

## News & Views

### Assessing Legal Advocacy to Advance Roma Health in Macedonia, Romania, and Serbia

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#### Abstract

Across Europe, Roma suffer extreme marginalisation, negatively impacting their health. Many cannot access healthcare at all. For others, the health system is a hostile place. At the same time, good legal frameworks are in place to protect health rights, and there is increasing recognition of systemic violations experienced by Roma. Essential to building on this momentum and closing the gap between standards and implementation is Roma ability to conduct legal advocacy. Since 2010, the Open Society Foundations has supported Roma engagement in Macedonia, Romania and Serbia in the following advocacy strategies: i) legal empowerment, ii) documentation and advocacy, iii) media advocacy, and iv) strategic litigation. This article presents a framework developed to evaluate the effectiveness of these efforts and a baseline against which outcomes can be measured in a few years. The evaluation framework provides a qualitative assessment of Roma capacity, accountability for violations, changes in law and practice, and impact on communities. Findings reveal that that presently Roma lack knowledge of their rights and rarely challenge violations. Accountability in healthcare is practically non-existent. However, where legal advocacy has been used, violations decrease, and power dynamics shift. As healthcare becomes more responsive to communities, it also better serves non-Roma citizens.

#### Keywords

Roma; health; human rights; law; advocacy; assessment; evaluation; minorities

#### Introduction

Europe's largest and most neglected minority, Roma suffer extreme marginalisation and discrimination in all spheres of life. This situation leads to deeply negative implications for Roma health status, as demonstrated by worse health outcomes across the spectrum of indicators. Life expectancy among Roma is up

to ten years below average,<sup>1</sup> infant mortality rate is unacceptably high,<sup>2</sup> and preventive healthcare is scarcely accessible. Roma further report a shocking array of human rights abuses in healthcare settings, including outright denial of medical services, provision of substandard healthcare, and even segregation.<sup>3</sup> The current state of Roma health and human rights is a result of a number of systemic factors. Many Roma have little — if any — personal documentation, obstructing their access to most basic and essential services.<sup>4</sup> Furthermore, Roma communities experience disproportionate rates of unemployment and poverty,<sup>5</sup> and vast numbers live in unauthorised and typically segregated settlements where everyday living conditions are precarious at best.<sup>6</sup> 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.

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 European Union (EU) integration<sup>7</sup> and in the Decade of Roma Inclusion.<sup>8</sup> These instruments have contributed to increasing the recognition of Roma health and human rights abuses in healthcare settings.

Essential to building on this momentum and closing the gap between standards and implementation is the ability of civil society to carry out effective advocacy, with a view to increasing accountability for Roma rights violations in healthcare settings and addressing systemic impediments to Roma access to health rights. The Open Society Foundations (OSF)' Initiative on Legal Advocacy for Roma Health Rights, launched in 2010 by the Law and Health Initiative (LAHI) and

<sup>1</sup> Fundacion Secretariado Gitano, *Health and the Roma Community, Analysis of the Situation in Europe: Bulgaria, Czech Republic, Greece, Portugal, Romania, Slovakia, Spain*, (Madrid: FSG, 2012).

<sup>2</sup> In Serbia, Roma infant mortality is twice the national average. Statistical Office of the Republic of Serbia, *Republic of Serbia Multiple Indicator Cluster Survey 2011. Final report*, (Belgrade: Statistical Office of the Republic of Serbia, 2011) pp. 47-48.

<sup>3</sup> European Roma Rights Centre (ERRC), *Ambulance not on the Way: The Disgrace of Healthcare for Roma in Europe*, (Budapest: ERRC, 2006).

<sup>4</sup> In the Shuto Orizari region of Macedonia, nearly 50 per cent of Roma have no documentation whatsoever pertaining to citizenship, health insurance or healthcare. See B. Pavlovski, *Health, Healthcare and the Impact on the Health of the Roma in the Republic of Macedonia*, (Skopje: ESE, 2009) pp. 41-42.

