Council of Europe

Topic B: The Right of Roma Women to Health

Table of Contents

1. Introduction

With the entry of the first round of post-socialist nations into European Union in May 2004, Roma minority rights issues have come to the forefront of debates about human rights and belonging in Europe. Roma (or Gypsies) constitute the largest and poorest ethnic minority in Hungary and in Eastern Europe more broadly. When Poland, Hungary, Czech Republic, Slovakia, Slovenia, Estonia, Latvia, and Lithuania joined the European Union, approximately one and a half million Roma became citizens of the European Union. It has been said that Roma women are often double or even triple discriminated. Sadly, this is true - and a shame for the societies where they live. At the start of the twenty-first century,

millions of Roma across Europe still live in conditions of deprivation in access to basic healthcare.

Despite persistent effort by a variety of actors, the Roma community remains the poorest, the most segregated and unprivileged. In their struggle for survival, healthcare has become a primary social good for the Roma. Roma NGOs[1] and international institutions alike have shone a spotlight on a number of issues of concern to Roma: access to education, employment, social services and housing; the promotion of human rights and women's rights; and community development are all priorities. But access to healthcare is neglected as a human rights issue by most actors, the lack of access to quality medical care continues to contribute to the poor health of Roma. This includes both documented discrimination against Roma in health care settings across Eastern and Central Europe as well as perceptions by Roma of unequal treatment and discrimination. This discrimination and marginalization is further reflected in the fact that Roma are far more likely to be less educated, unemployed, and live in substandard housing than the majority population in each of these countries. It is these socio-economic characteristics that are the strongest determinants of Roma health status. Attempting to address these larger social determinants of health in order to close the gap in health status between Roma and majority populations is an enormous challenge. It is especially complex for governments still struggling with major systems transformations with extremely limited financial resources, including money for health programs. Even if strong willingness exists on the part of the government to address these inequities, it must be recognized that major hurdles exist in the widely entrenched discrimination against Roma in all segments and social strata of these societies.

The April 2000 *Report on the Situation of Roma and Sinti in the OSCE[2] Area* recognized inadequate health care as one of two principal elements of generally poor living conditions suffered by Romani communities. Particularly adverse effects were noted for Romani women, who often bear the double burden of ethnic discrimination by majority society and gender discrimination from within their communities. Many factors influencing Romani women's health were identified, including poor housing and sanitary conditions, lack of education, unemployment, and legal status. Discrimination in access to health care raised particular concern: Discriminatory and prejudicial attitudes are one of the key factors in the marginalization and sometimes exclusion of many Roma from public health campaigns and programmes; lack of practical access to health care generates specific concerns for Romani women. While *access* is only one of many dimensions of health, its improvement is a key step towards narrowing gaps in health care between advantaged and disadvantaged groups. Access to health care is a right and a prerequisite for good health without which full participation in social, economic and political life cannot be enjoyed: it is inseparable from access to public services such as education, housing, and social protection, and a precondition to accessing and maintaining employment. Ensuring access to health care for Romani women is thus a key element in ensuring their broader social and

[1] Non-Governmental Organizations
[2] Organization for Security and Cooperation in Europe

economic engagement and social inclusion.

For both moral and practical reasons it is in the interests not only of Roma women themselves, but their families, communities and the wider society that their good health is assured. Commitment to providing the conditions for a healthy, educated, and integrated Romani population on the part of the authorities and wider society will reap benefits for the whole population. Romani women tend to be the primary caregivers in their families and communities. They are also often intermediaries between their families and public services. At the same time, Romani women may neglect their own health while being excluded from education, housing, and other public goods. These factors inhibit Romani women's own personal development as well as that of their communities.

Despite documented cases of discrimination, relatively little attention has been paid to Romani women or health compared to other issues affecting Romani communities. Several factors contribute to this reality. Family and home responsibilities combined with adherence to rigid gender roles in some Romani communities prevent many women from addressing these issues in the public sphere and over a sustained period. Romani women are often overlooked in Roma integration and empowerment efforts. Where national strategies to improve the situation of Roma address health, it is often limited to education initiatives or in the narrow context of maternal health. Greater attention to the discriminatory and gender-related dimensions impeding Romani women's access to health is required. More generally, the translation of government intentions into concrete actions is often impeded, whether by a lack of resources, enforcement authority, or political will (whether at national, local or regional level).

