

THE OPEN SOCIETY PUBLIC HEALTH PROGRAM

# **Roma Health Rights in Macedonia, Romania, and Serbia**

*A Baseline for Legal Advocacy*

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Consultant to the Law and Health Initiative and the Roma Health Project.

## Executive Summary

As the continent's largest and most neglected minority, Roma populations across Europe continue to live in conditions highly harmful to their health. Life expectancy among Roma is up to 10 years below average, their infant mortality rate is unacceptably high, and preventive health care is scarcely accessible to them.

The current state of Roma health and human rights cannot be understood outside its socioeconomic context. Roma face systemic discrimination and exclusion in various spheres of life, such as citizenship, education, employment, housing and access to justice. Many Roma have little—if any—personal documentation, obstructing their access to most basic and essential services. Furthermore, Roma communities experience disproportionate rates of unemployment and poverty, and vast numbers of Roma live in unauthorized and typically segregated settlements where everyday living conditions are precarious at best. Limited education among Roma hinders not only their employment prospects but their general awareness about health and human rights. Compounding these problems are negative public attitudes and stereotypes about Roma, which remain deep-rooted and continue to give rise to more tangible forms of discrimination and rights violations, both in health care settings and elsewhere.

Roma report a shocking assortment of human rights abuses in health care settings in particular, including outright denial of medical services and provision of substandard health care. Roma patients' right to medical information, privacy and informed consent are often not respected, and Roma routinely experience degrading treatment in health care facilities that would never be experienced or tolerated by other ethnic groups. For instance, in Macedonia, Roma have reported being forced to pay for free services and being detained if they prove unable to do so. And in Romania, the segregation of Roma in hospital settings is an increasingly common problem.

However, inspiration can be drawn from the many international and regional legal instruments on human rights, in addition to the commitments undertaken by the Macedonian, Romanian and Serbian governments as part of their participation in EU integration and/or the Decade of Roma Inclusion. These instruments have contributed to the increasing recognition of Roma health and human rights abuses in health care settings. Essential to building on this momentum is the ability of Roma-centered NGOs to carry out effective legal advocacy, with a view to increasing accountability for Roma rights violations in health care settings and addressing systemic impediments to Roma access to health care.

The Open Society Foundations (OSF) **Initiative on Legal Advocacy for Roma Health Rights**, launched in 2010 by the Law and Health Initiative (LAHI) and the Roma Health Project (RHP), aims to increase the capacity of NGOs in three focus countries—Macedonia, Romania, and Serbia—to carry out legal advocacy for Roma health and human rights. The Initiative's two guiding objectives are (i) to increase accountability for Roma rights violations in health care settings; and (ii) to address systemic impediments to Roma access to health care. Several NGO projects have been supported under this initiative starting in late 2010.

This baseline assessment—completed in 2012 and drawing on findings from 2010—represents an analysis of the current state of legal advocacy for Roma health rights in Macedonia, Romania, and Serbia. It seeks to establish a point of reference and develop an evaluation framework for a subsequent impact assessment to be conducted at the end of 2014.

OSF's support for legal initiatives focuses on legal empowerment in communities, documentation and advocacy, media advocacy, and strategic litigation. This baseline assessment analyses each of these areas on four different levels: (i) the capacity of Roma-centered NGOs to engage in legal advocacy for Roma health rights; (ii) the effect of legal advocacy on accountability for Roma health and human rights violations; (iii) the effect of legal advocacy on systemic barriers to Roma health rights; and (iv) the effect of legal advocacy on communities (principally Roma communities, but also health care providers and the general public). What follows are the main findings of this baseline assessment on the state of legal advocacy for Roma health and human rights in Macedonia, Romania, and Serbia.

### **Legal empowerment in Roma communities**

As of the writing of this assessment, the NGOs' capacity to educate and empower Roma around their health rights is varied and faces multiple constraints. These constraints range from limited knowledge about health and human rights legal frameworks to reluctance on the part of victims to challenge health care authorities. Furthermore, there is very little accountability in place for Roma rights violations in health care settings. Government authorities in all three focus countries show very little interest in genuinely engaging with Roma to eliminate systemic barriers to their health rights. In turn, Roma-centered NGOs often lack the skills and capacities necessary to effectively communicate and advocate for Roma health rights issues before the relevant authorities. Preliminary results show that the availability of legal services and education can substantially increase Roma ability to pursue legal claims. Particularly promising are community-based paralegal programs.

### **Documentation and advocacy**

Although a few NGOs in each focus country actively document human rights violations, there remains some confusion between what is involved in such documentation and what is involved in filing cases for court purposes. Often, neither Roma individuals nor NGOs can accurately detect, identify, and document human rights violations in a health care context. Even where abuses of Roma rights are well-documented, lacking the link to advocacy, very little has been observed in terms of legal or policy changes. However, there is a marked increase in Roma-centered NGOs that have begun specializing in health rights and strategically connecting documentation of health rights violations to both domestic and international advocacy, including strategic litigation.

### **Media advocacy**

The capacity of Roma-centered NGOs to engage with media outlets varies widely, but most such NGOs do not strategically integrate the media into their advocacy work. Thus, media advocacy does not currently contribute to increased accountability for Roma health rights violations, which remain largely invisible. This state of affairs is due in part

to a lack of media advocacy skills among many Roma-centered NGOs, but also to a lack of interest and hostility about Roma issues among the general public and, by extension, the mainstream media. Just as media advocacy does not yet serve as a means of enforcing accountability, it does not yet function to remove systemic barriers to recognition of Roma health rights. At the time of assessment, much improvement would be needed to result in quality public information on Roma health rights and an improved public perception of Roma communities. There is, however, potential opportunity with local community media outlets.

### **Strategic litigation**

Aside from a few NGOs with some experience in strategic litigation (albeit not health-related), most Roma-centered NGOs have neither the experience nor the capacity to engage in strategic litigation focused specifically on health rights. There are several obstacles to using strategic litigation to enforce accountability in health care settings, ranging from victims' reluctance to pursue legal action to the inadequacy of legal tools at their disposal. As a result, strategic litigation currently only operates to enforce protection of Roma health rights to a limited extent. At the time of assessment, however, Roma-centered NGOs are starting to develop this expertise. A number of strategic litigation cases have either already had an impact on policy or are pending in each focus country. Increasing legal challenges, particularly when pursued in parallel with other forms of advocacy, could translate into a shift in health practice.

## Introduction

Members of Roma communities throughout Europe face discriminatory treatment and other obstacles inimical to their health. These dire conditions have resulted in a life expectancy among Roma that is 10 years below average, in addition to high rates of infant mortality and low vaccination rates. One explanation for this crisis is socioeconomic: Roma populations are characterized by high levels of unemployment, poverty and illiteracy, and their precarious legal status bars them from most measures of social protection. Deep rooted discrimination and rejection on the part of majority populations perpetuate the powerlessness and exclusion of Roma communities.

Improving the overall health of Roma communities requires addressing a host of underlying factors, some of which have been recognized already in domestic and international initiatives. For instance, the European Union—to which several southern and eastern European countries continue to aspire to join—attends closely to the situation of Roma, having devoted a special chapter of the European Commission’s annual report to these countries’ progress toward accession. The Decade of Roma Inclusion, the first multinational initiative to systematically address the barriers Roma face to full integration and equality, has included *health* among its four top priorities, alongside *education, employment and housing*.

However, more work is required to breathe life into formal regulations and policies on Roma in order to see meaningful improvements in their health. Where regional NGOs have been working at length on human rights issues as they pertain to Roma populations, they tend not to focus directly on health, and their resources are often insufficient to sustain legal advocacy for the benefit of Roma.

### Methodology

This assessment represents an analysis of the current state of legal advocacy for Roma health rights in Macedonia, Romania, and Serbia. It aims to establish a point of reference and an evaluation framework, including impact assessment indicators, for a forthcoming impact assessment of this Initiative.

While reviewing the state of Roma health and human rights, OSF’s consultant researched the socioeconomic factors underlying poor health in Roma communities, as well as patterns of rights violations against Roma in health care settings. Given the lack of official statistics and other current quantitative data, this baseline assessment employs various sources—namely, interviews with regional NGOs, community surveys, and other information culled from OSF grantee reports and publications.

The state of legal advocacy for Roma health in Macedonia, Romania and Serbia was assessed using the following four focus points: (i) legal empowerment of Roma communities; (ii) human rights documentation and advocacy; (iii) media advocacy; and (iv) strategic litigation. For each of these focus points, the baseline assessment analyzes the capacity of Roma-centered NGOs to carry out legal advocacy, the level of accountability in place for Roma rights violations, any changes in law or policy resulting

from legal advocacy, and any changes in Roma communities following legal advocacy efforts.

The impact of OSF support will be measured by comparing the present baseline assessment with the outcomes of a future assessment, which will be conducted at the end of 2014 using the same set of indicators. These future findings will enable OSF to revise its strategic objectives for supporting legal advocacy for Roma health rights.

OSF is the principal donor for legal advocacy specifically focused on Roma health rights in Macedonia, Romania and Serbia.<sup>1</sup> This makes it easier to trace and attribute emergent changes in the field of health rights advocacy to OSF-supported NGO interventions. However, because Roma health is informed by multiple determinants—e.g., access to documentation, insurance, housing, employment, and education—changes in access to health among Roma populations may sometimes be byproducts of other initiatives addressing such factors. This will be taken into consideration when assessing the impact of the Initiative on Legal Advocacy for Roma Health Rights.

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<sup>1</sup> The involvement of other donors has been limited to supporting NGOs in service delivery only. For example, a number of projects funded by the World Bank and the EU are aimed specifically at encouraging vaccination of Roma children, gynecological screening for Roma women, etc. While such interventions have proven useful while they lasted, their impact has not been enduring.



# Background: The State of Roma Health and Human Rights

## Socioeconomic background

The state of Roma health and human rights in Macedonia, Romania and Serbia cannot be understood outside its socioeconomic context. Roma face systemic discrimination and exclusion in areas ranging from citizenship, education and employment to housing and access to justice, all of which bear significantly on the health of Roma populations.

### ***Lack of documentation***

Without formally recognized citizenship and other identifying documents, Roma communities' access to health insurance, health care and social assistance is severely limited. This lack of documentation among Roma may also explain the dramatic discrepancies between official and unofficial estimates of the size of Roma populations.<sup>2</sup> In the Shuto Orizari region of Macedonia, nearly 50% of Roma have no documentation whatsoever pertaining to citizenship, health insurance or health care.<sup>3</sup> The Serbian government, for its part, concedes that 90% of the country's internally displaced persons (IDPs) lack proper documentation, which means that 3,600 Roma IDPs have no access to non-emergency health care services.<sup>4</sup> Governments in these regions have proven slow to remedy this problem.<sup>5</sup>

### ***Unemployment and poverty***

Across Macedonia, Romania and Serbia, Roma face disproportionate rates of unemployment and poverty. A lack of formal employment results not only in an irregular or low income but a denial of insurance and the other social benefits enjoyed by legally employed workers. In Romania, only 17% of Roma have paid

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<sup>2</sup> In 2009, the Macedonian State Statistical Office estimated the Roma population as being below 55,000, while NGO estimates range from 80,000 to 260,000. See Keti Andrijevska Jovanova and Pavlina Zefik, *National Report of the Republic of Macedonia*, available at: [www.socialwatch.eu/2009/Macedonia.html](http://www.socialwatch.eu/2009/Macedonia.html), last accessed on 30 October 2012. In Romania, the official figure is under 620,000 versus an NGO estimate of 2.2 million. See *The Romanian Census 2011*, available at: [www.insse.ro/cms/files/statistici/comunicate/alte/2012/Comunicat%20DATE%20PROVIZORII%20RPL%202011.pdf](http://www.insse.ro/cms/files/statistici/comunicate/alte/2012/Comunicat%20DATE%20PROVIZORII%20RPL%202011.pdf), last accessed on 30 October 2012. In Serbia, the official number is 108,000, while unofficial estimates start at 250,000. See [info.worldbank.org/etools/docs/library/.../Session2P1Matkovic.ppt](http://info.worldbank.org/etools/docs/library/.../Session2P1Matkovic.ppt), last accessed on 30 October 2012.