<sup>5</sup> Over 70 per cent in some cases. European Commission Against Racism and Intolerance (ECRI), *Fourth Report on "the Former Yugoslav Republic of Macedonia"*, (Strasbourg: CRI, 2010) p. 22, para. 52.

<sup>6</sup> European Union Agency for Fundamental Rights (FRA), *Housing Conditions of Roma and Travellers European Union: Comparative Report*, (Vienna: FRA, 2009).

<sup>7</sup> Conditions for EU membership include "stable institutions guaranteeing democracy, the rule of law, human rights and respect for and protection of minorities." European Commission Directorate General for Enlargement, 2013. *Conditions for Membership*. Retrieved 28 April 2013, [ec.europa.eu/enlargement/policy/conditions-membership/index\\_en.htm](http://ec.europa.eu/enlargement/policy/conditions-membership/index_en.htm).

<sup>8</sup> Decade of Roma Inclusion, *Official Website*. Retrieved 28 April 2013, [www.romadecade.org/](http://www.romadecade.org/).

the Roma Health Project (RHP), aims to increase the capacity of nongovernmental organisations (NGOs) in three focus countries — Macedonia, Romania and Serbia — to carry out legal advocacy for Roma health and human rights. It also sets out to develop an assessment framework to this end and a baseline of the current status against which efforts can be measured.

This article is divided into four sections. The first section provides background on the state of Roma health rights and the legal framework that can be used for protection. The second section describes advocacy efforts supported under the OSF project. The third section sets out an evaluation framework for assessing these efforts, and the fourth section provides a baseline of the current status against which subsequent outcomes can be measured.

## 1. Background: Roma Health and Human Rights

### 1.1. Roma Rights Violations

Members of Roma communities report shocking abuses of their human rights in healthcare settings. Roma rights violations range from outright denial of healthcare services, even in emergencies, to provision of substandard medical care, degrading treatment, and segregation.

Medical personnel routinely insult Roma, in part by making abusive references to Roma ethnicity, culture, hygiene, and reproduction.<sup>9</sup> Many Roma patients, including pregnant women, also report being pushed and slapped by healthcare professionals.<sup>10</sup> Roma-centred NGOs contend that such hostile and humiliating treatment often discourages Roma patients from exercising their right to health and from visiting healthcare centres until their medical conditions have become very serious.<sup>11</sup>

Roma women are particularly vulnerable to the denial of access to healthcare. In Macedonia and Serbia, 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>12</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 paediatric care, vaccinations, and other services. In Romania, 23 per cent of Roma women surveyed said they had

<sup>9</sup> Silvia Vranceanu, "Playing Russian Roulette with Roma Health." *OSF Voices*, 10 Sept. 2012. Retrieved 28 April 2013, [www.opensocietyfoundations.org/voices/playing-russian-roulette-roma-health](http://www.opensocietyfoundations.org/voices/playing-russian-roulette-roma-health).

<sup>10</sup> Interviews with the staff of the Roma NGO Ambrela in Shuto Orizari, Skopje, Macedonia, 9 July 2010.

<sup>11</sup> Interviews with Roma Health Mediators and the staff of the NGO Roma Centre for Democracy (RCD), Valjevo, Serbia, 10 July 2010.

<sup>12</sup> Interviews with Roma NGOs in Macedonia and Serbia, 8-12 July 2010.

experienced gender discrimination in healthcare settings, and 95 per cent of these women also believed that healthcare professionals discriminate against Roma more generally.<sup>13</sup> In Serbia, it has been reported that hospital staff abandon pregnant Roma women while they are in labour on the grounds that “Roma women have many children [and] know how to give birth on their own.”<sup>14</sup>

In Macedonia, Roma have reported being forced to pay for free services and being falsely detained or had their documents confiscated by the hospital staff if they prove unable to do so.<sup>15</sup>

