment in the course of seeking care. Roma may be separated from other patients on the basis of ethnicity. Such events may be isolated “the result of one individual’s prejudice” or widespread and systemic. Given that women are more likely than men to interact with the health services, Romani women are disproportionately affected by these incidents.

Indirect discrimination occurs when apparently neutral legislation, regulation, policy or practice, impacts negatively and disproportionately on a particular group. [4] In the context of access to healthcare, indirect discrimination may result from policies that overlook the needs of minority populations, for instance, in determining the location of clinics. Health research may fail to examine the needs of rural women or of migrant communities. Health information may not be available in a language or manner accessible to Romani women. Criteria for social benefits that limit the number of children for whom assistance is available may exclude a disproportionate number of Roma, who tend to have larger families. Such legislation, policies and practice may perpetuate inequalities and must be prohibited in order to achieve change. [5]

Various socio-cultural and psychological factors may compound these difficulties and discourage Romani women from paying attention to their own health. A poor understanding of the value of preventive screenings combined with the desire to forego attention to personal well-being in the interest of attending to family care may cause Roma women to regard health services as generally inapplicable or unavailable to themselves. In turn, certain traditions associated with religious beliefs, purity practices, and maintaining family honour through vigilance over a

daughter's virginity may be a source of pressure on women to conceal their interest in and efforts to obtain reproductive or sexual healthcare. These practices may result in increased health risks for women, especially adolescents, who may not have the opportunity to learn about warning signs of reproductive and other health problems. In some cases, unequal gender dynamics within Romani communities may impede access to care in a manner that may constitute gender discrimination.

## 2. Human Rights Principles

### 2.1 *Non-discrimination and equality*

Poor health status and inadequate access to care manifest themselves variously in different countries and conditions. While solutions must be tailored to specific needs, the underlying public policy considerations remain the same: ensuring access for Roma, including women, on an equal basis with members of the majority population. This follows from the principles of non-discrimination and equality enshrined in international human rights standards which call for everyone to enjoy equality of opportunity in all areas of public and private life, without discrimination on the basis of race, ethnicity or national origin. [6] Discrimination on grounds of gender is likewise prohibited. [7]

Whatever the form of discrimination, its function as an impediment to accessing adequate healthcare requires a response from the state. Under international law, states have an obligation to combat all forms of discrimination and to provide effective remedy and appropriate sanctions where such discrimination exists. Specifically, under the European Union's "Race Equality Directive" [8] which will enter into force in July 2003 and with which EU candidate states must also comply "states are required to act to combat discrimination, direct or indirect, on the grounds of racial or ethnic origin, in both the public and private sectors, and including in public healthcare bodies. [9] To this end they are required to abolish laws, regulations and administrative provisions contrary to the principle of equal treatment, ensure the implementation of effective proportionate and dissuasive sanctions, and adopt relevant laws specifically to implement the Directive. [10]

### 2.2 *Positive action and special measures*

A human rights approach highlights the need for equality, both formally and

substantively. Thus, states are required not only to protect against discrimination, but to take positive action in order to ensure the equal enjoyment of rights. [11] Specifically in relation to health, states have a duty to facilitate the enjoyment of the “highest attainable standard of physical and mental health” on an equitable basis. [12] They must ensure that minimum standards are respected with regard to the basic health needs. [13] These standards include, *inter alia*, ensuring equitable distribution of and the right of access to health facilities, goods and services on a non-discriminatory basis, especially for marginalized groups. [14]

State responsibility derives from the positive obligation to ensure equal access for all groups within society, regardless of their ethnic or cultural background and specific associated barriers. Under the ICCPR, states parties are obliged to ensure that “traditional, historical, religious or cultural attitudes are not used to justify violations of women’s right to equality before the law and to equal enjoyment of all Covenant rights”. [15] And under CEDAW, states parties agree to take “all appropriate measures to modify the social and cultural patterns of conduct of men and women, with a view to achieving the elimination of prejudices and customary and all other practices which are based on the idea of the inferiority or the superiority of either of the sexes or on stereotyped roles for men and women.” [16]

The enjoyment of rights and freedoms on an equal footing, however, does not mean identical treatment in every instance. [17] Indeed, the principle of equality sometimes requires states to take affirmative action in order to ensure equal opportunities to groups who have been historically and systematically disadvantaged and where the consequent conditions prevent or impair their enjoyment of human rights. In such cases, positive measures may be required to diminish or eliminate conditions which cause or help to perpetuate discrimination and so redress the imbalance. [18]

An important complement to special measures on behalf of Roma is awareness-raising among the wider population that such measures, including preferential treatment in specific cases, serve not to place Roma women in an advantageous position, but to level the playing field. Acknowledgment of the extent to which discrimination is a cause of existing inequalities should be clear. In light of these obligations, states should take steps to understand the unique dimensions of Romani culture(s) regarding health, with the goal of providing effective interventions to achieve equality of access to care. Consideration might be given to ways in which the provision of information and services can empower Romani women to make independent and informed choices about health and related

aspects of their lives.