<sup>3</sup> Borjan Pavlovski, *Health, Health care and the Impact of the Health of the Roma in the Republic of Macedonia, Skopje*: ESE, 2009 (hereafter, *ESE Report*) pp. 41-42, on file.

<sup>4</sup> Response of the Serbian Government to the European Commission against Racism and Intolerance (ECRI) First Report on Serbia, 2008, Annex, p. 60, available at: [hudoc.ecri.coe.int/XML/Ecri/ENGLISH/Cycle\\_03/03\\_CbC\\_eng/SCG-CbC-III-2008-25-ENG.pdf](http://hudoc.ecri.coe.int/XML/Ecri/ENGLISH/Cycle_03/03_CbC_eng/SCG-CbC-III-2008-25-ENG.pdf), last accessed on 30 October 2012. Also, Report of the Organization for Security and Co-operation in Europe—Office for Democratic Institutions and Human Rights Roundtable, Belgrade, April 2010, available at: [www.osce.org/odihr/75578](http://www.osce.org/odihr/75578), last accessed on 30 October 2012.

<sup>5</sup> The 2007 Decade Watch report on Macedonia notes: “No significant efforts have been made by the Government to challenge major problems, such as the exclusion of Roma from access to health insurance, and obstacles in accessing health care created by the lack of personal documents.” The report is available at: [www.romadecade.org/files/downloads/DecadeWatch/DecadeWatch%202007%20Update%20-%20Final%20%2830-07-08%29.pdf](http://www.romadecade.org/files/downloads/DecadeWatch/DecadeWatch%202007%20Update%20-%20Final%20%2830-07-08%29.pdf), last accessed on 30 October 2012.

jobs,<sup>6</sup> while in Serbia, 64% of Roma are self-employed, 93% work without a labor contract and 96% have never exercised the right to health insurance or pensions.<sup>7</sup>

### ***Inadequate housing***

In all three focus countries, vast numbers of Roma live in unauthorized and segregated settlements lacking basic infrastructure and often in close proximity to garbage dumps or toxic waste disposal sites.<sup>8</sup> In Serbia, 72% of Roma settlements are not properly registered, 43.5% are classified as slum housing, and 60% are isolated from hospitals and other health care centers.<sup>9</sup> These conditions greatly increase the likelihood of epidemics.<sup>10</sup> Long distances from health care centers necessitate significant transportation costs, which prove prohibitive for those with low or irregular income,<sup>11</sup> while living in unauthorized housing operates as yet another obstacle to obtaining identification documents.

The Decade Watch report on Romania has noted the following:

“The lack of security of tenure continues to be a major problem affecting many Roma ... [and] has given rise to an escalating number of forced evictions of Roma, which has rendered many individuals homeless and has intensified the ghettoization of Roma [...].”<sup>12</sup>

### ***Lack of education and rights awareness***

A lack of education generally results in limited employment opportunities and limited chances to overcome poverty, but it also results in a low awareness of health care issues and human rights. High rates of illiteracy plague Roma populations in all three focus countries. In Romania, an estimated 30% of Roma adults are illiterate<sup>13</sup>—a figure that jumps to 50% for Roma women when considered alone.<sup>14</sup> In Serbia, Roma illiteracy is estimated at 23% for women and 22% for men.<sup>15</sup> An estimated 25% of Macedonian Roma aged over 25 are illiterate. Given Roma women’s

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<sup>6</sup> European Union’s Fundamental Rights Agency, *EU Minorities and Discrimination Survey (MIDIS), Data in Focus Report: The Roma*, 2009, p. 14, available at: [fra.europa.eu/fraWebsite/attachments/EU-MIDIS\\_ROMA\\_EN.pdf](http://fra.europa.eu/fraWebsite/attachments/EU-MIDIS_ROMA_EN.pdf), last accessed on 30 October 2012.

<sup>7</sup> Supra note 4, p. 59.

<sup>8</sup> See ECRI, *The Third Report on Macedonia*, para 104, available at: [hudoc.ecri.coe.int/XML/Ecri/ENGLISH/Cycle\\_03/03\\_CbC\\_eng/MKD-CbC-III-2005-4-ENG.pdf](http://hudoc.ecri.coe.int/XML/Ecri/ENGLISH/Cycle_03/03_CbC_eng/MKD-CbC-III-2005-4-ENG.pdf), last accessed on 30 October 2012. See also the Strategy for Roma Inclusion in Macedonia, p. 27, available (in Macedonian) on: [www.mtsp.gov.mk/WBStorage/Files/strategija\\_romi.pdf](http://www.mtsp.gov.mk/WBStorage/Files/strategija_romi.pdf), last accessed on 30 October 2012.

<sup>9</sup> Supra note 4, p. 72.

<sup>10</sup> A recent dysentery epidemic in Serbia had a significant impact on Roma children. Information from YUROM, August 2012, letter on file.

<sup>11</sup> Roma Center for Democracy, *Improving Access to Health care – Report*, available at: [www.romadecade.org/files/ftp/Improving%20Access%20to%20Health%20Care%20Valjevo%20282%29.pdf](http://www.romadecade.org/files/ftp/Improving%20Access%20to%20Health%20Care%20Valjevo%20282%29.pdf), last accessed on 30 October 2012. Also, ESE Shadow Report to CEDAW, 2012, on file.

<sup>12</sup> Available at: [www.romadecade.org/files/downloads/DecadeWatch/DecadeWatch%202007%20Update%20-%20Final%202830-07-08%29.pdf](http://www.romadecade.org/files/downloads/DecadeWatch/DecadeWatch%202007%20Update%20-%20Final%202830-07-08%29.pdf), last accessed on 30 October 2012.

<sup>13</sup> Available at: [www.unesco.org/uii/litbase/?menu=4&programme=53](http://www.unesco.org/uii/litbase/?menu=4&programme=53), last accessed on 30 October 2012.

<sup>14</sup> Interview with Romani CRISS, Bucharest, Romania, 19 July 2010.

<sup>15</sup> *Multiple Indicator Cluster Survey (MICS) 4 results for Serbia*, published in September 2010, available at: [content.yudu.com/Library/A1vfaq/MICS4/resources/8.htm](http://content.yudu.com/Library/A1vfaq/MICS4/resources/8.htm), last accessed on 30 October 2012.

traditional role as family caretakers, a lack of education affects them particularly harshly, rendering them less able to take proper care of both themselves and their families.<sup>16</sup>

### ***Negative public attitudes***

Negative attitudes and stereotypes about Roma communities are deep-rooted, resilient, and prevalent across the focus region. Public prejudices and unfavorable opinions about Roma are difficult to eradicate from majority populations and often lead to more tangible forms of discrimination and rights violations, notably in health care. Romanian NGOs have identified discriminatory attitudes among health care professionals as one of the most pressing problems facing Roma in health care settings.<sup>17</sup> In Serbia, NGOs have found that harassment of Roma patients by medical personnel is one of the main reasons that an estimated 13% of Roma avoid health care centers if they can.<sup>18</sup> Overall, negative attitudes toward Roma, as expressed in health care settings, lead many Roma to distrust state institutions more broadly, not only deterring them from accessing the health care system but compounding their social marginalization.

### **Violations of Roma health and human rights**

Despite current frameworks designed to promote health and human rights, members of Roma communities report a shocking assortment of human rights abuses and violations in health care settings, including outright denial of health care services, provision of substandard medical care, abusive treatment, and segregation. The following section exposes some of the most common health care and human rights violations experienced by Roma.

### ***Degrading treatment***

Roma experience degrading treatment in health care settings in all three focus countries. Medical personnel routinely insult Roma, in part by making abusive references to Roma ethnicity, culture, hygiene, and reproduction.<sup>19</sup> Many Roma patients, including pregnant women, also report being pushed and slapped by health care professionals.<sup>20</sup> Roma-centered NGOs contend that such hostile and humiliating treatment often discourages Roma patients from exercising their right to health and from visiting health care centers until their medical conditions have become very serious.<sup>21</sup>

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<sup>16</sup> See Advancing Education of Roma in Macedonia: Country Assessment and the Roma Education Fund's Strategic Directions, Budapest, 2007, available at: [demo.itent.hu/roma/portal/downloads/Education%20Resources/Macedonia\\_report.pdf](http://demo.itent.hu/roma/portal/downloads/Education%20Resources/Macedonia_report.pdf), last accessed on 30 October 2012.

<sup>17</sup> Interview with Roma-centered NGOs in Romania, July 2010.

<sup>18</sup> See: [www.eph.org/IMG/pdf/ROMA\\_AND\\_THEIR\\_RIGHTS\\_TO\\_HEALTH\\_CARE\\_Compatibility\\_Mode\\_.pdf](http://www.eph.org/IMG/pdf/ROMA_AND_THEIR_RIGHTS_TO_HEALTH_CARE_Compatibility_Mode_.pdf), last accessed on 30 October 2012.

<sup>19</sup> Silvia Vrinceanu, "Playing Russian Roulette with Roma Health," available at: [www.opensocietyfoundations.org/voices/playing-russian-roulette-roma-health](http://www.opensocietyfoundations.org/voices/playing-russian-roulette-roma-health), last accessed on 30 October 2012. Also see: [www.romadecade.org/files/ftp/Improving%20Access%20to%20Health%20Care%20Valjevo%20%282%29.pdf](http://www.romadecade.org/files/ftp/Improving%20Access%20to%20Health%20Care%20Valjevo%20%282%29.pdf), last accessed on 30 October 2012.

<sup>20</sup> Interview with the NGO Ambrela in Shuto Orizari, Skopje, Macedonia, 9 July 2010.

<sup>21</sup> Interview with RHMs and the staff of the NGO Roma Center for Democracy, Valjevo, Serbia, 10 July 2010.

### ***Denial of health care services***

In all three focus countries, Roma are systematically denied access to health services. In some cases, doctors refuse to add Roma patients to GP lists or to make house calls in Roma settlements even in emergency situations, citing their lack of documentation.<sup>22</sup> These refusals are often motivated, however, by doctors' own prejudices or those of their non-Roma patients, and they have in some cases resulted in the death of Roma patients.<sup>23</sup>

### ***Compound discrimination against Roma women***

Roma women are particularly vulnerable to the denial of access to health care. In Macedonia, pregnant Roma women have been prevented from giving birth in hospitals by medical personnel who have exploited their lack of understanding of their right to health.<sup>24</sup> In addition to the obvious health risks associated with homebirths, many such births go unregistered and, as a result, these children are denied subsequent access to pediatric care, vaccinations, and other health care services. In Romania, 23% of Roma women surveyed said they had experienced gender discrimination in health care settings, and 95% of these women also believed that health care professionals discriminate against Roma more generally.<sup>25</sup> In Serbia, it has been reported that hospital staff abandon pregnant Roma women while they are in labor on the grounds that "Roma women have many children [and] know how to give birth on their own."<sup>26</sup>

### ***Extortion***

Even though health care is constitutionally guaranteed and must be freely provided to insured persons and those eligibly exempt from insurance requirements, the reality in all three focus countries is that patients inevitably make—and doctors expect—informal payment for health care services. Because most members of Roma communities are poor, they are often unable to provide such payment and, consequently, are treated less favorably. At times, expectations of bribes rise to the level of extortion. In Macedonia, Roma-centered NGOs have documented cases where medical personnel demanded payment from Roma for their children's vaccinations even though the Macedonian legislation guarantees these vaccinations free of charge.<sup>27</sup>

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<sup>22</sup> Information from Romani CRISS, letter on file.