In Romania, there is a growing body of evidence of racial segregation in Romania's public hospitals.<sup>16</sup> Segregation in healthcare settings can be difficult to detect and even more difficult to prove, and NGOs seldom have the capacity to recognise and document it as it happens. Even so, Romanian NGOs carried out a monitoring visit of Hospital No. 1 in Craiova (gynaecology, maternity and paediatrics 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 hospitalised in the same room as Roma children without tuberculosis); and verbal abuse by non-Roma patients, leading to discriminatory treatment by medical staff.<sup>17</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-centred 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 per cent of Roma surveyed in Romania could not name a single institution where they could bring complaints of discrimination.<sup>18</sup> Ignorance about the law and the available remedies means that many rights violations experienced by Roma

<sup>13</sup> OSF Public Health Program, 2008. “Left Out.” *Fact-sheet*. Retrieved 30 August 2013, [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/). See also L. Surdu and M. Surdu, *Broadening the Agenda: The Status of Romani Women in Romania*, (Budapest: OSF, 2006) p. 18.

<sup>14</sup> Law Scanner, *Protection of Patients' Rights — Equal for All*, (Belgrade: Law Scanner, May 2012).

<sup>15</sup> Semi-structured interviews conducted with Roma individuals and Roma-centred NGOs in Skopje, Macedonia, July 2010.

<sup>16</sup> Romani CRISS, 2011. “Roma Children Segregation in Hospitals Contested in Romania for the First Time.” *Press-release*, December 2. Retrieved 28 April 2013, [www.romanicriss.org/PDF/Press%20release%20children%20segregation%20in%20hospital%20Marie%20Curie%20dec%202011.pdf](http://www.romanicriss.org/PDF/Press%20release%20children%20segregation%20in%20hospital%20Marie%20Curie%20dec%202011.pdf).

<sup>17</sup> Information from Romani CRISS, on file. Also, interview with the staff of the Roma-centred NGO in Zalau, Romania, 21 July 2010. The NGO managed to take pictures of the pediatric ward, showing clean, neat and decorated rooms of non-Roma children. However, Roma children's rooms are dirty and poorly furnished, with broken appliances and scratched walls.

<sup>18</sup> European Union Agency for Fundamental Rights (FRA), 2011. *EU-MIDIS Data in Focus Report 3: Rights Awareness*. Retrieved 30 August 2013, [fra.europa.eu/sites/default/files/fra\\_uploads/854-EU-MIDIS\\_RIGHTS\\_AWARENESS\\_EN.PDF](http://fra.europa.eu/sites/default/files/fra_uploads/854-EU-MIDIS_RIGHTS_AWARENESS_EN.PDF).

go unchallenged, undermining even basic accountability for such violations. This climate of impunity makes health rights violations more likely not only for Roma patients, but for all patients.

### 1.2. *Legal Framework on Health and Human Rights*

At the same time, strong legal and policy frameworks are in place, providing an opportunity to address these violations and ensure state accountability. International and European human rights instruments set out a comprehensive framework designed to protect and promote health and human rights. The main international treaties from which such rights are derived include: the 1965 International Convention on the Elimination of All Forms of Racial Discrimination (ICERD);<sup>19</sup> the 1966 International Covenants on Civil and Political Rights (ICCPR)<sup>20</sup> and on Economic, Social and Cultural Rights (ICESCR),<sup>21</sup> with the General Comment 14 by the Council on Social, Economic and Cultural Rights dealing specifically with health;<sup>22</sup> the 1979 Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW);<sup>23</sup> the 1984 UN Convention Against Torture (CAT),<sup>24</sup> and the 1989 UN Convention on the Rights of the Child (CRC).<sup>25</sup>

The European regional instruments include: the 1950 European Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR),<sup>26</sup> with Optional Protocol 12 on discrimination;<sup>27</sup> the 1961 (Revised) European Social Charter;<sup>28</sup> the 1995 Framework Convention for the Protection of National Minorities (FCNM),<sup>29</sup> and the 1997 Council of Europe's Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine (known as "the European Convention on Human Rights and Biomedicine").<sup>30</sup>

The rights stipulated in those instruments include among others: the right to life and bodily integrity; freedom from torture and inhuman or degrading

<sup>19</sup> Retrieved 30 August 2013, [www2.ohchr.org/english/law/cerd.htm](http://www2.ohchr.org/english/law/cerd.htm).