### ***2.3 Participation in policy-making***

The basic democratic principle of participation is one that should underpin all public policy-making processes. [19] Experience shows that design, implementation and monitoring of policies with the active participation of those most affected stand the best chance of success. In the context of Romani women's health, the U.N. Committee on the Elimination of Racial Discrimination is clear: states should initiate and implement programmes and projects in the field of health for Roma, particularly women and children, and involve them in designing and implementing those programmes. [20]

In order to achieve the most comprehensive and effective outcomes, it is important that states involve Romani women in developing policies and programmes on behalf of Roma. More generally, states should mainstream gender issues and the incorporation of a gender perspective to public policy making, e.g. give adequate consideration to the biological and socio-cultural factors "including men's behaviour" that impact upon health. [21]

Greater attention should also be paid to informing Roma women about public health services and how to utilize them, as well as specific preventative issues such as immunization, nutrition, and the harmful effects of tobacco use. This information will enhance women's capacity to organise themselves, assist others and mediate between their own communities and healthcare providers.

Improving access to public healthcare for Roma women depends upon the development of trust and mutual respect between Roma and non-Roma. In this respect, positive examples exist of ways to narrow the gap between health institutions and Roma communities, by means of "health mediators". A mediator system serves to improve access to healthcare institutions by facilitating the exchange of information "and hence understanding and interaction" among Romani communities, healthcare workers and authorities. Insofar as most mediators tend to be women, some important by-products of this institution for women include: employment; the acquisition of negotiation skills; the assumption of a key role in assisting communities to combat stereotypes of Roma; and influence over the process of balancing integration with diverse aspects of Romani culture. While mediator programmes are not a cure-all for the often-great disparities between majority and Roma health status and access to services, states might consider support for training and institutionalisation of

mediators as an important force for systematic change.

### **3. A multi-sectoral approach to improving access to healthcare**

#### ***3.1 Education and health***

Prerequisites to caring for one's physical and mental well-being include some knowledge of what that well-being entails as well as access to the means of achieving it. Schools are a key source of information on hygiene, nutrition, disease prevention and access to the health system – whether through education, access to school nurses, vaccinations, etc. When Romani children have difficulties in accessing education, they are less likely to acquire the tools with which to take control over their own health and other life choices. Romani girls may face additional difficulties in accessing education if they are withdrawn from schools by their parents to protect their virginity, prepare for marriage, or assume household duties. These girls may not acquire the literacy and critical thinking skills to care for themselves and their families, as well as to modify cultural practices which adversely impact their well-being.

It is essential that policy-makers are receptive, sensitive, and sufficiently imaginative to approach problems from fresh perspectives, particularly where matters of culture are at issue. In the context of education, states should facilitate attendance at all levels, but particularly in kindergarten programmes, in order to give Roma children a good start in the education process. States may also consider education policies such as home learning to fill the gaps in Romani girls' education.

#### ***3.2 Housing and health***

Poor living conditions, problems securing a permanent domicile, and a lack of services appropriate to isolated communities, nomadic communities, or caravan dwellers can all impact negatively on access to healthcare. As the primary users and maintainers of housing – often the locus of their employment, child-care, and social interaction – adequate housing constitutes a primary stake for Romani women. Unfortunately, many Roma are forced to live in conditions that pose health and safety hazards – whether due to a lack of affordable dwellings or as a consequence of discrimination and harassment in other locales. For Roma living in rural settlements or caravan sites, the isolation and possible stigma are sources of economic, physical and psychological hardship. Public



services are not easily accessible; healthcare and other service providers may intentionally or inadvertently avoid these communities. Mobile clinics and other creative programmes may be required to fill the gaps in mainstream services for Roma in these situations.

Where permanent residence is required to access public services, Roma may be disadvantaged by the improper discretion of authorities in providing such documentation, or by laws or policies that provide for legal caravan sites in a manner that does not satisfy their needs. Measures should be taken to facilitate registration as permanent residents, and to provide access to healthcare in the interim for persons living in unstable conditions.