<sup>23</sup> Interviews with Roma-centered NGOs and RHMs in Macedonia, Romania and Serbia, July 2010.

<sup>24</sup> Interview with the NGO Mesecina, Gostivar, Macedonia, 8 July 2010; interview with the NGO Ambrela in Shuto Orizari, Skopje, Macedonia, 9 July 2010.

<sup>25</sup> From "Left Out -- Fact Sheet," available at: [www.opensocietyfoundations.org/publications/left-out-roma-and-access-health-care-eastern-and-south-eastern-europe](http://www.opensocietyfoundations.org/publications/left-out-roma-and-access-health-care-eastern-and-south-eastern-europe), last accessed on 30 October 2012. See also Surdu, L. and M. Surdu. *Broadening the Agenda: The Status of Romani Women in Romania, Budapest*: Open Society Institute, 2006, p. 18.

<sup>26</sup> Law Scanner, *Protection of Patients' Rights – Equal for All*, Belgrade, May 2012, on file.

<sup>27</sup> Interview with the NGO Mesecina, Gostivar, Macedonia, 8 July 2010.

### ***Substandard medical care***

While the notion of malpractice usually concerns an individual doctor's error or negligence, it applies also to health care professionals' treatment of Roma as less important patients. In Macedonia, several such malpractice cases are pending as a result of situations where Roma patients have suffered bodily harm or died because of alleged medical negligence.<sup>28</sup> Journalists and NGOs in Romania have documented several cases where Roma infants have died because doctors failed to attend to their mothers while these were in labor;<sup>29</sup> in one particular case, an infant died after being prescribed medication unsuitable for children.<sup>30</sup> Roma-centered NGOs maintain that many such cases would not have arisen had the patients in question been non-Roma. The challenge of proving malpractice in these cases is aggravated by the custom of 'professional courtesy' among doctors, according to which doctors are unlikely to testify against one another and patients who complain risk experiencing retaliation from other medics.

### ***Denial of medical information***

One common concern among Roma and non-Roma patients alike is that doctors fail to properly explain their medical conditions, the treatment required, their options and their future prognosis, which these doctors claim is due to the burdens of their administrative work.<sup>31</sup> It has been reported time and again, however, that doctors fail to provide Roma with medical information on the grounds that Roma patients "would not understand anyway."<sup>32</sup> In one case in Novi Sad, Serbia, a Roma woman claimed she agreed to five abortions only because, in each case, her doctor told her there was a problem with the fetus but failed to elaborate further.<sup>33</sup> Roma communities also miss out on publicly available health-related information, testing and other preventive measures as a result of their own illiteracy and the failure of health care authorities to provide adequate information to Roma communities.<sup>34</sup>

### ***Violations of privacy and confidentiality***

All three focus countries have been sites of egregious violations of Roma patients' right to privacy, confidentiality and informed consent. In Macedonia, the NGO Health Education and Research Association has reported multiple cases where both Roma and non-Roma patients were tested for HIV without their knowledge, let alone their consent. In other cases, patients were not asked permission to be used as research subjects by medical students.<sup>35</sup> In Romania, hospitals have often issued birth

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<sup>28</sup> Information from the NGO Roma SOS, Prilep, and from the Regional Ombudswoman, Bitola, Macedonia, 7 July 2010.

<sup>29</sup> Available at: [www.opensocietyfoundations.org/voices/playing-russian-roulette-roma-health](http://www.opensocietyfoundations.org/voices/playing-russian-roulette-roma-health), last accessed on 30 October 2012.

<sup>30</sup> Information from a Roma-centered NGO in Zalau, Romania, 21 July 2010.

<sup>31</sup> The ESE Report, p. 74. Also, supra note 26.

<sup>32</sup> Interviews with Roma-centered NGOs in Romania, 19-22 July 2010.

<sup>33</sup> Interviews with Roma residents in a settlement in Novi Sad, Serbia, 11 July 2010.

<sup>34</sup> The study is available at: [www.romadecade.org/files/ftp/Improving%20Access%20to%20Health%20Care%20Valjevo%20%28%29.pdf](http://www.romadecade.org/files/ftp/Improving%20Access%20to%20Health%20Care%20Valjevo%20%28%29.pdf), last accessed on 30 October 2012.

<sup>35</sup> Interviews with the staff of HERA, Skopje, Macedonia, 6 July 2010.

certificates for Roma newborns that indicated their mothers' nationality as "gypsy", in violation of their parents' consent as well as of Romanian laws forbidding such identification.<sup>36</sup>

### ***False imprisonment***

Yet another pattern of Roma rights violations in a health care context has been reported in Macedonia. Allegedly, Roma patients—including newborns—are routinely kept in hospitals until their families pay for their stay. Medical personnel sometimes confiscate identification documents from these Roma until they have paid for the medical services they have received.<sup>37</sup> These practices run counter to the basic human rights guaranteed by Macedonia's Constitution and the many international treaties by which Macedonia is bound.

### ***Segregation***

Segregation in health care settings can be difficult to detect and even more difficult to prove, and NGOs seldom have the capacity to recognize and document it as it happens. Even so, there is a growing body of evidence of racial segregation in Romania's public hospitals. Romanian NGOs carried out a monitoring visit of Hospital No. 1 in Craiova (gynecology, maternity and pediatrics units) and uncovered several rights violations, including:

- segregated rooms for Roma women and children (many of them unclean and lacking proper beds)
- negligent treatment by doctors in breach of basic health and safety standards (e.g., a Roma child with tuberculosis was hospitalized in the same room as Roma children without tuberculosis)
- verbal abuse by non-Roma patients, leading to discriminatory treatment by medical staff.<sup>38</sup>

Such segregatory treatment has also been documented in other regions of Romania.<sup>39</sup> Just as Roma are more likely to experience violations of their right to health, they are less likely to see the benefits of any sort of accountability. Both Roma patients themselves and the Roma-centered NGOs advocating on their behalf are often poorly informed about existing health and human rights legislation and the mechanisms available for redress. According to the European Union's Minorities and Discrimination Survey (EU MIDIS) in 2009, as many as 89% of Roma surveyed in Romania could not name a single institution where they could bring complaints of

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<sup>36</sup> Information from Romani CRISS, letter on file. Also, interviews with the staff of RRC, Cluj, Romania, July 2010.

<sup>37</sup> Such cases were cited in the ECRI report on Macedonia, para 110, supra note 8. Also, an OSF grantee, the NGO LIL, is currently implementing a project documenting false imprisonment of Roma in Macedonian hospitals.

<sup>38</sup> Information from Romani CRISS, on file.

<sup>39</sup> Interview with a Roma-centered NGO in Zalau, Romania, 21 July 2010. The NGO managed to take pictures of the pediatric ward, where non-Roma children's rooms are clean, neat and decorated in a child-appropriate manner, with flowers and teddies. However, Roma children's rooms are dirty and poorly furnished, with broken appliances and scratched walls.

discrimination.<sup>40</sup> Ignorance about the law and the remedies available means that many rights violations experienced by Roma go unchallenged, undermining even basic accountability for such violations, particularly in health care settings. This climate of impunity makes health rights violations more likely not only for Roma patients, but for all patients in the three focus countries.

### **Promising legal and policy tools**

This section provides information about the major global and European legal instruments concerning health and patients' rights that the Macedonian, Romanian and Serbian governments have signed and ratified,<sup>41</sup> as well as the commitments made by these focus countries as part of their participation in EU integration initiatives and the Decade of Roma Inclusion. As will be explored, there are several international and regional legal provisions on health and human rights—in addition to regional policy frameworks—that are relevant to Roma rights.

#### ***Treaty provisions on health and human rights***

Although the right to health is widely recognized as a precondition to the enjoyment of other human rights, it is itself contingent on the fulfillment of other fundamental rights and freedoms. These fundamental rights include the rights to life, liberty, security of the person, information and public participation, as well as freedom against discrimination and torture.

#### ***Right to life***

The right to life is guaranteed by every modern state constitution and all major human rights treaties, including the 1950 European Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR) 2(1),<sup>42</sup> the 1966 International Covenant on Civil and Political Rights (ICCPR) 6(1)<sup>43</sup> and the 1989 UN Convention on the Rights of the Child (CRC) 6.<sup>44</sup> One threat to the right to life lies in the denial of access to health care or the provision of grossly inadequate health care, as exemplified by the above-cited cases of negligent treatment of pregnant Roma women in Romanian hospitals.

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<sup>40</sup> Supra note 6, p. 3.

<sup>41</sup> Annex II to this assessment indicates the status of ratifications of these instruments by country as of 30 October 2012.

<sup>42</sup> Article 2(1) states: "Everyone's right to life shall be protected by law." Available at: [conventions.coe.int/Treaty/en/Treaties/Html/005.htm](http://conventions.coe.int/Treaty/en/Treaties/Html/005.htm), last accessed on 30 October 2012.

<sup>43</sup> Article 6(1) states: "Every human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his life." Available at: [www2.ohchr.org/english/law/ccpr.htm](http://www2.ohchr.org/english/law/ccpr.htm), last accessed on 30 October 2012.

<sup>44</sup> Article 6 states: "States Parties recognize that every child has the inherent right to life. States Parties shall ensure to the maximum extent possible the survival and development of the child." Available at: [www2.ohchr.org/english/law/crc.htm](http://www2.ohchr.org/english/law/crc.htm), last accessed on 30 October 2012.

### ***Right to bodily integrity***

The right to bodily integrity is affirmed by the International Convention on the Elimination of All Forms of Racial Discrimination (ICERD) 5(b),<sup>45</sup> the Framework Convention for the Protection of National Minorities (FCNM) 6(2),<sup>46</sup> CRC 19(1)<sup>47</sup> and the Council of Europe's 1997 Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine (the European Convention on Human Rights and Biomedicine) 5.<sup>48</sup> Threats to the right to bodily integrity arise from medical negligence and failure to respect patients' rights (e.g., requirements of informed consent for medical procedures ranging from abortion and sterilization to medical experimentation).

### ***Freedom from torture and from cruel, inhuman, or degrading treatment***

Torture and cruel, inhuman, or degrading treatment or punishment are outlawed by several international and regional treaties, such as ICCPR 7,<sup>49</sup> the 1985 UN Convention Against Torture,<sup>50</sup> CRC 37<sup>51</sup> and ECHR 3.<sup>52</sup> The 1987 European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment establishes a mechanism for monitoring member states' compliance with ECHR 3.<sup>53</sup> Cruel treatment can include threats posed to Roma mothers that their newborns will be kept in hospital until their medical bills have been paid.

The European Convention on Human Rights defines degrading treatment as treatment that "grossly humiliates the victim before others". The Elements of Crimes used by the International Criminal Court (ICC) provides that when determining whether certain treatment is degrading, the complainant's cultural background must

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<sup>45</sup> Article 5(b) guarantees "[t]he right to security of person and protection by the State against violence or bodily harm, whether inflicted by government officials or by any individual group or institution." Available at: [www2.ohchr.org/english/law/cerd.htm](http://www2.ohchr.org/english/law/cerd.htm), last accessed on 30 October 2012.

<sup>46</sup> Article 6(2) states: "The Parties undertake to take appropriate measures to protect persons who may be subject to threats or acts of discrimination, hostility or violence as a result of their ethnic, cultural, linguistic or religious identity." Available at: [conventions.coe.int/Treaty/en/Treaties/Html/157.htm](http://conventions.coe.int/Treaty/en/Treaties/Html/157.htm), last accessed on 30 October 2012.