<sup>20</sup> Retrieved 30 August 2013, [www.ohchr.org/en/professionalinterest/pages/ccpr.aspx](http://www.ohchr.org/en/professionalinterest/pages/ccpr.aspx).

<sup>21</sup> Retrieved 30 August 2013, [www.ohchr.org/EN/ProfessionalInterest/Pages/CESCR.aspx](http://www.ohchr.org/EN/ProfessionalInterest/Pages/CESCR.aspx).

<sup>22</sup> The ICESCR's supervisory body, the Committee on Economic, Social and Cultural Rights (CESCR), explains that the right to health requires that healthcare 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. Retrieved 30 August 2013, [www.unhcr.ch/tbs/doc.nsf/%28symbol%29/E.C.12.2000.4.En](http://www.unhcr.ch/tbs/doc.nsf/%28symbol%29/E.C.12.2000.4.En).

<sup>23</sup> Retrieved 30 August 2013, [www.un.org/womenwatch/daw/cedaw/text/econvention.htm](http://www.un.org/womenwatch/daw/cedaw/text/econvention.htm).

<sup>24</sup> Retrieved 30 August 2013, [www.un.org/documents/ga/res/39/a39r046.htm](http://www.un.org/documents/ga/res/39/a39r046.htm).

<sup>25</sup> Retrieved 30 August 2013, [www.ohchr.org/en/professionalinterest/pages/crc.aspx](http://www.ohchr.org/en/professionalinterest/pages/crc.aspx).

<sup>26</sup> Retrieved 30 August 2013, [conventions.coe.int/Treaty/en/Treaties/Html/005.htm](http://conventions.coe.int/Treaty/en/Treaties/Html/005.htm).

<sup>27</sup> Retrieved 30 August 2013, [conventions.coe.int/Treaty/en/Treaties/Html/177.htm](http://conventions.coe.int/Treaty/en/Treaties/Html/177.htm).

<sup>28</sup> Retrieved 30 August 2013, [conventions.coe.int/Treaty/Commun/QueVoulezVous.asp?NT=035&CL=ENG](http://conventions.coe.int/Treaty/Commun/QueVoulezVous.asp?NT=035&CL=ENG).

<sup>29</sup> Retrieved 30 August 2013, [conventions.coe.int/Treaty/en/Treaties/Html/157.htm](http://conventions.coe.int/Treaty/en/Treaties/Html/157.htm).

<sup>30</sup> Retrieved 30 August 2013, [conventions.coe.int/Treaty/en/Treaties/Html/164.htm](http://conventions.coe.int/Treaty/en/Treaties/Html/164.htm).

treatment; right to liberty and security of the person; freedom from discrimination and prohibition against segregation. There is also a recognised right to the highest attainable standard of health and a set of patients' rights encompassing: the right to medical information, privacy, confidentiality, informed consent and personal self-determination.<sup>31</sup>

### 1.3. Policy Frameworks

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

#### 1.3.1. EU Accession

Before candidate countries can join the EU, they have to accept *acquis communautaire* and make EU law part of their own national legislation. Accession candidates must also fulfil certain political criteria, including institutional stabilisation and the safeguard of democracy, the rule of law, human rights and respect for and protection of minorities.<sup>32</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>33</sup> and the Race Equality Directive.<sup>34</sup>

#### 1.3.2. Roma Decade

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 OSF, the World Bank, the European Commission, the Council of Europe and other international agencies and organisations. It has become the first truly international and comprehensive initiative to address Roma rights and exclusion in key areas, including healthcare. Participating countries have developed national action plans for each of the Decade's

<sup>31</sup> OSF Public Health specifically developed a Fact Sheet explaining the international and European framework for protection human rights in the patient care. Retrieved 30 August 2013, [www.opensocietyfoundations.org/sites/default/files/protection-human-rights-patient-care-fact-sheet-english-20121101.pdf](http://www.opensocietyfoundations.org/sites/default/files/protection-human-rights-patient-care-fact-sheet-english-20121101.pdf).