It is widely recognized that vulnerable groups such as women, children, and ethnic minorities suffer disproportionately as victims of forced evictions. Roma communities may be unfamiliar with laws and regulations governing housing and evictions, and might seek to avoid interaction with local authorities, given the often precarious conditions in which many of them live.

Evictions impact on health in a variety of ways, both psychological and physical. Typical consequences include trauma; stress due to protecting families from anxiety and violence; separation from support networks; exposure to vigilante attacks; disruption of daily living and childcare routines; health risks from unsuitable or dangerous emergency stopping places; and loss of access to healthcare services. [22] States should take measures to minimize the impact of evictions on access to health, education and social services. When those affected are unable to provide for themselves, states must “take all appropriate measures, to the maximum of its available resources, to ensure that adequate alternative housing, resettlement or access to productive land, as the case may be, is available.” [23]

### **3.3. Statelessness, lack of documentation, and health**

Problems of statelessness, registration and a lack of appropriate documentation affect access to services in all areas of public life, including health services. [24] Many Roma, particularly those in countries facing crisis and post-crisis situations lack basic documents such as birth certificates, identity documents or those specifically related to health insurance. Likewise, many live in illegal settlements or lack legal title to their place of residence, further compounding problems in accessing healthcare. Statelessness, and consequent lack of status within the state of residence, as well as problems with documentation etc., must not be

allowed to impede access to rights. In this regard, states need to be proactive in efforts to ensure that Roma have all necessary documentation for accessing health services, e.g. by providing information about accessing information documents, facilitating birth registration and reducing the costs of registration procedures for those on low incomes. In the interim, access to health information and basic mainstream health services should be assured for those without documentation.

### **3.4 Social benefits and health**

Access to social protection includes access to non-contributory health insurance and other health-related benefits. Many Roma lack access to information about social benefits, and may be unaware that access to a doctor often depends on registration with an unemployment office as proof of entitlement to care. Eligibility criteria such as civil marriage may have a disparate impact on Roma; abuse of social worker discretion in determining eligibility for benefits may further impede access. Economic barriers range from the sometimes high cost of identity documents, such as birth certificates or proofs of civil marriage, to unaffordable transport costs or the means to visit unemployment offices periodically to retain eligibility.

Forced mobility and forced stopping have been found to have extremely adverse impacts on access to social services through a combination of instability, stress, discrimination, and lack of information. Roma who follow semi-nomadic or nomadic lifestyles often face a *de facto* loss of access to social benefits, since payments are normally made to a permanent residence. As with medical records, client-held social benefits records or other non-territory based systems might be explored to avoid loss of these entitlements.

## **4. Some policy-making guidelines**

### **4.1. Statistics and ethnic data**

Statistical data on the ethnic composition of populations is an important tool for establishing the nature and extent of discrimination in access to healthcare. Reliable data is essential both for ascertaining the full health status of Romani populations and (together with good analysis) for the design of appropriate targeted policies in response to identified needs. More generally, states have a responsibility to assess the impact of health service reforms on various ethnic



groups, including Roma. There exists surprisingly little information on Roma women, and on their health situation in particular. This is partly because wider research may intentionally or inadvertently ignore the situation of Roma health (for example, by relying on household-based studies which effectively exclude itinerant groups) or women's health. The problem is further compounded by the sensitive nature of the collection and (mis)use of ethnic data. There is, nevertheless, increasing recognition among Roma and non-Roma alike of the importance of data collection to sound policy development. In this respect, anonymous data collection, properly disaggregated on the basis of ethnicity and sex, along with legal regulation and political commitment should provide adequate safeguards against the abuse of existing or newly-collected data. [25]

#### ***4.2. National programmes***

It is important that measures aimed at improving the health of Roma are not treated as isolated issues (so serving to reinforce the divide between Roma and non-Roma), but are mainstreamed into general health policies. Moreover, coherence and coordination in all aspects of policy-making is required in order to reflect the needs of the entire Romani population. Thus, public policies for Roma should be formulated with the input of Romani women and incorporate a gender component. [26] This requirement extends not only to women's health issues but to all aspects of Roma integration plans. Likewise, state gender equality programmes should incorporate a minorities component. [27] Indeed, states might consider appointing a minority gender adviser to oversee these processes.

#### ***4.3 Equal treatment bodies***

The implementation and effectiveness of anti-discrimination legislation can be further guaranteed through the establishment of bodies for the promotion of equal treatment (including ombudsmen, advisory boards etc.). Specific institutional mechanisms aimed at addressing the concerns of the Roma population can also be established. [28] Measures should be taken to ensure that Roma women have meaningful input in and access to such bodies.