<sup>47</sup> Article 19(1) states: "States Parties shall take all appropriate legislative, administrative, social and educational measures to protect the child from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse, while in the care of parent(s), legal guardian(s) or any other person who has the care of the child." Supra note 44.

<sup>48</sup> Article 5 states: "An intervention in the health field may only be carried out after the person concerned has given free and informed consent to it." Available at: [conventions.coe.int/Treaty/en/Treaties/Html/164.htm](http://conventions.coe.int/Treaty/en/Treaties/Html/164.htm), last accessed on 30 October 2012.

<sup>49</sup> Article 7 states: "No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his free consent to medical or scientific experimentation." Supra note 43.

<sup>50</sup> The UN Convention defines torture as "any act by which severe pain or suffering, whether physical or mental, is intentionally inflicted on a person ... for any reason based on discrimination of any kind, when such pain or suffering is inflicted by or at the instigation of or with the consent or acquiescence of a public official or other person acting in an official capacity." Available at: [www.hrweb.org/legal/cat.html](http://www.hrweb.org/legal/cat.html), last accessed on 30 October 2012.

<sup>51</sup> Article 37 states: "No child shall be subjected to torture or other cruel, inhuman or degrading treatment or punishment." Supra note 44.

<sup>52</sup> Article 3 states: "[N]o one shall be subjected to torture or to inhuman or degrading treatment or punishment." Supra note 42.

<sup>53</sup> The text of the Convention is available at: [conventions.coe.int/Treaty/en/Treaties/Html/126.htm](http://conventions.coe.int/Treaty/en/Treaties/Html/126.htm), last accessed on 30 October 2012.



be considered, e.g., whether the treatment would be considered humiliating to another person of the same ethnicity.<sup>54</sup> This definition resonates with the humiliating treatment that many Roma face in health care settings in the three focus countries.

***Right to the highest attainable standard of health***

The right to the highest attainable standard of physical and mental health is recognized in several international and regional legal instruments, most notably the 1966 International Covenant on Economic, Social and Cultural Rights (ICESCR) 12.<sup>55</sup>

The ICESCR's supervisory body, the Committee on Economic, Social and Cultural Rights (CESCR), explains in its General Comment 14 that the right to health requires that health care be readily available, accessible and acceptable in terms of its quality, and that this right depends also on the recognition of the civil and political rights underlying it. The CESCR continues:

“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 healthy working conditions, and a healthy environment (paragraphs 4, 11, 12).

“States have a special obligation to provide those who do not have sufficient means with the necessary health insurance and health care facilities, and to prevent any discrimination on internationally prohibited grounds (paragraph 19).”<sup>56</sup>

The right to health is also affirmed in CRC 24,<sup>57</sup> the Revised European Social Charter 11,<sup>58</sup> the 1979 Convention on the Elimination of All Forms of Discrimination

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<sup>54</sup> See: [www.icrc.org/customary-ihl/eng/docs/v1\\_cha\\_chapter32\\_rule90](http://www.icrc.org/customary-ihl/eng/docs/v1_cha_chapter32_rule90), last accessed on 30 October 2012.

<sup>55</sup> Available at: [www2.ohchr.org/english/law/cescr.htm](http://www2.ohchr.org/english/law/cescr.htm), last accessed on 30 October 2012.

<sup>56</sup> Available at: [daccessdds.un.org/doc/UNDOC/GEN/G00/439/34/PDF/G0043934.pdf?OpenElement](http://daccessdds.un.org/doc/UNDOC/GEN/G00/439/34/PDF/G0043934.pdf?OpenElement), last accessed on 30 October 2012.

<sup>57</sup> Article 24 discusses “the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.” Article 14(2), para b, further obliges State Parties to ensure that rural women “have access to adequate health care facilities, including information, counselling and services in family planning.” Supra note 44.

<sup>58</sup> Article 11 states: “Everyone has the right to benefit from any measures enabling him to enjoy the highest possible standard of health attainable”, while Article 13 guarantees that “[a]nyone without adequate resources has the right to social and medical assistance.” Available at: [conventions.coe.int/Treaty/en/Treaties/Html/035.htm](http://conventions.coe.int/Treaty/en/Treaties/Html/035.htm), last accessed on 30 October 2012.

Against Women (CEDAW) 12,<sup>59</sup> and the European Convention on Human Rights and Biomedicine 3.<sup>60</sup>

***Right to liberty and security of the person***

The right to liberty and security of the person is stipulated in ICERD 5b,<sup>61</sup> ICCPR 9(1) and 11,<sup>62</sup> CRC 37b and 37c<sup>63</sup> and ECHR 5(1),<sup>64</sup> and it is violated when patients are confined to hospitals for treatment against their wishes or prevented from leaving health care institutions because of their inability to pay for treatment, as is experienced by many Roma patients in Macedonia.

***Right to privacy and confidentiality***

The right to privacy and confidentiality is inscribed in ICCPR 17(1),<sup>65</sup> CRC 16(1),<sup>66</sup> ECHR 8(1)<sup>67</sup> and the European Convention on Human Rights and Biomedicine 10(1).<sup>68</sup> Violations of this right occur when health care professionals wrongly disclose Roma medical information or when Roma patients are subjected to medical research or intrusive medical procedures without their informed consent.

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<sup>59</sup> Article 12 states: “States Parties shall take all appropriate measures to eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, access to health care services, including those related to family planning. States Parties shall ensure to women appropriate services in connection with pregnancy, confinement and the post-natal period, granting free services where necessary, as well as adequate nutrition during pregnancy and lactation.” Available at: [www2.ohchr.org/english/law/cedaw.htm](http://www2.ohchr.org/english/law/cedaw.htm), last accessed on 30 October 2012.

<sup>60</sup> Article 3 states: “Parties, taking into account health needs and available resources, shall take appropriate measures with a view to providing, within their jurisdiction, equitable access to health care of appropriate quality.” Supra note 48.

<sup>61</sup> Article 5b assures “[t]he right to security of person and protection by the State against violence or bodily harm, whether inflicted by government officials or by any individual group or institution.” Supra note 45.

<sup>62</sup> Article 9(1) states: “Everyone has the right to liberty and security of person. No one shall be subjected to arbitrary arrest or detention. No one shall be deprived of his liberty except on such grounds and in accordance with such procedure as are established by law.” Article 11 states: “No one shall be imprisoned merely on the ground of inability to fulfil a contractual obligation.” Supra note 43.

<sup>63</sup> Article 37b states: “No child shall be deprived of his or her liberty unlawfully or arbitrarily. The arrest, detention or imprisonment of a child shall be in conformity with the law and shall be used only as a measure of last resort and for the shortest appropriate period of time.” Article 37c states: “Every child deprived of liberty shall be treated with humanity and respect for the inherent dignity of the human person [...]” Supra note 44.

<sup>64</sup> Article 5(1) states: “Everyone has the right to liberty and security of person. No one shall be deprived of his liberty save ... in accordance with a procedure prescribed by law.” Supra note 42.

<sup>65</sup> Article 17(1) states: “No one shall be subjected to arbitrary or unlawful interference with his privacy, family, home or correspondence, nor to unlawful attacks on his honour and reputation.” Supra note 43.

<sup>66</sup> Article 16(1) states: “No child shall be subjected to arbitrary or unlawful interference with his or her privacy, family, or correspondence, nor to unlawful attacks on his or her honour and reputation.” Supra note 44.

<sup>67</sup> Article 8(1) states: “Everyone has the right to respect for his private and family life, his home and his correspondence.” Supra note 42.

<sup>68</sup> Article 10(1) states: “Everyone has the right to respect for private life in relation to information about his or her health.” Supra note 48.

### ***Right to information***

The right to information includes the right to medical information and is laid out in ICCPR 19,<sup>69</sup> FCNM 9(1),<sup>70</sup> CRC 13<sup>71</sup> and the European Convention on Human Rights and Biomedicine 10(2).<sup>72</sup> In a health care context, this right is routinely violated among Roma and non-Roma patients alike in most central and eastern European countries as a result of the traditional paternalism imposed on present-day doctor-patient relationships.

### ***Right to participation in public policy***

The right to political participation extends to public health policy and is affirmed in ICCPR 25a,<sup>73</sup> ICERD 5(c),<sup>74</sup> FCNM 15<sup>75</sup> and CEDAW 7b and 14(2)c.<sup>76</sup> Roma are prevented from enjoying this right when they are left unaware of their rights or are denied the conditions of their exercise, e.g., through the lack of citizenship or other identifying documentation.

### ***Right to non-discrimination and equal treatment***

The right to non-discrimination and equal treatment is enshrined in ICERD 5e,<sup>77</sup> CEDAW 12,<sup>78</sup> CRC 2(2),<sup>79</sup> FCNM 4(1),<sup>80</sup> the European Convention on Human Rights

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<sup>69</sup> Article 19 states: “Everyone shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds...” Supra note 43.

<sup>70</sup> Article 9(1) states: “The Parties undertake to recognise that the right to freedom of expression of every person belonging to a national minority includes freedom to hold opinions and to receive and impart information.” Supra note 46.

<sup>71</sup> Article 13(1) states: “The child shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information.” Supra note 44.

<sup>72</sup> Article 10(2) states: “Everyone is entitled to know any information collected about his or her health.” Supra note 48.

<sup>73</sup> Article 25a stipulates the right “[t]o take part in the conduct of public affairs, directly or through freely chosen representatives.” Supra note 43.

<sup>74</sup> Article 5(c) guarantees “[p]olitical rights, in particular the right to participate in elections—to vote and to stand for election—on the basis of universal and equal suffrage, to take part in the Government as well as in the conduct of public affairs at any level and to have equal access to public service.” Supra note 45.

<sup>75</sup> Article 15 states: “The Parties shall create the conditions necessary for the effective participation of persons belonging to national minorities in cultural, social and economic life and in public affairs, in particular those affecting them.” Supra note 46.

<sup>76</sup> Article 7b guarantees the equal right of women “[t]o participate in the formulation of government policy and the implementation thereof and to hold public office and perform all public functions at all levels of government.” Article 14(2)c guarantees the right of rural women “[t]o participate in the elaboration and implementation of development planning at all levels.” Supra note 59.

<sup>77</sup> Article 5e affirms the “right to public health, medical care, social security and social services without discrimination on any grounds.” Supra note 45.

<sup>78</sup> Article 12 requires State Parties “to eliminate discrimination against women in the field of health care,” while Article 14(2)b requires them to “take into account the particular problems faced by rural women” and ensure women in rural areas have “access to adequate health care facilities, including information, counseling and services in family planning.” Supra note 59.

<sup>79</sup> Article 2(2) states: “States Parties shall take all appropriate measures to ensure that the child is protected against all forms of discrimination or punishment on the basis of the status, activities, expressed opinions, or beliefs of the child’s parents, legal guardians, or family members.” Supra note 44.

<sup>80</sup> Article 4(1) states: “[A]ny discrimination based on belonging to a national minority shall be prohibited.” Supra note 46.

and Biomedicine 11<sup>81</sup> and the 2000 Protocol 12 to the ECHR,<sup>82</sup> which establishes a free-standing right against discrimination. Many violations of Roma rights in health care settings occur in conjunction with discrimination, such as the denial of medical services, the provision of substandard health care and ethnic segregation in health care facilities.

### ***Prohibition against segregation***

ICERD 3 explicitly bars racial or ethnic segregation: “States Parties particularly condemn racial segregation and apartheid and undertake to prevent, prohibit and eradicate all practices of this nature in territories under their jurisdiction.”<sup>83</sup>

**Annex III** outlines the complaint mechanisms available for violations of legally guaranteed health and human rights in the three focus countries.

### **EU accession and Decade of Roma Inclusion**

In addition to the international and regional treaty provisions cited above, the EU accession process and the Decade of Roma Inclusion impose specific commitments on participating states to guarantee human rights on the part of Roma populations.