As a consequence, the particular experiences of Romani women's interaction with health institutions and related public services are not often heard, either at national or international levels. Nonetheless, many Romani women and organizations at all levels have made significant contributions to addressing their health and the health of their communities. The work of some of these groups is described herein. This is a period of health reforms especially throughout Central and Eastern Europe, with growing challenges of accommodating migrants and responding to increasingly multicultural societies in the West. Candidate countries for European Union accession have been called upon to remedy poor living conditions and social discrimination of Roma, as well as to improve Roma integration into social development strategies.

The World Conference against Racism, Racial Discrimination, Xenophobia and Related Intolerance recognized[3] the need to develop a more systematic and consistent approach to evaluating and monitoring racial discrimination against women, as well as the disadvantages, obstacles and difficulties women face in the full exercise and enjoyment of their rights because of racism and related intolerance. At this time, a sharing of experience may be particularly useful to identify problems, propose solutions, and exchange lessons learned in improving access to health care and related public services for Romani women and their communities. With this awareness, States can progress individually and in

[3] http://www.un.org/en/ga/durbanmeeting2011/pdf/DDPA_full_text.pdf , Declaration articles 8,9,10

cooperation to achieve these goals.

The life expectancy of the Roma community continues to be below the national average as a result of inadequate living conditions – such as substandard housing and extreme poverty-. Furthermore, women continue to be the target of inhuman and degrading treatment in the form of neglect and/or verbal abuse, segregation in maternity wards and extortion at the hands of doctors and other hospital staff. Poverty is also a factor that has an impact on Romani women access to health care, particularly since the introduction of the "visiting fee".

Women in the Roma communities are not only victims though. Many of them are strong, forceful personalities whom deserve our respect and admiration. Some of them are in the forefront against repression and anti-Gypsism. They are human rights defenders in their world.

2. The right to health

The broad concept of health affecting different aspects of human life is gradually becoming more and more accepted: physical, psychological and socio-cultural aspects and not only absence of disease. The 1948 constitution of the WHO defines health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity." The WHO[4] considers health as a fundamental human right and therefore all people must have access to basic health-care resources.

The right to protection of health lies at the heart of the activities carried out by the Council of Europe in the social domain. National representatives from 47 member states work together with specialist experts to set out minimum guarantees to safeguard human rights and indeed patients' rights at the European level. Membership of the Council of Europe presupposes the obligation for states to ensure their people's prerogative to basic human rights, and among such basic rights is the right to health protection.

This right is guaranteed in Article 11 of the Charter[5] complements Articles 2 and 3 of the European Convention on Human Rights, as interpreted by the case-law of the European Court of Human Rights, by imposing a range of positive obligations designed to secure the effective exercise of that right. Article 11 provides for a series of rights to enable persons to enjoy the highest possible standard of health attainable. These are reflected in:

- measures to promote health;
- health care provision in case of sickness.

Women's right to health

The following rights concern more directly the mother but they also affect the unborn child.

[4] World Health Organization

[5] http://www.coe.int/t/dghl/monitoring/socialcharter/Theme%20factsheets/FactsheetHealth_en.pdf , The Right to health and the European Social Charter

i) right to maternity leave

Article 8 (right of employed women to protection of maternity) of the Charter guarantees women a period of paid maternity leave; maternity leave of at least fourteen weeks should be guaranteed, six of which must be taken post-natally.

ii) right to maternity pay

Maternity pay must be assured, either by social security benefits or from public funds. The obligation to guarantee maternity pay may only be fulfilled by the continued payment of a salary or through payment of a benefit equal to the salary or close to its value.

iii) Prohibition of dismissal during pregnancy

The Charter prohibits dismissal from the time the working mother notifies her employer that she is pregnant until the end of her maternity leave.

iv) Right to health of the mother and maternal and infant health protection

Under Article 11 (right to protection of health), states are required to bring infant and maternal mortality under control. All measures should be taken to obtain a result as close as possible to "zero risk". The Committee monitors maternal and infant mortality rates.