<sup>32</sup> Retrieved 30 August 2013, [europa.eu/legislation\\_summaries/enlargement/ongoing\\_enlargement/l14536\\_en.htm](http://europa.eu/legislation_summaries/enlargement/ongoing_enlargement/l14536_en.htm).

<sup>33</sup> Art. 35 affirms the "right of access to preventive healthcare 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." Retrieved 30 August 2013, [www.europarl.europa.eu/charter/pdf/text\\_en.pdf](http://www.europarl.europa.eu/charter/pdf/text_en.pdf).

<sup>34</sup> Retrieved 30 August 2013, [eur-lex.europa.eu/smartapi/cgi/sga\\_doc?smartapi!celexapi!prod!CELEXn umdoc&lg=EN&numdoc=32000L0043&model=guichett](http://eur-lex.europa.eu/smartapi/cgi/sga_doc?smartapi!celexapi!prod!CELEXn umdoc&lg=EN&numdoc=32000L0043&model=guichett).

priority areas. Civil society can provide input into this process and monitor its implementation and impact on both domestic and international levels.

## **2. Overview of the Legal Advocacy for Roma Health Rights Initiative**

### *2.1. Strategies for Engagement*

Recent years have seen mounting recognition of the abuses of Roma health and human rights in healthcare settings. In order to build on this momentum, Roma-centred NGOs must be able to carry out effective legal advocacy to address these violations as well systemic barriers to Roma health.

In 2010, two OSF programmes — LAHI and the Roma 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. That needs assessment tailored existing initiatives advocating Roma human rights for a healthcare 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 launched the 'Legal Advocacy for Roma Health Rights', whose two guiding objectives for future projects are: (1) increasing accountability for violations of Roma rights in healthcare settings; and (2) addressing systemic impediments to Roma access to healthcare.

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 department providing information on health rights and to advocate for Roma rights before health authorities at different levels and litigate strategic cases. Association for Emancipation, Solidarity and Equality of Women (hereafter, "ESE"), based in Skopje, Macedonia, worked with Roma-centred NGOs Humanitarian and Charitable Association of Roma (hereafter, "KHAM") and Centre for Democratic Development and Initiatives (hereafter, "CDRIM") to train paralegals to provide services to Roma communities in Shuto Orizari, a Roma settlement in Macedonia and Delcevo.

### *2.2. Supported Projects*

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.

### 2.2.1. *Macedonia*

In Macedonia, ESE continued its collaboration with two Roma-centred NGOs on developing a paralegal programme to empower Roma communities. In addition, the third Roma-centred NGO, the Roma Resource Centre (RCC) joined the partnership to enhance its capacity to provide paralegal services in Shuto Orizari. This programme includes a legal advocacy component based on systemic issues identified through the provision of legal services.

The Prilep-based Roma SOS also continued its project, a Health Advising Centre which promotes human rights awareness among the local Roma community and women especially. The NGO's legal department, which identifies and litigates strategic cases and informs the community about their rights, was strengthened.

Several other NGOs received grants for legal advocacy. The Skopje-based Health Education and Research Association (HERA) worked to advance Roma women's enjoyment of reproductive rights in Shuto Orizari by advocating that the Ministry of Health provide incentives for doctors to open a gynaecological practice there. In addition, HERA documents and challenges violations of Roma women's reproductive rights, such as outright denial of healthcare. Another Skopje-based NGO, Healthy Options Project Skopje (HOPS), seeks to address the situation of Roma using drugs (including women and children) in respect of their enjoyment of the right to health. Finally, the Skopje-based LIL monitors implementation and documents violations of Macedonia's Law on the Protection of Patients' Rights and other relevant legal frameworks as a basis for advocacy and litigation.