#### ***4.4. Monitoring at all levels of governance***

The development and effective implementation and monitoring of programmes at all levels is required, particularly where implementation of national strategies relies on local authorities. This is especially important in the context of primary

healthcare, which is primarily a local phenomenon. [29] In this respect, transparency in public administration is key. States should use all available instruments to ensure systematic legal control of decisions by authorities involved in Roma-integration plans. Emphasis should be placed on eliminating the initiation or tolerance of discriminatory practices by local authorities.

## Conclusion

Closer examination of the specific ways in which discrimination affects Roma, particularly women, in the context of healthcare has begun to attract attention at the intergovernmental, national and local levels. At the same time, greater attention to Roma women is helping to ensure that their specific needs and interests will form an integral part of policies elaborated on behalf of Roma. The intergovernmental initiative described above will expand upon the guidelines described here, as well as present good practices as a basis for governments and civil society to build better access to healthcare for Roma women and their communities along the principles of equality and non-discrimination.

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*The views expressed in this article are those of the authors and are not necessarily shared by the Council of Europe, High Commissioner, the OSCE, or EUMC.*

## Footnotes

[1] The term “Roma” is used here to refer to ethnic groups who identify themselves as “Romani” or those, such as Gypsies and Travellers in the United Kingdom, Ireland and elsewhere, who share similar aspects of culture and history, and who confront similar issues of discrimination and social exclusion.

[2] See, OSCE High Commissioner on National Minorities, “The Situation of Roma and Sinti in the OSCE Region”, The Hague: April 2000, which identified inadequate healthcare as one of two principal elements of generally poor living

conditions suffered by Romani communities.

[3] This process is a joint initiative of the Council of Europe's Migration and Roma/Gypsies Department, the European Union's Monitoring Centre on Racism and Xenophobia (EUMC) and the Organization for Security and Cooperation in Europe's High Commissioner on National Minorities (HCNM) and Office for Democratic Institutions and Human Rights (ODIHR). A report on the findings of this research, conducted in 15 European countries, is scheduled for finalisation in late 2002.

[4] See, Committee on the Elimination of all Forms of Racial Discrimination, General Recommendation 14 on definition of discrimination, UN Doc. A/48/18, 22 March 1993, para. 2: "In seeking to determine whether an action has an effect contrary to the Convention, [the Committee] will look to see whether that action has an unjustifiable disparate impact on the group distinguished by race, colour, descent or national origin".

[5] Theodor Meron (ed.), *Human Rights Law-Making in the United Nations*, (New York: Oxford University Press) 1986, at p. 60.

[6] The prohibition of discrimination is typically a feature of all major human rights conventions and is further elaborated in specialized treaties such as the International Convention on the Elimination of All Forms of Racial Discrimination (ICERD); Council of Europe Framework Convention for the Protection of National Minorities (Framework Convention), and the OSCE Document of the Copenhagen Meeting of the Conference on the Human Dimension of the CSCE, 1990 (Copenhagen Document).

[7] For provisions on equality of the sexes, see, inter alia: the International Covenant on Civil and Political Rights (ICCPR); the International Covenant on Economic, Social and Cultural Rights (ICESCR); the Universal Declaration of Human Rights (UDHR); the European Convention on Human Rights and Fundamental Freedoms (ECHR). See also, the International Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW).

[8] Council Directive 2000/43 of 29 June 2000 implementing the principle of equal treatment between persons irrespective of racial or ethnic origin, Official Journal L 180, 19/07/2000 pp.0022 - 0026.

[9] Ibid., para. 12, Article 3 (1)e, and Article 5.

[10] *Ibid.*, Articles 14 - 16. It is noteworthy that OSCE participating states have also committed themselves, in the Istanbul Summit Declaration, para. 31, to “ensure that laws and policies fully respect the rights of Roma and Sinti and, where necessary, to promote anti-discrimination legislation to this effect”.