Under Article 8 of the Charter, working mothers must be granted time off to nurse their babies. Such time off must be treated as normal working time and remunerated as such.

3. The situation of Roma in Europe

> *"Anti-Gypsyism or Romaphobia is still widespread in Europe and is promoted and used by extremists, which can culminate in racist attacks, hate speech, physical attacks, unlawful evictions and police harassment",*
> ***warn MEPs in an own-initiative report adopted by 510 votes to 36, with 67 abstentions***

Today the Roma are still subjected to discrimination, marginalization and segregation. Discrimination is widespread in every field of public and personal life, including access to public places, education, employment, health services and housing. The Romani community is still not regarded as an ethnic or national minority group in every member state, and thus it does not enjoy the rights pertaining to this status in all the countries concerned. The effective participation of the Romani minority in public life is a vital element in all democratic societies, but the participation must always take a voluntary form. There is a need to strengthen, clarify and harmonize the work of multilateral organizations. The Council of Europe can and must play an important role in improving the legal status, the level of equality and the living conditions of the Roma.

The Roma are recognized legally

a) as a national or ethnic minority group in Austria, Croatia, the Czech Republic, Hungary, "the former Yugoslav Republic of Macedonia", Norway, Poland, Romania, Slovakia, Sweden, Ukraine and the Federal Republic of Yugoslavia;

b) as a traditional national minority in Finland;
c) as a racial group protected under the Race Relation Act 1976 in the United Kingdom.

The Roma have no special legal status in Belgium, Denmark, Germany, Greece, Italy, the Netherlands, Slovenia and Switzerland. There are no Roma living in Andorra, Iceland and Malta.

The rapporteur of the Parliamentary Assembly of the Council of Europe has not received any official information about the legal status of the Roma from the following member states: Albania, Bulgaria, Cyprus, Estonia, France, Georgia, Ireland, Latvia, Liechtenstein, Lithuania, Moldavia, Portugal, the Russian Federation, San Marino, Spain, and Turkey.

Roma people's health statistics

Health patterns among Roma are also negatively influenced by high levels of poverty, low levels of education, and limited access to health care and services. Discriminatory and prejudicial attitudes are one of the key factors in the marginalization and sometimes exclusion of many Roma from public health campaigns and programs; lack of practical access to health care generates specific concerns for Romani women.

Statistics from many countries show that the incidence of certain types of environment-related illnesses is typically several times higher for Roma than for the general population. Communicable diseases such as tuberculosis (TB), hepatitis, poliomyelitis, and measles are all reported to be prevalent amongst Roma communities in various States. The last reported cases of poliomyelitis in Bulgaria, the fYROM and Romania, for example, all occurred in Romani communities. Romani children, in particular, are also susceptible to dermatological problems such as scabies and impetigo which are more easily communicated in unsanitary conditions.

While the number of cases of TB is generally on the increase, both in Western Europe and Central and Eastern Europe, it is the most socially and economically disadvantaged groups, such as Roma, who are most at risk, not only in terms of infection rate, but also in terms of recovery. In 1990 in Bulgaria the morbidity rates for TB among Romani children was 60 per 1000 compared with 22 per 1000 for the national average, and in former Czechoslovakia the rate was more than double the national average. Sedentary, crowded living conditions also contribute to the high incidence, in many Romani communities, of smoking, alcohol and drug addiction.

The burden of dealing with the health consequences of these problems is borne disproportionately by Romani women, both as mothers and as the primary health-care providers within the family. Frequently, the perception within non-Roma society is that Roma are more exposed to infections than other groups and that, consequently, they are responsible for spreading epidemics. This perception must be countered by efforts to ensure that discriminatory attitudes in society which hold Roma responsible for spreading

disease and view the illnesses that afflict Roma as being exclusively their responsibility are combated. Health problems related to the social condition of Roma, such as the prevalence of communicable diseases, must be regarded as a matter of public health.