### 2.2.2. *Romania*

In Romania, the Bucharest-based Romani CRISS carries out a project with two components: i) to gather information about Roma rights violations in healthcare settings (with a special focus on segregation in maternity wards) as a basis for advocacy and ii) to empower and build the capacity of two local Roma-centred human rights NGOs.<sup>55</sup> Romani CRISS' advocacy focuses on modifying regulations and state policies to ensure that Roma have adequate access to healthcare. 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.

<sup>55</sup> The NGO Equal Opportunities for Women and Children Association (Zalau) and the Hope and Trust Association (Constanta).



Another Romanian NGO supported as part of the OSF initiative was the Bucharest-based Roma Centre for Health Policies — SASTIPEN. Its project seeks to monitor discrimination against Roma in access to healthcare services, in particular by modifying the procedures for resolving patients' complaints before the local Colleges of Physicians. This project has generated public debate on the need to harmonise procedures for resolving health rights cases, based on the cases documented and managed by SASTIPEN.

### 2.2.3. Serbia

In Serbia, the Belgrade-based Bibija implements a 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 healthcare settings.

The Belgrade-based Law Scanner carries out the project *Protection of Patients' Rights — Equal Protection for All*, designed to increase awareness among healthcare professionals and the general public about patients' rights and to strengthen the protection of human rights in healthcare settings.

## 3. Developing an 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 of Roma situation, and the very nature of legal advocacy calls rather for a qualitative analysis. The OSF Initiative on Legal Advocacy and Health Rights has developed a set of qualitative indicators (Table 1) for measuring whether and how the current situation with Roma health rights will change as a result of OSF-supported legal advocacy. Also, in order to have a point of reference to compare future changes to, the baseline assessment has been carried to take “snapshots” of the state of affairs at the beginning of this initiative.

The assessment measures the state of legal advocacy for Roma health in the focus countries across the following four focus areas: (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 assessment analyses: i) the capacity of Roma-centred NGOs to carry out legal advocacy, ii) the level of accountability in place for Roma rights violations, iii) any changes

**Table 1. Assessment Indicators**

Advocacy Area /Indicators	Legal Empowerment	Documentation and Advocacy	Media Advocacy	Strategic Litigation
Level I: NGO capacity	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?
Level II: Enforcing accountability	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?
Level III: Changing law and policy	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?
Level IV: Effect on communities	Do Roma participate in broader legal advocacy for their health and human rights?	Has Roma access to healthcare 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 healthcare been reduced or deterred?

in law or policy resulting from legal advocacy, and iv) any changes in Roma communities following legal advocacy efforts.

The analysis relied on community surveys, semi-structured interviews with key stakeholders in three countries, and OSF publications and grantee reports as the main sources of information to gauge the situation in each of the focus areas. Additionally, reports and other secondary sources provided information on the socioeconomic factors underlying poor health in Roma communities, as well as on patterns of rights violations against Roma in healthcare settings.

Since OSF is the principal donor for legal advocacy specifically focused on Roma health rights in Macedonia, Romania and Serbia, this makes it easier to trace and attribute emergent changes in the field of health rights advocacy to the focus projects. 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 by-products of other efforts addressing such factors. This will need to be taken into consideration when assessing the impact of the Legal Advocacy for Roma Health Rights Initiative in future.

#### 4. The Baseline

The findings of the baseline assessment of the state of legal advocacy for Roma health rights in Macedonia, Romania and Serbia are as follows.

##### 4.1. *Legal Empowerment in Roma Communities*

As of 2012, Roma remained largely unaware of their health and human rights and remedies available to them. NGOs' capacity to educate and empower Roma in respect of their health rights is varied and faces multiple constraints. These constraints ranged from limited knowledge among NGOs about specific health and human rights legal frameworks to reluctance on the part of victims to challenge healthcare authorities. Within the framework of the legal advocacy initiative, productive transfers of knowledge have taken place from NGOs well-versed in health and patients' rights to those requiring training.