[11] See, Human Rights Committee (HRC) General Comment No. 4 on equality between the sexes, Article 2; HRC General Comment No. 18 on non-discrimination, para. 5. The full text of all general comments by UN treaty committees up to April 2001 is given in UN doc. HRI/GEN/1/Rev.5, 26 April 2001, online here:  
[http://www.unhchr.ch/tbs/doc.nsf/\(Symbol\)/HRI.GEN.1.Rev.5.En?OpenDocument](http://www.unhchr.ch/tbs/doc.nsf/(Symbol)/HRI.GEN.1.Rev.5.En?OpenDocument)

[12] See, ICESCR (to which all EU member and accession states, with the exception of Turkey, are party), Article 12(1); and the Convention on the Rights of the Child, Article 24(1). In addition, the (revised) 1996 European Social Charter binds States Parties to guarantee rights to *inter alia* social security and social and medical assistance, without discrimination on medical ground. See, Articles 12, 13 and E.

[13] See, the Committee on Economic, Social and Cultural Rights (CESC), General Comment 14 on the right to the highest attainable standard of health, particularly para. 12 outlining dimensions of accessibility, based on the principle of non-discrimination. See, also, CEDAW, Article 12, which provides that: “States Parties shall take all appropriate measures to eliminate discrimination against women in the field of healthcare in order to ensure, on a basis of equality of men and women, access to healthcare services, including those related to family planning.”

[14] CESC General Comment 14, *Ibid.*, para. 43.

[15] HRC, General Comment 28, para. 3.

[16] CEDAW Article 5(a).

[17] See, for example, HRC General Comment No. 18, para. 8.

[18] *Ibid.*, para. 10.

[19] See, in particular, CEDAW, Article 7; and Article 3 of the ICCPR, whereby States Parties undertake to ensure to men and women equally the rights recognized in the Covenant, including the right to take part in public affairs,

directly or through chosen representatives, as enshrined in Article 25. The Framework Convention, in Article 15, requires States Parties to “create the conditions for the effective participation of national minorities in public affairs affecting them”. Paragraph 25 of the Copenhagen Document similarly protects the right of persons belonging to national minorities to effective participation in public affairs.

On minority participation generally see, the *Lund Recommendations on the Effective Participation of National Minorities in Public Life* which were elaborated in September 1999 by independent experts upon request of the OSCE HCNM; for the full text of the Lund Recommendations, see *Helsinki Monitor*, Vol. 11(2000), No. 4, pp. 45-61. See also, the European Roma Rights Center Pamphlet *Political Participation and Democracy in Europe: A Short Guide for Romani Activists* (Budapest: December 2001).

[20] CERD Committee, General Recommendation 27 on Discrimination against Roma (Fifty-Seventh Session, 2000), U.N. Doc. A/55/18, annex V, 16 August 2000, para. 34.

[21] See, CEDAW Committee, General Recommendation No. 23 on Political and Public Life. See also CESCR General Comment 14, Para. 20.

[22] Cemlyn, S., “Traveller Children’s Right to be Treated with Common Humanity,” *Childright*, Nov 1995, No. 121, p5.

[23] See Committee on Economic, Social and Cultural Rights, General Comment No. 7: The Right to Adequate Housing (Art. 11.1): Forced Evictions: E/C.12/1997/4, para 16.

[24] In this connection, the European Roma Rights Centre has sponsored a conference on “Personal Documents and Threats to the Exercise of Fundamental Rights among Roma in the Former Yugoslavia”, from 6-8 September in Igalo, Montenegro.

[25] See, OSCE Conference on Equality of Opportunities for Roma and Sinti: Translating Words into Facts, Bucharest, 10-13 September 2001, Summary of the Working Group Rapporteur’s Reports and Recommendations, p.3. See also: Project on Ethnic Relations, Report on the Roundtable “Roma and Statistics”, Strasbourg, France, 22-23 May 2000; and Krizsan, A. (ed.) *Ethnic Monitoring and Data Protection: the European Context*, CPS Books: Central European University Press: 2001.

[26] The CEDAW Committee promotes the mainstreaming of gender issues and contribution of a gender perspective to public policy-making at national and international levels. See, CEDAW Committee, General Recommendation No. 23 on Political and Public Life.

[27] Bitu, N., Presentation on “Living Conditions”, Seminar on Roma in the OSCE Area, 14-15 June 2000, Bratislava, The Hague: October 2000.

[28] The Race Directive, in para. 24 and Article 13, requires the establishment of such bodies with competence to analyse problems, study possible solutions and provide concrete assistance for victims.

[29] Primary healthcare is essential healthcare based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation [â€¦] It forms an integral part both of the country's health system, of which it is the central function and main focus, and of the overall social and economic development of the community. Declaration of Alma-Ata, International Conference on Primary Healthcare, Alma-Ata, USSR, 6-12 September 1978, Para. VI. Online here: <http://www.who.int/hpr/archive/docs/almaata.html> .