Candidate countries have to accept the so-called “*acquis communautaire*” before they can join the EU, and make EU law part of their own national legislation. Accession candidates must also fulfill certain political criteria, including institutional stabilization and the safeguard of democracy, the rule of law, human rights and respect for and protection of minorities.<sup>84</sup> The European Commission, an executive arm of the EU, monitors compliance with these requirements, and currently Macedonia and Serbia are candidates for EU accession.

The EU accession process has already resulted in Romania’s membership and, therefore, the country is already bound by EU legislation, including the EU Charter of Fundamental Rights<sup>85</sup> and the Race Equality Directive, which applies *inter alia* to “social protection, including social security and health care” (Art. 3(e)).<sup>86</sup> The Race Equality Directive 2(b) sets out a definition of “indirect discrimination” highly relevant to Roma populations in Macedonia, Romania, and Serbia, deeming it to occur “where an apparently neutral provision, criterion or practice would put persons of a racial or ethnic origin at a particular disadvantage compared

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<sup>81</sup> Article 11 provides: “Any form of discrimination against a person on grounds of his or her genetic heritage is prohibited.” Supra note 48.

<sup>82</sup> “The enjoyment of any right set forth by law shall be secured without discrimination on any ground such as sex, race, color, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status.” Available at: [conventions.coe.int/treaty/en/treaties/html/177.htm](http://conventions.coe.int/treaty/en/treaties/html/177.htm), last accessed on 30 October 2012.

<sup>83</sup> Supra note 45.

<sup>84</sup> More information is available at: [europa.eu/legislation\\_summaries/enlargement/ongoing\\_enlargement/114536\\_en.htm](http://europa.eu/legislation_summaries/enlargement/ongoing_enlargement/114536_en.htm), last accessed on 30 October 2012.

<sup>85</sup> Article 35 affirms the “right of access to preventive health care and the right to benefit from medical treatment under the conditions established by national laws and practices” and specifies that the EU must guarantee “a high level of protection of human health.” Available at: [www.europarl.europa.eu/charter/pdf/text\\_en.pdf](http://www.europarl.europa.eu/charter/pdf/text_en.pdf), last accessed on 30 October 2012.

<sup>86</sup> Available at: [eur-lex.europa.eu/smartapi/cgi/sga\\_doc?smartapi!celexapi!prod!CELEXnumdoc&lg=EN&numdoc=32000L0043&model=guichett](http://eur-lex.europa.eu/smartapi/cgi/sga_doc?smartapi!celexapi!prod!CELEXnumdoc&lg=EN&numdoc=32000L0043&model=guichett), last accessed on 30 October 2012.

with other persons.” The Court of Justice of the European Union in Luxembourg has jurisdiction to hear individual complaints about violations of fundamental rights under EU law, while the European Commission can also open infringement procedures against member states that fail to comply with EU legal provisions.

The Decade of Roma Inclusion was launched in 2005 by the governments of eight central and eastern European states (including the three focus countries), with support and encouragement from the Open Society Foundations, the World Bank, the European Commission, the Council of Europe and other international agencies and organizations. It has become the first truly international and comprehensive initiative to address Roma rights and exclusion in key areas, including health care. Participating countries have developed national action plans for each of the Decade’s priority areas.<sup>87</sup> Civil society can provide input into this process and monitor its implementation and impact on both domestic and international levels.

Progress in the area of health care has been markedly slower than that in other areas, such as education. The current level of implementation of the Decade’s commitments, particularly in the area of health care, has drawn criticism from NGOs in all three focus countries.<sup>88</sup> With increased investment of resources and energy in health care services and health rights advocacy, Roma health could see the same kinds of advances that have been achieved already in the area of education.

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<sup>87</sup> Available at: [www.romadecade.org/](http://www.romadecade.org/).

<sup>88</sup> Interviews with Roma-centered NGOs in Macedonia, Serbia and Romania, July 2010.

# Open Society Foundations Initiative on Legal Advocacy for Roma Health Rights

## Strategies for engagement

Recent years have seen mounting recognition of the abuses of Roma health and human rights in health care settings. In order to build on this momentum, Roma-centered NGOs must be able to carry out effective legal advocacy with a view to increasing accountability for these violations and addressing systemic impediments to Roma access to health care.

In 2010, two OSF programs—the Law and Health Initiative (LAHI) and the Roma Health Project (RHP)—commissioned a needs assessment in Macedonia, Romania, and Serbia in order to guide grant making and capacity building for the advancement of Roma rights. This assessment tailored existing initiatives advocating Roma human rights for a health care context and consisted of a survey of NGO needs and donor engagement opportunities. In all three focus countries, Roma civil society provided LAHI and RHP with positive feedback, particularly given the timeliness and necessity of the initiative. As a result of this assessment, LAHI and RHP identified two guiding objectives for future initiatives, namely, (1) increasing accountability for violations of Roma rights in health care settings; and (2) addressing systemic impediments to Roma access to health care.

Attached to each of these objectives are four proposed implementation strategies, as follows: (i) legal empowerment in Roma communities; (ii) human rights documentation and advocacy; (iii) media advocacy; and (iv) strategic litigation.

LAHI and RHP assigned several pilot grants to NGOs at the end of 2010 to enable them to engage in legal advocacy for Roma health rights. **Roma SOS**, based in Prilep, Macedonia, used its grant to establish a legal center providing information on health rights and to advocate for Roma rights before health authorities at different levels. **Association for Emancipation, Solidarity and Equality of Women (ESE)**, based in Skopje, Macedonia, worked with Roma-centered NGOs **Humanitarian and Charitable Association of Roma (KHAM)** and **Centre for Democratic Development and Initiatives (CDRIM)** to train paralegals to provide services to Roma communities in the Shuto Orizari and Delcevo municipalities. **Roma Access**, based in Constanta, Romania, put its funding to work by developing methodology for documenting human rights violations in health care institutions.

In 2011, LAHI and RHP issued a joint call for project proposals on legal advocacy for Roma health rights which advanced one or both of the guiding objectives. While previous grantees saw their projects extended by further funding, several new grants were also provided to NGOs in the three focus countries. The full list of legal advocacy grantees and their project summaries is available in **Annex I**.

**Assessment framework**

The next challenge for the OSF Initiative on Legal Advocacy for Roma Health Rights was to develop a framework for assessing the effectiveness and impact of its support for these NGO interventions and, if necessary, to revisit the strategies originally selected.

A dearth of statistical data precludes any quantitative impact assessment on Roma rights, and the very nature of legal advocacy calls rather for a qualitative analysis. The OSF Initiative on Legal Advocacy for Roma Health Rights aims to enable Roma communities to claim and defend their human and health rights. From this perspective, increased human rights reporting, viable legal challenges (even if unsuccessful), and broader coverage of Roma health issues in public fora should be considered signs of success for Roma legal empowerment and health rights advocacy.

The OSF Initiative on Legal Advocacy and Health Rights has developed a set of qualitative indicators for measuring whether and how the current situation with Roma health rights will change by the end of 2014 as a result of OSF-supported legal advocacy. The present baseline assessment has taken “snapshots” of the state of affairs at the beginning of this initiative in order to serve as a point of reference for the future.

The OSF Initiative on Legal Advocacy for Human Rights is focused on community empowerment, documentation and advocacy, media advocacy, and strategic litigation, analyzing each area based on four different levels:

- the capacity of Roma-centered NGOs to engage in legal advocacy for health rights
- accountability for Roma health rights violations, as achieved through legal advocacy
- the effect of legal advocacy on communities (mainly Roma, but also health care providers)
- the effect of legal advocacy on systemic barriers to Roma health rights.

<b>ADVOCACY AREA / INDICATORS</b>	<b>Legal empowerment</b>	<b>Documentation and advocacy</b>	<b>Media advocacy</b>	<b>Strategic litigation</b>
<b>Level I: NGO capacity</b>	Can NGOs educate and empower Roma on health rights?	Can NGOs document health rights violations and draw on them in their legal advocacy?	Do NGOs integrate media into their legal advocacy?	Do NGOs use legal frameworks to address health rights violations?
<b>Level II: Enforcing accountability</b>	Do Roma know and claim their health rights?	Do documentation and advocacy bring about greater enforcement of Roma health rights?	Does media advocacy bring about greater enforcement of health rights by exposing Roma rights violations?	Are those responsible for Roma health rights violations brought to justice?
<b>Level III: Changing law and policy</b>	Do authorities engage with Roma to address systemic barriers to Roma health rights?	Have there been changes in law and policy as a result of documentation and advocacy?	Does media advocacy influence decision makers and bring about systemic changes (in law and policy)?	Do legal norms and policies improve as a result of strategic litigation?
<b>Level IV: Effect on communities</b>	Do Roma participate in broader legal advocacy for their health and human rights?	Has Roma access to health care improved as a result of documentation and advocacy?	Does media advocacy result in better information on Roma health rights and in the public becoming more positive towards Roma?	Have illegal practices in health care been reduced or deterred?



## Legal empowerment in Roma communities

### ***NGO capacity***

In 2012, NGO capacity to educate and empower Roma on health rights varied widely and faced multiple constraints. The greatest of these constraints was insufficient knowledge among NGOs about health and patients' rights and the mechanisms available for legal redress in cases of rights violations. Although a few organizations in all three countries had this expertise, the majority of Roma-centered NGOs require training and capacity building. Within the framework of the legal advocacy initiative, OSF has supported productive transfers of knowledge from NGOs well-versed in health and patients' rights to those requiring training.

In Macedonia, the Association for Emancipation, Solidarity and Equality of Women has provided paralegal training to its partner NGOs, Humanitarian and Charitable Association of Roma, the Centre for Democratic Development and Initiative, and to Roma Resource Center. A legal expert in Romania has provided such training to a number of Roma-centered NGOs, and similar initiatives are underway in Serbia. By 2014, OSF's support should result in the increased capacity of Roma-centered NGOs to educate and empower Roma communities on health rights, which should lead to greater accountability in health care settings.

### ***Enforcing accountability***

Accountability for Roma rights violations in health care settings is practically nil, not least because Roma patients are scarcely aware of their rights. In all three focus countries, the level of awareness among Roma of their health and human rights is abysmal. In surveys conducted in Roma communities, many Roma admit that they have little, if any, knowledge of their rights. According to the EU MIDIS study, as many as 89% of Roma respondents in Romania could not name a single institution where they could complain about discrimination.<sup>89</sup> Illiteracy among Roma populations exacerbates this situation and has rendered the provision of printed information ineffective.

Local NGOs claim that medical personnel frequently take advantage of the fact that Roma do not know their rights or the relevant laws. Even though public health professionals are required to vaccinate Roma children and send outreach teams to Roma settlements, they often fail to do so, or else demand money from Roma for state-guaranteed free health services.<sup>90</sup> The NGOs have also reported multiple cases where public health professionals exploited pregnant Roma women's lack of rights awareness to deny them health care services.<sup>91</sup>

Despite violations of their right to health, Roma seldom make formal complaints, as evidenced by the countless documented instances of gross human rights abuses in

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<sup>89</sup> Supra note 6, p. 3.

<sup>90</sup> Information from the NGO Mesecina in Gostivar, Macedonia, 8 July 2010.

<sup>91</sup> Information from NGOs in Macedonia, Romania and Serbia, July 2010.

health care settings that have gone unpunished. A reluctance to remedy injustices results in a lack of legal accountability for human rights violations.

With OSF support, the grantee NGOs have adopted a variety of approaches to legal empowerment in Roma communities in order to encourage them to claim their health rights. These strategies range from door-to-door information campaigns to peer education, Roma health mediators (RHM) to paralegal programs. Some of these initiatives have already proven effective in reaching out to Roma communities, although considerable challenges remain.