Despite violations of their right to health, Roma seldom make formal complaints, which in itself is exploited by medical personnel. For example, 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>36</sup> The NGOs have

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<sup>36</sup> E. Eminova and N. Milevska-Kostova, *Report on the Condition of Housing and Health of Roma Community in Macedonia*, (Gostivar, Macedonia: Mesecina, 2008).

also reported multiple cases where public health professionals exploited pregnant Roma women's lack of rights awareness to deny them healthcare services.<sup>37</sup> A reluctance to remedy injustices results generally in a lack of legal accountability for human rights violations.

At the same time, preliminary project results show that the availability of legal services can substantially increase Roma ability to pursue legal claims. For instance, HOPS reported that within a few months of offering legal services in Skopje, its number of cases in progress increased nearly threefold, from an average of 15 per month to an average of 40 per month.<sup>38</sup> Other NGOs in Macedonia have also reported that paralegal assistance and mediation, where available, have lessened the open and outright abuse of Roma in healthcare settings.<sup>39</sup> Additionally, legal information sessions have been widely attended, attracting both Roma and non-Roma community members facing similar obstacles in accessing healthcare.<sup>40</sup>

Government authorities still show little interest in genuinely engaging with Roma to eliminate systemic barriers to their health rights. In turn, Roma-centred NGOs often lack the skills to effectively communicate Roma health rights issues before the relevant authorities. There have been, however, limited attempts on the part of these NGOs to engage in broader legal advocacy, by forming cross-issue coalitions with other groups. Hence, this initiative has also provided opportunities for expertise exchange among NGOs.

One indicator of successful legal empowerment in future assessment would be an increased number of viable legal challenges. It is essential to emphasise 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 serve as a reliable indicator that Roma have become aware of their health rights and begun asserting them when necessary.

#### 4.2. *Documentation and Advocacy*

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

<sup>37</sup> Semi-structured interviews with Roma individuals and Roma-centred NGOs in Macedonia, Romania and Serbia, conducted in July 2010.

<sup>38</sup> Healthy Options Project Skopje (HOPS), 2012. *Advancement of the Right to Health and Access to Drug Addiction Treatment for Roma Drug Users. Final Project Grant Report* (internal OSF document, on file).

<sup>39</sup> OSF Grantee Convening on Legal Advocacy for Health Rights in Ohrid, Macedonia, 9-11 July 2012. Conference Report (internal OSF document, on file).

<sup>40</sup> Semi-structured interviews with Roma-centred NGOs in Macedonia, conducted in July 2012.

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 healthcare settings.

At the start of this initiative in 2010, hardly any NGOs worked on — let alone specialised in — the area of Roma health rights advocacy. It is a positive sign that after only two years, a number of NGOs have taken up legal advocacy work in a healthcare context and made strides in this area. Those with the capacity for human rights documentation have begun using it for the purposes of domestic and international advocacy and connecting it with strategic litigation. Still, 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 and policy change without direct application to advocacy, litigation, and lobbying efforts, in addition to public information campaigns. For example, the network of Roma-centred NGOs in Romania, in co-operation with the Independent Journalism Centre (IJC), has documented several cases of doctors abusing or neglecting Roma patients, including certain cases resulting in death,<sup>41</sup> but no healthcare professionals have borne any legal responsibility as a result of these documentation efforts. Similarly, despite well-documented abuses of Roma rights in all the focus countries, there have been few meaningful changes at the level 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 to access health insurance.<sup>42</sup>

The initiative has also helped Roma-centred NGOs to hone their documentation and advocacy skills. After only two years, NGOs focusing on documentation and advocacy have already reported modest improvements in the provision of services as a result of documenting and exposing Roma health rights violations.<sup>43</sup> In future assessment, a significant indicator of the impact of legal advocacy on Roma access to healthcare would be an increased perception among Roma patients that healthcare has become more accessible and respectful of their human rights.