4. The Roma population's perception of health

In some sectors of the Roma community, health is not perceived as a top priority. Housing, finances or employment all come before health in terms of this group's perceived needs. A large percentage of Roma conceive health as the absence of disease, and disease as an incapacitating phenomenon linked to death. This unique perspective on health and disease leads to several consequences:

- Health only becomes a concern in the presence of very dramatic symptoms and incapacitating consequences thus making it difficult to approach the concept of prevention.
- Once the individual (and his family) perceive the presence of disease, action taken must be immediate and definitive in light of the direct relationship existing between disease and death.
- The diagnosis is a matter of "*putting a label on one's affliction.*" Thus, the attitude adopted is ambivalent. Complete avoidance prevails in the absence of symptoms and incapacitating consequences (in these cases the diagnosis may be perceived as a manifestation of a disease that previously did not exist).
- If symptoms disappear under treatment, all other therapeutic guidelines are generally ignored because from the perspective of this concept of health, the disease has vanished.

The concept of health and disease transcends the individual and extends into the realm of group and community issues (especially in terms of the extended family). This characteristic (which, as we will see later, does have positive effects) also implies a series of weaknesses in light of the fact that:

- The decisions taken by an individual with respect to his health are strongly influenced by his extended family. This makes the relationship with the health-care system more complex because it is no longer a relationship between the health-care system and one individual; it is between the system, the individual and his extended family. This characteristic has very visible and striking effects such as the presence of many family members at doctors' surgeries, emergency rooms or at hospital, which others can sometimes find very annoying. Other effects are less visible at the outset but have very clear consequences: the instructions that the health-care professional gives his patient may be subsequently "re-interpreted" by the extended family.
- The result of the prevailing concept of health and disease prevalent among an important proportion of the Roma population, together with this interaction between

the individual and his family, is that many ailments are treated within the family rather than by the health-care system until symptoms and consequences become alarming. This makes early detection very difficult. It is the woman's role to see that health is cared for. The next question is "who takes care of the caretaker?" Women's health tends to come last on the list of priorities. The following situations may arise:

- Out-patient home-based care for women is usually very difficult; first of all because this means that homes must be properly equipped and second of all because it is very difficult for women to take on the role of "patient" at home. - In the case of mental health, women tend to abandon treatment prematurely.

The perceived immediate need to cure illness as quickly as possible is a product of the close association between disease and death. This means that the diagnosis of a health-care professional is urgently needed to determine the problem's degree of seriousness.

The improper use of some health-care services is another of the consequences of the above-mentioned concept of health and disease prevalent among an important proportion of the Roma population:

- Excessive use of emergency room services.
- Infrequent use of ambulance services; patients are generally transported by the family.
- Appointments at doctor's surgeries are not usually made.

The extended family usually has a very clear idea of the course family member's lives should take. If these ideas are very rigid and if the person in question does not want and/or cannot adhere to them, the consequences for the social, mental and even physical well-being of the person could be very negative.

5. Health of Roma Women and Girls

The inequality reinforced by gender-specific structures further limits Roma women's opportunities to enjoy the highest attainable standards of health. In many instances, lack of equal opportunities to access health care is aggravated by the disadvantaged position of Roma women in comparison to Roma men in social fields such as education and employment. As a result of fewer opportunities to access the labor market and lower educational levels, Roma women are more likely to be excluded from health insurance. Exclusion from the health care system has a disproportionate impact on Roma women's health.

Discrimination against Roma women in the area of health care is particularly evident in the areas of reproductive and maternal health and emergency care due to these being the most commonly used health care services. There is a particular reluctance to see the gynecologist as a result of shame caused by a patriarchal education. Coercive sterilization has been a particularly problematic practice imposed on Roma women, in particular in

certain Central and Eastern European countries (though there have also been some cases in Sweden). Sometimes described as a hold-over from Communist times, sterilization without prior full and informed consent has been performed as recently as 2007 and 2008. It is hard to know exactly how many Roma women have been subjected to this serious human rights violation, since it is hard for the victims to report the crime for many reasons – many women find out late, if at all, that they have been sterilized, and resulting feelings of shame and unworthiness can lead them to keep it even from their family, and even more so from the wider community or from lawyers. In addition, admittance of wrongdoing and apologies have often been proffered only after lengthy (court and ombudsman[6]) proceedings, with little hope of winning damages. It can be hoped that, following recent findings at international level, for example by the CEDAW[7] Committee, this will change and victims will start finding the heart to come forward and claim – and receive – damages – as happened recently in Hungary, Slovakia and the Czech Republic.