Preliminary project results show that the availability of legal services can substantially increase Roma ability to pursue legal claims. For instance, the Macedonian NGO Healthy Options Project Skopje, which implemented a legal advocacy project in 2011, reported that within a few months of offering legal services, its number of cases in progress increased nearly threefold, from an average of 15 per month to an average of 40 per month.<sup>92</sup> NGOs in Macedonia have reported that paralegal assistance and mediation, where available, have lessened the open and outright abuse of Roma in health care settings.<sup>93</sup> Additionally, legal information sessions have been widely attended, attracting both Roma and non-Roma community members facing similar obstacles in accessing health care.<sup>94</sup>

One indicator of successful legal empowerment in 2014 would be an increased number of viable legal challenges. It is essential to emphasize the viability of these legal challenges as well as their increase in number, while downplaying their actual outcomes. The inadequacy of formal legal mechanisms may prevent highly compelling cases from holding up in court, and a mere statistical increase in the number of complaints is a poor indicator as well, because some complaints may be ill-founded. An increase in the number of viable complaints, however, may indeed serve as an indicator of increased legal empowerment in Roma communities, whose members will have become aware of their rights and begun asserting them when necessary in health care settings.

### ***Changes in law and policy***

At present, government authorities show little interest in genuinely engaging with Roma to eliminate systemic barriers to Roma health rights. Roma-centered NGOs, in turn, often lack the knowledge and skills necessary to communicate about Roma health rights effectively before these authorities.

The OSF Initiative on Legal Advocacy for Roma Health Rights supports several Roma-centered NGO initiatives that aim to tackle systemic barriers by engaging with state

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<sup>92</sup> Healthy Options Project Skopje final grant report, July 2012, on file. Also, an OSF grantee under a different initiative, the Hungarian Civil Liberties Union (HCLU), reported that the availability of legal services in several Roma settlements has resulted in: (i) increased confidence of Roma in claiming their rights, i.e., increased legal empowerment; and (ii) reduced discrimination, because the prospect of being held accountable served to deter potential discrimination against or abuse of Roma. Letter from HCLU staff is on file.

<sup>93</sup> Information from Roma-centered NGOs at the OSF grantee convening on legal advocacy for health rights, Ohrid, Macedonia, 9-11 July 2012.

<sup>94</sup> Information from the NGOs Centre for Democratic Development and Initiative (CDRIM), Association for Emancipation, Solidarity and Equality of Women (ESE), and Humanitarian and Charitable Association of Roma (KHAM), Macedonia, September 2011.

actors. For example, the Macedonian NGO Health Education and Research Association has been advocating that the predominantly Roma Shuto Orizari region be classified as a disadvantaged area. This recognition would allow greater state resources to be allocated to the area to compensate for its inadequate health care services. Other NGOs have applied innovative approaches to addressing systemic barriers, such as enlisting state bodies as allies. Roma SOS in Macedonia, for instance, cooperates strategically with the regional ombudsperson, who not only provides Roma SOS with advice, but places additional pressure on other state bodies to heed the NGO's recommendations.

However, many NGO initiatives challenging systemic obstacles to Roma health rights have stalled for lack of cooperation from the relevant health care authorities. This may call for revising current NGO advocacy strategies or improving NGO advocacy capacity to apply pressure on government authorities, possibly using the EU accession or Decade of Roma Inclusion frameworks.

In 2014, changes in the level of engagement and responsiveness on the part of relevant state authorities can serve as an indicator of the effectiveness of legal advocacy interventions and, hopefully, positive changes in health care policy and regulations will follow.

### ***Effect on communities***

The attempts of Roma communities to take part in broad legal advocacy for their health and human rights are presently very limited, in large part because of their low levels of literacy. Enabling Roma-centered NGOs to educate and empower Roma populations on their health rights, as well as enforcing accountability for Roma rights violations in health care settings, can foster conditions for increased Roma participation in advocacy for their health rights.

One significant obstacle, however, lies in many NGOs' lack of skills and experience in legal advocacy, specifically in challenging rights violations, lobbying for legal advancements in patients' rights, and advocating systemic changes that address the underlying determinants of health. OSF's support helps build these NGOs' capacity to engage in legal advocacy by providing them with technical assistance and opportunities for peer learning and collaboration, as well as encouraging them to participate in cross-issue coalitions and campaigns.

Greater participation on the part of Roma communities in legal advocacy could serve as a helpful indicator in 2014 of their increased legal empowerment, including efforts to form cross-issue coalitions with other groups mandated to challenge rights violations, extortion, and corruption in health care settings.

## **Documentation and advocacy**

### ***NGO capacity***

Documentation of rights violations is a fundamental component of legal advocacy, both domestically and internationally. Although certain NGOs in all three focus countries carry out human rights documentation, many of them show some confusion about the

difference between documenting human rights violations and filing cases for court purposes. Often, neither Roma individuals nor NGOs can accurately detect, identify and document human rights violations against Roma in health care settings.

It is important to recall that when the OSF Initiative on Legal Advocacy for Roma Health Rights started up in 2010, hardly any NGOs worked on—let alone specialized in—the area of Roma health rights advocacy. It is a positive sign that after only two years of OSF support, a number of NGOs have taken up legal advocacy work in a health care context and made remarkable strides in this area. Those with the capacity for human rights documentation have begun using it for the purposes of domestic and international advocacy. Bibija, ESE and Romani CRISS, in particular, have all submitted CEDAW shadow reports, and other NGOs have recently expressed interest in doing the same.

OSF also supports Roma-centered NGOs in all three focus countries in connecting their human rights documentation with other strategies, such as litigation. For instance, the Macedonian coalition of ESE, KHAM and CDRIM refer their own documented cases to NGOs with strengths in litigation, such as Roma SOS. Romani CRISS, for its part, draws on documented cases provided by other Roma-centered NGOs to carry out strategic litigation and advocacy.

An indicator of success in 2014 would be an increased use of documentation in NGO advocacy, for instance in strategic litigation and engagement with policymakers both domestically and internationally.

### ***Enforcing accountability***

Documentation and advocacy currently play only a limited role in enforcing Roma health rights and accountability for rights violations. Documentation alone is unlikely to contribute to increased accountability without direct application to advocacy, litigation, and lobbying efforts, in addition to public information campaigns. For example, the network of Roma-centered NGOs in Romania, in cooperation with the Independent Journalism Center, has documented several cases of doctors abusing or neglecting Roma patients, including certain cases resulting in death,<sup>95</sup> but no health care professionals have borne any legal responsibility as a result of these efforts.

OSF's support helps Roma-centered NGOs to hone their documentation and advocacy skills. One 2014 indicator of the impact of improved documentation and advocacy would be the identification of problematic legal provisions in all three focus countries and sustained advocacy for their reform, using documentation as an evidentiary and advocacy tool.

### ***Changes in law and policy***

Lacking the link to advocacy, where well-documented abuses of Roma rights in the three focus countries exist, there have been very few meaningful changes at the levels of law and policy. One notable exception lies in Serbia where, as a result of NGO advocacy, government authorities simplified procedures for Roma lacking identification paperwork

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<sup>95</sup> Supra note 19.

to access health insurance.<sup>96</sup> A lack of such paperwork seriously impedes access to health care in all three focus countries, and thus the success seen already in Serbia provides a useful blueprint for other countries.

One priority currently being explored involves documenting legal and administrative provisions that serve as obstacles to Roma access to health rights. The Macedonian NGO Association for Emancipation, Solidarity and Equality of Women (ESE) plans to make efforts to this end in the near future. LAHI and RHP are currently supporting Romani CRISS in targeting segregation in health care facilities, with the expectation that further work in documentation and advocacy will contribute to related advancements in law and policy by 2014. An indicator of the impact of health rights documentation and advocacy would be the gradual removal of obstacles to Roma access to health rights, whether in health care settings themselves or in areas having an impact on health, such as housing, employment, education and general access to justice.

### ***Effect on communities***

Efforts to improve documentation and advocacy have not yet enabled Roma communities to enjoy quality health services, and many Roma are still unable to access health care at all. A recent survey commissioned by the Minority Rights Center, a Serbian NGO, shows that the gap in access to health care between Roma and non-Roma is substantial.<sup>97</sup>

However, after only two years of OSF support, NGOs focusing on documentation and advocacy have reported modest improvements in the provision of services as a result of documenting and exposing Roma health rights violations.<sup>98</sup> In 2014, a significant indicator of the impact of legal advocacy on Roma access to health care would be an increased perception among Roma patients that health care has become more accessible and is being provided in a manner more respectful of their human rights.

## **Media advocacy**

### ***NGO capacity***

As of 2012, the capacity of Roma-centered NGOs to engage with the media varies widely, though most of them focus only sporadically on integrating it into their advocacy work. A handful of NGOs have developed rather sophisticated approaches to using the media as an effective advocacy and public information tool. Romani CRISS, for instance, has produced several infomercials designed to raise public awareness about Roma exclusion from various areas.<sup>99</sup> For the most part, however, Roma-centered NGOs still limit their media engagements to occasional press conferences and interviews, with no strategic plan or meaningful follow up.

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<sup>96</sup> Information from the Serbian NGO Praxis, also available at: [www.praxis.org.rs](http://www.praxis.org.rs).

<sup>97</sup> Minority Rights Center survey is on file.

<sup>99</sup> Romani CRISS short movie on Roma and education, available at: [www.youtube.com/watch?v=PcTHnObwDo8](http://www.youtube.com/watch?v=PcTHnObwDo8), last accessed on 30 October 2012.

Although LAHI and RHP have encouraged the development of media strategies in grant proposals on legal advocacy, most Roma-centered NGOs lack the understanding and skills necessary to make the most of media advocacy, and there has been no noticeable change since 2010.

As of 2012, the Health and Media Initiative of OSF's Public Health Program has been involved in supporting legal advocacy for Roma health rights by providing funding and training to interested NGOs. The effect of this additional support on NGO capacity will also be assessed at the end of 2014.

### ***Enforcing accountability***

Under present conditions, media advocacy does not lead to greater accountability for Roma health rights violations. This is due not only to a lack of media advocacy skills among Roma-centered NGOs but to a lack of interest and even hostility among the general public and, by extension, the mainstream media. However, a number of Roma-centered NGOs have taken steps toward enforcing Roma health rights through media advocacy. Romani CRISS, for example, has cooperated with the Romanian media to document particularly egregious abuses of Roma rights in health care institutions, ranging from segregation, to racially motivated medical negligence. The Macedonian NGO Roma SOS, for its part, consistently provides feedback on its ongoing strategic litigation cases to journalists with whom it has forged good working relationships. Additionally, the Macedonian NGOs, Humanitarian and Charitable Association of Roma (KHAM) and Health Education and Research Association (HERA), have had some success collaborating with local community media outlets.

However, widespread prejudice against Roma and a lack of general public interest in Roma issues complicate this task. In Romania, opinion surveys indicate that a majority of the general public believes it acceptable to exclude Roma, and even to beat them.<sup>100</sup> Meanwhile, Roma SOS staff in Macedonia report that the media channels where their case information is presented tend to distance themselves from Roma-related programs, and that journalists face resistance when they try to present balanced coverage of Roma issues.<sup>101</sup>

It will prove important in 2014 to assess any changes in the use of media for enforcing accountability for Roma health rights violations by bringing such violations to light.

### ***Changes in law and policy***

Just as media advocacy does not yet serve to enforce accountability for Roma rights violations in health care settings, it does not yet function to challenge systemic barriers to Roma health rights. Mainstream media coverage of Roma-related issues tends to stereotype Roma and perpetuate one-sided portrayals of their communities, while failing to provide information on the multiple barriers Roma face in claiming their right to health.