Regarding coercive sterilisation, Roma women are particularly vulnerable to abuse by medical practitioners at the time of pregnancy and childbirth. Practices of extreme abuse include death after childbirth, serious damage of the women's health, as well as forceful termination of the women's reproductive capacity through coercive sterilization. Roma women are at risk of being subjected to sterilization without their full and informed consent, without an explanation about the intervention, its nature, possible risks, or what the consequence of being sterilized would be. Instances of coercive sterilization of Roma women have occurred in a number of Council of Europe member states.

Advice on family planning should be included in the education process and family codes developed which guarantee women's rights to decide freely and responsibly on the number and spacing of their children. It should include a proper understanding of maternity as a social function and the recognition of the common responsibility of women in the upbringing and development of their children.

6. Recommendations

Concrete action to promote equality and ensure non-discrimination in access to health care must be taken at the State and local levels, and can be supported with the cooperation of intergovernmental and non-governmental initiatives. International and regional anti-discrimination norms should be implemented including through comprehensive national anti-discrimination legislation that expressly prohibits direct and indirect discrimination and against victimization, supported by express instructions against discrimination in access to

[6] An ombudsman is a person who acts as a trusted intermediary between an organization and some internal or external constituency while representing not only but mostly the broad scope of constituent interests

[7] Committee on the Elimination of Discrimination against Women

health care and other public services. States should also consider supporting equal treatment by establishing a legal duty for their public authorities to promote equality. They should examine the need for special measures to ensure full equality in practice and create the conditions for equal enjoyment of access to health care for Roma, particularly women.

Special measures may also be required to ensure that traditional and cultural attitudes do not impede Romani women's rights to the highest attainable health and to take part in the conduct of affairs affecting them. These measures should be combined with mutually re-enforcing capacity building of targeted actors within the Romani community and awareness-raising campaigns of the goals of these measures among the wider population.

Where they do not exist, governments of the Council of Europe should consider the establishment or designation of specialized bodies which can act independently to promote the equal treatment of all persons without discrimination including on racial or ethnic grounds. These bodies should give consistent attention to the field of health care and take account of gender related issues. Such bodies could play a key role in heightening awareness among health care workers and authorities on the various types of discrimination to which Roma may be subject, investigating and supporting complaints as appropriate, undertaking independent research and surveys, and helping to enact and enforce comprehensive anti-discrimination legislation, particularly at the local level.

Concrete steps should be taken to address elements of Romani culture that may impede access to services. A women's rights and gender adviser could help devise such programmes. Access to health information and services throughout the lifecycle should be available to all Roma, including adolescents, rural or isolated and mobile communities. Attention should be given to educating adolescent Romani women, their sexual partners, and parents on the risks associated with early pregnancy. More broadly, education about the right to autonomy and freedom of choice in all decisions relating to sexuality should be a central component of community-wide interventions to improve access to care.

Special measures to address the gender dimensions of women's health and well being in the larger society should include Romani communities, e.g. through awareness-raising among Romani men concerning their role in protecting women's health and preventing domestic violence. Efforts should be made to ensure that interventions in the larger society concerning domestic violence, mental health, and substance abuse address the needs of Romani women. The need for anti-discrimination, gender and culture sensitivity training for authorities, health and other personnel who provide support services for Romani women should be evaluated. Information and services should be provided on a culturally sensitive basis and with attention to the special ways in which Romani women experience these problems.

In the interim, access to health and other public services for which official documentation is required should be provided to persons in need, regardless of race or ethnicity. Where differences of treatment exist based on nationality or legal status, these should be regularly re-examined with a view to promoting equal treatment as appropriate. Improving access to health care for Romani girls and women is inseparable from fulfilling

their right to education.