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<sup>100</sup> Information from Roma-centered NGOs in Romania, July 2010.

<sup>101</sup> Information from Roma SOS at the OSF grantee convening on legal advocacy for Roma health rights, Ohrid, Macedonia, 9-11 July 2012.

It will prove challenging to engage the mainstream media's interest in Roma health rights and to convince media outlets to expose systemic rights violations and barriers to health care access. However, LAHI and RHP's support in parallel areas of legal advocacy, such as community empowerment, NGO capacity building and technical assistance, should provide an added impetus to media advocacy.

In 2014, the use of media to challenge and change legal policy and regulations obstructing Roma rights will serve as an indicator of the effectiveness of NGO media advocacy and, of course, actual changes in law and policy would be clear signs of success.

### ***Effect on communities***

At the time of this assessment, media advocacy does not result in quality public information on Roma health rights or in making the public's view of Roma more positive. News articles on Roma health are few and far between and more likely to appear in Roma minority media. However, various mass media—including social media—are an excellent untapped resource for providing the general public with balanced information about Roma populations, as well as for teaching Roma about their health rights. The potential benefits of such information include fostering public understanding of Roma and tolerance toward them, particularly among health care professionals, and furthering the legal empowerment of Roma communities through a far-reaching and cost-effective method.

As mentioned above, LAHI and RHP have urged grantees to integrate media advocacy into their project implementation and provided support intended to improve the capacity of Roma-centered NGOs to engage in media advocacy.

One indicator of successful media advocacy in 2014 would be the extent to which mainstream media have begun to cover Roma health issues. While difficult to realize within such a short time frame, an improvement in the quality of public information available about Roma health rights would be another such indicator, as would a change in perception among Roma communities regarding mainstream media coverage of their health-related challenges.

## **Strategic litigation**

### ***NGO capacity***

The capacity of Roma-centered NGOs to engage in strategic litigation is still very limited, and even those that have developed some experience in it have yet to focus their efforts on health rights. However, LAHI and RHP have seen notable progress among OSF-supported NGOs—which are inevitably those with the greatest capacity for legal advocacy—over the last two years. In particular, Roma SOS and Romani CRISS each had between two and four legal cases pending at the time of assessment. OSF continues to support capacity building for Roma-centered NGOs in the field of patients' rights in order to enable them to effect strategic litigation.

In 2014, an indicator of increased NGO capacity would be an improvement in the effective use of domestic, regional and international human rights mechanisms for remedying Roma health and human rights violations.<sup>102</sup>

### ***Enforcing accountability***

There are multiple obstacles to using strategic litigation to enforce accountability in health care settings, which means that strategic litigation currently does not serve to enforce protection of Roma health rights. In all three focus countries, the legal remedies available are rarely effective. Patients' rights legislation in Macedonia and Romania currently exists only on paper, whereas in Serbia, there is no patients' rights legislation whatsoever, and so-called "patients' advocates" hired by hospitals routinely fail to carry out their role as independent defenders of patients' rights.

The prospect of winning health-related challenges for the benefit of Roma communities is dim, not only because of the inadequacy of legal remedies in place, but because of the high costs of legal proceedings, NGOs' limited expertise in patients' and other health rights, and a lack of trial attorneys experienced in and knowledgeable about patients' and other health rights. These obstacles unduly deter Roma clients from proceeding with legal challenges.

In Serbia, OSF grantee Law Scanner has documented a threefold drop in the number of complaints filed about patients' rights violations since 2010, despite an initial wave in 2007, when patients' rights advocates were first introduced in the country. This drop is explained not by a decline in the number of violations in the area but by a lack of meaningful outcomes following such complaints. Because no alleged perpetrators ever faced disciplinary action, patients simply stopped bothering to record their complaints.<sup>103</sup> OSF aims to make legal provisions on health rights more effective in enforcing health rights protection.

One indicator of the impact of strategic litigation to be assessed in 2014 would be whether perpetrators of Roma rights violations in health care settings were brought to justice, which would also signal strengthened legal capacities on the part of OSF-supported NGOs and an increase in the legal empowerment of Roma communities.

### ***Changes in law and policy***

Strategic litigation has been very limited as a means of addressing systemic barriers to recognition of Roma rights, not least because of the amount of time it takes for a case to travel through the legal system. LAHI and RHP have supported NGOs in using strategic litigation to overturn legal and administrative provisions that prevent Roma from claiming their health rights, and to catalogue numerous such provisions containing hidden barriers to Roma health care access. It may also prove useful to challenge legal provisions denying remedies to victims of health rights violations.

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<sup>102</sup> Currently, Roma-centered NGOs themselves recognize their limited capacities and expertise in the area of patients' rights. In preparation for the OSF Grantee Convening on Legal Advocacy for Roma Health Rights (July 2012), NGOs completed questionnaires indicating their training needs. Training on patients' rights legislation and mechanisms for redress was requested by most participating NGOs.

<sup>103</sup> Supra note 26.



There have already been some successful challenges to administrative barriers. For example, the Serbian NGO Praxis has succeeded in persuading the government to simplify residence registration procedures so that undocumented Roma can receive their health cards more easily.<sup>104</sup> In Macedonia, Roma SOS has successfully challenged the bylaws of the Health Insurance Fund, requiring the submission of documents to verify income, which had placed a disproportionate burden on Roma with seasonal employment trying to obtain health cards.<sup>105</sup> The changes have also benefited non-Roma, who lack identity documents or work seasonally. Romani CRISS, for its part, plans to prepare drafts for a Ministerial Order and an Instruction by the National Council for Combating Discrimination and to advocate the prohibition of discrimination and segregation in access to medical services.<sup>106</sup>

The 2014 assessment should document further challenges—and hopefully, changes—to legal regulations and policies currently obstructing Roma health rights.

### ***Effect on communities***

At present, strategic litigation has limited effect on stopping illegal practices in health care settings. Very few legal challenges actually come to fruition, as a result of inadequate legislation, deficient mechanisms for redress, inexperienced lawyers, lengthy and complex proceedings, and the prohibitive costs of litigation. A lack of legal challenges means a lack of justice against perpetrators, which in turn results in a failure to deter future rights violations and a lack of pressure to review current practices.

In 2014, the effectiveness of strategic litigation should be assessed in conjunction with any changes in the legal systems of the focus countries, including (i) changes resulting from novel jurisprudence; (ii) the increased effectiveness of “legal procedures that have been underutilized; (iii) amendments to health rights legislation; (iv) improvements in the capacity of Roma-centered NGOs to carry out strategic litigation; and (v) increased legal awareness among Roma themselves.

An increase in viable legal challenges resulting from health rights violations and, in particular, court decisions imposing civil or criminal responsibility on health care professionals should result in changes in medical practices affecting Roma. Parallel advocacy strategies, such as media advocacy and stakeholder dialogue, should ensure that such changes in the behavior of health care professionals are based not simply on the fear of lawsuits but also on a genuine change in attitudes resulting from a better understanding of the situation of Roma populations.

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<sup>104</sup> Praxis, *Analysis of the Main Obstacles and Problems in Access of Roma to the Rights of Health and Health care*, Belgrade, 2011, available at: [www.praxis.org.rs/index.php?option=com\\_docman&task=doc\\_view&gid=206&Itemid=66](http://www.praxis.org.rs/index.php?option=com_docman&task=doc_view&gid=206&Itemid=66), last accessed on 30 October 2012.

<sup>105</sup> Letter from Roma SOS, Prilep, Macedonia, May 2011, on file.

<sup>106</sup> Interim grant report by Romani CRISS, on file.

## **Annex I:**

### **Projects Supported by the OSF Initiative on Legal Advocacy for Roma Health Rights**

#### **Macedonia**

The Skopje-based **Association for Emancipation, Solidarity and Equality of Women** promotes women's leadership in pursuing the recognition of women's rights, human rights in general, and social justice. Since 2010, LAHI, RHP and Foundation Open Society—Macedonia have funded ESE's efforts to collaborate with two Roma-centered NGOs—the **Centre for Democratic Development and Initiatives** and the **Humanitarian and Charitable Association of Roma** in developing a paralegal program to empower Roma communities and enforce Roma health rights in Shuto Orizari and Delcevo. This program includes a legal advocacy component based on systemic issues identified through the provision of legal services. Recently, a third NGO—the **Roma Resource Center**—has joined the program to enhance its capacity to provide paralegal services in Shuto Orizari, the largest Roma settlement in Macedonia.

The Skopje-based **Health Education and Research Association (HERA)** aims to achieve full enjoyment of human rights on the part of women, men and youth who require access to high-quality confidential information in order to make informed choices regarding reproduction and the prevention, care and treatment of sexually transmitted infections and HIV. HERA also advocates for the rights of people living with HIV and AIDS and their families. LAHI and RHP support one of HERA's projects, which aims to advance Roma women's enjoyment of reproductive rights in Shuto Orizari by advocating that the Ministry of Health recognize the municipality as a disadvantaged area and, consequently, that it provide incentives for doctors to open a gynecological practice there. In addition, HERA documents and challenges violations of Roma women's reproductive rights, such as outright denial of health care. To this end, HERA has planned a series of initiatives, including preparing legal submissions to the Ombudsman and the State Commission for Anti-Discrimination Law, to be followed up with strategic litigation.

The Skopje-based **Healthy Options Project Skopje** initiated its harm reduction project in 1997, focusing at first on people who use drugs. A new program was developed in 2000 to target sex workers and their families. Healthy Options Project Skopje's 2011 legal advocacy project, supported by OSF, aims to advance the health rights of Roma people who use drugs, in particular their right to drug dependence treatment and their access to justice in cases of rights violations. This project, which was extended through 2012, also strives to map the situation of Roma people who use drugs (including women and children) in respect of their enjoyment of the right to health.

The Skopje-based **LIL** was founded in 2005 with the mission of protecting Roma women and children and, in particular, those who lack identification papers. In fulfilling this mission, LIL acts as a mediator between the Roma community and Macedonian state bodies and institutions. At present, LAHI and RHP support LIL's project to monitor implementation and document violations of Macedonia's Law on the Protection of

Patients' Rights and other relevant legal frameworks. Based on this data, LIL undertakes strategic litigation, convenes stakeholder meetings, and conducts media campaigns to address systemic rights violations and barriers to health care, such as improper birth registration, discrimination, excessive health care fees, denials of reimbursement, and detention in health care facilities resulting from inability to pay. Through these activities, LIL hopes to empower Roma to actively seek equal treatment in health care settings.

The Prilep-based **Roma SOS**. aims to inspire active involvement in social life and capacity building among young Roma activists, with a particular focus on Roma girls, who promote Roma integration by advocating for the recognition of their human rights. Roma SOS. runs a Health Advising Center which promotes human rights awareness among the local Roma community and women especially. Since 2010, LAHI, RHP and Foundation Open Society—Macedonia have supported Roma SOS.'s legal department, which identifies and litigates strategic cases and informs the community about their rights. Roma SOS. has already proven successful in one anti-discrimination case, which led Macedonia's Health Insurance Fund to amend its administrative procedures so that Roma would no longer be indirectly excluded from obtaining health insurance.

## **Romania**

The Bucharest-based **Romani CRISS**, founded in 1993, defends and promotes the human rights of Roma throughout Romania. Romani CRISS provides legal assistance in cases of abuse and strives to combat and prevent discrimination against Roma in all areas of public life, including education, employment, housing and health. In 1997, Romani CRISS developed a health mediation program by signing a cooperation agreement in 2001 with the Ministry of Health and the Organization for Security and Cooperation in Europe—Office for Democratic Institutions and Human Rights, which was renewed in 2005 and 2008. LAHI and RHP currently support a Romani CRISS project that aims to gather information about Roma rights violations in health care settings (with a special focus on segregation in maternity wards) as a basis for advocacy and to empower and build the capacity of two local Roma-centered human rights NGOs: (i) the **Equal Opportunities for Women and Children Association** (Zalau); and (ii) the **Hope and Trust Association** (Constanta). Romani CRISS's advocacy focuses on modifying legislation and state policies to ensure that Roma have adequate access to health care, by sending recommendations and amendments to key stakeholders, forming working groups with experts, and organizing national conferences and media events. Romani CRISS is also in the process of developing advocacy tools to bring about positive legislative and policy changes, as well as changes in public opinion toward Roma. These advocacy tools include strategic litigation cases, a report and documentary promoting respect for Roma health rights, and working with two Roma-centered NGOs to increase overall capacity to monitor and denounce human rights violations in health care facilities.

The Bucharest-based **Roma Center for Health Policies—SASTIPEN** works to promote social dialogue and to secure the participation of local community members in developing and implementing public policy. In 2011, OSF supported SASTIPEN's project to monitor discrimination against Roma in access to health care services, in particular by modifying the procedures for resolving patients' complaints before the local Colleges of Physicians. This project established the framework necessary to generate public debate

on the need to harmonize procedures for resolving health rights cases, taking into account the cases already documented and managed by SASTIPEN.

## **Serbia**

The Belgrade-based **Bibija**, founded in 1998, works to promote the human rights of Roma women and girls and to improve their social position in Serbia. Over the last 12 years, Bibija has implemented 18 projects on improving Roma women's health in 20 Roma settlements across Serbia, in addition to carrying out advocacy and lobbying initiatives on domestic and international levels. LAHI and RHP support a Bibija project aimed at building the legal advocacy capacity of two NGOs focusing on Roma women—**Novi Becej** and **Romani Cikna**. This project also provides information to the local Roma community about existing legal mechanisms for rights protection and facilitates dialogue among various stakeholders in order to encourage state institutions to monitor, document and resolve cases of Roma rights violations in health care settings.

The Belgrade-based **Law Scanner** was established to serve as an independent institution in Serbia. Law Scanner works on patients' and human rights protection and social policy, in addition to providing legal aid to the general public. In 2011 and 2012, OSF supported the Law Scanner project *Protection of Patients' Rights—Equal Protection for All*, which was designed to increase awareness among health care professionals and the general public about patients' rights and to strengthen the protection of human rights in health care settings.

## Annex II: Human Rights Treaty Ratifications by Focus Country

Year	<i>Instrument Supervisory body (as applicable)</i>	Macedonia	Romania	Serbia
1950	<i>European Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR) and Protocol 12 (2005)</i> European Court of Human Rights (ECtHR)	ratified	ratified	Ratified
1953	<i>European Convention on Social and Medical Assistance, with Protocol on Refugees</i> Committee of Ministers of the Council of Europe (CM)	not signed or ratified	not signed or ratified	not signed or ratified
1960	<i>Convention Relating to the Status of Stateless Persons</i>	ratified	ratified	Ratified
1965	<i>International Convention on the Elimination of All Forms of Racial Discrimination (ICERD)</i> Committee on the Elimination of Racial Discrimination (CERD)	ratified	ratified	Ratified
1966	<i>International Covenant on Civil and Political Rights (ICCPR)</i> Human Rights Committee (HRC)	ratified	ratified	Ratified
1966	<i>International Covenant on Economic, Social, and Cultural Rights (ICESCR)</i> Committee on Economic, Social and Cultural Rights (CESCR)	ratified	ratified	Ratified
1972	<i>European Code of Social Security</i> Committee of Ministers of the Council of Europe (CM)	not signed or ratified	not signed or ratified	not signed or ratified
1973	<i>International Convention on the Suppression and Punishment of the Crime of Apartheid</i>	ratified	ratified	Ratified
1975	<i>Convention on the Reduction of Statelessness</i>	not signed or ratified	ratified	Ratified
1977	<i>European Convention on the</i>	not signed or	not signed	not

<b>Year</b>	<b><i>Instrument Supervisory body (as applicable)</i></b>	<b>Macedonia</b>	<b>Romania</b>	<b>Serbia</b>
	<i>Legal Status of Migrant Workers</i> Committee of Ministers of the Council of Europe ( <b>CM</b> )	ratified	or ratified	signed or ratified
<b>1979</b>	<i>Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW)</i> Committee on Elimination of Discrimination Against Women ( <b>CEDAW Committee</b> )	ratified	ratified	Ratified
<b>1984</b>	<i>Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (CAT)</i> Committee Against Torture ( <b>CAT Committee</b> )	ratified	ratified	Ratified
<b>1987</b>	<i>European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment</i> European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment ( <b>CPT</b> )	ratified	ratified	Ratified
<b>1990</b>	<i>International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families</i> Committee on Migrant Workers ( <b>CMW</b> )	not signed or ratified	not signed or ratified	Signed
<b>1990</b>	<i>Convention on the Rights of the Child (CRC)</i> Committee on the Rights of the Child ( <b>CRC Committee</b> )	ratified	ratified	Ratified
<b>1996</b>	<i>European Social Charter (Revised) (ESC)</i> European Committee of Social Rights ( <b>ECSR</b> )	ratified	ratified	Ratified
<b>1997</b>	<i>European Convention on Nationality</i> Committee of Ministers of the Council of Europe ( <b>CM</b> )	ratified	ratified	not signed or ratified

<b>Year</b>	<b><i>Instrument Supervisory body (as applicable)</i></b>	<b>Macedonia</b>	<b>Romania</b>	<b>Serbia</b>
<b>1997</b>	<i>Convention on Human Rights and Biomedicine</i> (“ <i>Oviedo Convention</i> ”) Committee of Ministers of the Council of Europe ( <b>CM</b> )	ratified	ratified	Signed
<b>1998</b>	<i>Framework Convention for the Protection of National Minorities</i> ( <b>FCNM</b> ) Committee of Ministers of the Council of Europe ( <b>CM</b> ) and Advisory Committee ( <b>AC</b> ) on FCNM	ratified	ratified	Ratified
<b>2006</b>	<i>UN Convention on the Rights of Persons with Disabilities</i> Committee on the Rights of Persons with Disabilities ( <b>CPRD</b> )	ratified	ratified	Ratified

### Annex III: Legal Complaint Mechanisms by Focus Country

Redress mechanism	Macedonia	Serbia	Romania
<p><i>Patients ombudsman (general patients' rights, access to health care)</i></p>	<p><i>Patients Counsellor (under the amended Law on the Protection of Patients' Rights):</i> Has offices at five in-patient health care institutions across Macedonia. Reports to Minister of Health. Receives patients' complaints and mediates conflicts between patients and health care institutions.</p>	<p><i>Patients Advocate (under the Law on Patients' Rights):</i> Has offices at all health care institutions and pharmacies. Reports to the head of the health care institution and its board, in addition to reporting to the Ministry of Health every six months. Receives patients' complaints and mediates between patients and health care institutions. Limited institutional independence.</p>	<p>No equivalent</p>



<b>Redress mechanism</b>	<b>Macedonia</b>	<b>Serbia</b>	<b>Romania</b>
<p><i>Ministry of Health (first instance of administrative recourse)</i></p>	<p><i>Commission for the Promotion and Protection of Patients' Rights:</i> Both local and at the level of the Ministry of Health. Parallel procedure to that of the Patients Counselor, but not yet in force.</p> <p><i>Sanitary and Health Directorate:</i> Receives patients' complaints; exercises authority over health care institutions to mandate resolution to problems. In practice, not very effective due to excessive wait times and alleged bias in favor of health care institutions.</p>	<p><i>Health Inspection Commission:</i> Can investigate excessive delays in Patients Advocate's proceedings, among other problems.</p>	<p>Ministry of Health does not deal with patients' complaints.</p>

<b>Redress mechanism</b>	<b>Macedonia</b>	<b>Serbia</b>	<b>Romania</b>
<i>Malpractice Commission</i>	No equivalent	No equivalent	<i>Malpractice Commissions:</i> Operate on a county level, receive patients' complaints, and issue decisions that can be appealed in the administrative section of the Tribunal. Not a compulsory mechanism; no record of effectiveness.
<i>Ombudsman (rights violations by public bodies; no binding power)</i>	<i>Ombudsman:</i> Operates on national and regional levels; independent, with a solid record of cases defending human rights. Can provide interim relief but has limited power to sanction—a weakness exploited by other bodies.	<i>Ombudsman and network of local delegations:</i> Can intervene after the bodies above have been addressed. Issues non-binding recommendations and initiates disciplinary procedures.	<i>Ombudsman:</i> Does not have legally binding authority, has not been active, and is not considered an effective recourse.

<b>Redress mechanism</b>	<b>Macedonia</b>	<b>Serbia</b>	<b>Romania</b>
<i>Data Protection / Access to Information bodies (violations of rights to privacy and to receive medical information)</i>	<i>Directorate for Personal Data Protection: Mixed record.</i>	<i>Agency on Free Access of Information and Privacy: Has authority to issue legally binding directives. Can be called on in cases of violations of patients' rights to privacy and/or to access to medical information (important for access to medical records, which hospitals tend to withhold).</i>	<i>Data Protection Agency: No record of work on patients' privacy rights.</i>
<i>Medical ethics bodies (non-state and non-legal entities with limited authority, but can suspend medical licenses for malpractice and unethical conduct)</i>	<i>Medical Chamber: Informal professional body. Can investigate doctors and strip them of licenses, but such proceedings are very rare in practice.</i>	<i>Physicians' Chamber (and Chamber of Medical Personnel): Informal professional body. Can investigate doctors and strip them of licenses, but very rare in practice. Pioneered malpractice insurance.</i>	<i>Romanian College of Physicians (professional association, not a state body): Receives patients' complaints and mediates conflicts between patients and doctors. Can suspend doctors' licenses. In practice, not very effective due to alleged bias favoring doctors. Its decisions can be challenged in the administrative section of the Tribunal (second instance in administrative procedure).</i>

<b>Redress mechanism</b>	<b>Macedonia</b>	<b>Serbia</b>	<b>Romania</b>
<i>Administrative Court</i>	<i>Administrative Court.</i> Its decisions can be challenged in the High Administrative Court.	<i>Administrative Court.</i> Its decisions can be challenged in the High Administrative Court.	<i>Administrative section of the first instance court.</i> Its decisions can be challenged in the administrative sections of the Tribunal and the Appeals Court.
<i>Civil and Criminal Courts (all rights violations and appeals)</i>	<i>Civil and/or Criminal section of the First Instance Court.</i> Its decisions can be challenged in the relevant section of the Appeals Court.	<i>Civil Court and/or Criminal section of the First Instance Court.</i> Its decisions can be challenged in the relevant section of the Appeals Court.	<i>Civil and/or Criminal section of the First Instance Court.</i> Its decisions can be challenged in the relevant sections of the Tribunal and the Appeals Court.
<i>Supreme Court (reviews legality of decisions of lower courts, but cannot review the merits of individual cases)</i>	<i>Supreme Court.</i> Last instance for civil and criminal cases.	<i>Supreme Court.</i> Last instance for civil and criminal cases.	<i>Supreme Court.</i> Last instance for administrative, civil and criminal cases.

<b>Redress mechanism</b>	<b>Macedonia</b>	<b>Serbia</b>	<b>Romania</b>
<i>Constitutional Court (can only handle complaints about constitutionality of legislation, not individual rights violations)</i>	<i>Constitutional Court:</i> Receives complaints concerning the constitutionality of legislation. Has resulted in the repeal of certain insurance law provisions.	<i>Constitutional Court:</i> Receives complaints concerning the constitutionality of legislation; can address delays in judicial proceedings.	<i>Constitutional Court:</i> Receives complaints concerning the constitutionality of legislation; no record of work on health law.