Ensuring access to legal, habitable, culturally adequate and safe accommodation is paramount to improving health as well as access to the public services for which proof of domicile is required. Romani women should be consulted in policy- and law-making to develop and rehabilitate housing for their families and community. Special attention should be given to guaranteeing access to public services on an equal basis and without discrimination for Roma in rural or isolated and mobile communities. Priority should also be given to the non-discriminatory application of sanitary checks and evictions policies, with due concern for preserving access to public services and preventing homelessness.

In a few sentences, the Council of Europe of Rhodes MRC2011 should examine the following:

a) examine how ethnicity and socioeconomic status affect Roma women's health;
b) ensure that existing laws and policies in favor of gender equality include provisions for preventing and addressing the multiple barriers female members of minority groups face in exercising their fundamental human rights;
c) provide on a regular basis outreach services to reach Roma women and girls who otherwise have little access to medical services;
d) implement patient-oriented educational health programmes for Roma women;
e) ensure the availability of continuing medical education taking into account social and cultural factors with regard to the health of Romani women;
f) develop, support and evaluate interventions for preventing violence, including domestic violence.

The Council of Europe must also ensure that governments will reassure to Romani women all appropriate services in connection with pregnancy, confinement and the post-natal period. Acceptable health care services should be delivered in a way which ensures women's fully informed consent, respects their dignity, and guarantees the taking into account of their needs and perspectives. In order to remedy the damage done to victims of coercive sterilization as well as preventing occurrence of similar extreme violations of patient's rights, governments concerned should undertake the following:

1. Establish an independent commission to investigate the allegations and complaints of coercive sterilization; thoroughly investigate reported cases and make available procedures for women who believe they have been abusively sterilized, to report the issue. These procedures should ensure privacy rights. It is necessary to provide justice to all victims of coercive sterilizations;
2. Review the domestic legal order to ensure that it is in harmony with international standards in the field of reproductive rights;
3. Promote a culture of seeking full and informed consent for all relevant medical procedures.

7. Bibliography

1. http://www.unhcr.org/refworld/pdfid/4bdadc1c10.pdf , The situation of Roma in Europe and relevant activities of the Council of Europe
2. http://www.who.int/hhr/en/ , World Health Organization, Health and Human Rights
3. http://www.soros.org/initiatives/health/focus/roma/articles_publications/publications/leftout_20070420/leftout_20070423.pdf , Left Out: Roma and Access to Health Care in Eastern and South Eastern Europe, Open Society Institute, Public Health ProgrammeUnited Nations Development Program. *Avoiding the Dependency Trap: The Roma Human Development Report* (2003).
4. Hajioff S. and M McKee. "The health of the Roma people: a review of the published literature." *J Epidemiol Community Health*. 2000; 54(11): 864-869.
5. http://www.fra.europa.eu/fraWebsite/attachments/ROMA-HC-EN.pdf , Breaking the Barriers – Romani Women and Access to Public Health Care, by the European Monitoring Centre on Racism and Xenophobia
6. http://www.coe.int/T/DG3/RomaTravellers/archive/documentation/health/RomawomenHealth_en.asp , Conference on Roma Women and Access to Public Health Care: Ensuring Effective Access (Final Report)
7. http://www.nationalromacentrum.org/en/projects/project-in-realization/health-inequalities-regarding-romani-women , National Roma Centrum
8. http://www.thelancet.com/journals/lancet/article/PIIS0140-6736%2805%2971063-1/fulltext , Roma women reveal that forced sterilization remains (Ed Holt)
9. http://www.msps.es/profesionales/saludPublica/prevPromocion/promocion/desigualdadSalud/docs/Health_and_the_Roma_Community.pdf , Health and The Roma Community
10. http://www.msps.es/profesionales/saludPublica/prevPromocion/promocion/desigualdadSalud/docs/Health_and_the_Roma_Community.pdf, Health, Health care and impacts on the health of Roma
11. http://www.euromanet.eu/upload/39/67/Ethnic_Roma_women_EN.pdf , Ethnic minority and Roma women in Europe: A case for gender equality? (Final Report, financed by and prepared for the use of the European Commission, Directorate-General for Employment, Social Affairs and Equal Opportunities in the framework of a contract managed by the Istituto per la Ricerca Sociale and the Fondazione Giacomo Brodolini)