#### 4.3. *Media Advocacy*

The capacity of Roma-centred NGOs to engage with media outlets varies widely. A handful of NGOs have developed rather sophisticated approaches to using the

<sup>41</sup>) *Supra* note 9.

<sup>42</sup>) Praxis, *Analysis of the Main Obstacles and Problems in Access of Roma to the Rights of Health and Healthcare*, (Belgrade, Serbia: Praxis, 2011). Retrieved 30 October 2012. [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).

<sup>43</sup>) *Supra* note 39.

media as an effective advocacy and public information tool.<sup>44</sup> However, most NGOs still limit their media engagements to occasional press-conferences and interviews, with no strategic plan or meaningful follow-up, and generally lack the understanding and skills necessary to make the most of media advocacy.

Media advocacy does not currently contribute to increased accountability for Roma health rights violations, which remain largely invisible as a result. This state of affairs is due in part to a lack of media advocacy skills among many Roma-centred NGOs, but also due to widespread prejudice against Roma. In Romania, opinion surveys indicate that a majority of the general public believes it acceptable to exclude Roma.<sup>45</sup> Meanwhile, in Macedonia NGOs report that the media channels tend to distance themselves from Roma-related programmes and journalists covering Roma issues face resistance.<sup>46</sup>

Just as media advocacy does not yet serve as a means of enforcing accountability, it does not yet function to remove systemic barriers to Roma health rights, nor to provide quality public information on Roma health rights. The potential benefits of such information include fostering public understanding of Roma and tolerance toward them, particularly among healthcare professionals, and furthering the legal empowerment of Roma communities through dissemination of rights information. This would be an important complement to legal strategies. Already, the Macedonian NGOs KHAM and HERA have had some success collaborating with local community media outlets.

#### 4.4. *Strategic Litigation*

Aside from a few NGOs with some experience in strategic litigation (albeit not health-related), most Roma-centred NGOs have neither the experience nor the capacity to engage in strategic litigation focused on health rights. There are several obstacles to using strategic litigation to enforce accountability in healthcare settings, ranging from victims' reluctance and/or lack of financial means to pursue legal action to the inadequacy of legal tools at their disposal.

However, 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>47</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

<sup>44</sup> Romani CRISS, 2004. "Accordion" [Video]. Retrieved 28 April 2013, <http://www.tvspots.tv/video/40733/>.

<sup>45</sup> Sofia News Agency, 2010. "57 per cent Romanians Have 'Very Bad' Opinion of Roma — Survey." Sept. 15. Retrieved 28 April 2013, [www.novinite.com/view\\_news.php?id=120189](http://www.novinite.com/view_news.php?id=120189).

<sup>46</sup> *Supra* note 39.

<sup>47</sup> *Supra* note 39.

burden on Roma with seasonal employment trying to obtain health cards.<sup>48</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>49</sup>

In future assessment, the effectiveness of strategic litigation should be considered 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 under-utilised legal procedures; (iii) amendments to health rights legislation; (iv) improvements in the capacity of NGOs to carry out strategic litigation; and (v) increased legal awareness among Roma communities. An increase in viable legal challenges resulting from health rights violations and, in particular, court decisions imposing civil or criminal responsibility on healthcare 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 behaviour of healthcare 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 Roma's situation.

## Conclusions

At present Roma continue to suffer extreme marginalisation and discrimination in all spheres of life, with abysmal implications for their health status. Despite legal and policy frameworks in place, Roma experience violations of their most basic rights and face abuse unthinkable towards any other ethnic group. Barriers for Roma access to health rights are systemic, while accountability for Roma rights violations in healthcare settings or elsewhere is practically non-existent.

Legal advocacy has potential for bridging good legal standards and the actual practice, addressing Roma rights violations and improving Roma access to healthcare, with positive implications for the Roma health status overall. Supporting NGO capacity to carry out such advocacy is, therefore, critical. It is also crucial to be able to track the changes and evaluate which combination of advocacy strategies under what conditions is most effective.

A rigorous assessment is possible by breaking down advocacy into four main areas: legal empowerment, documentation and advocacy, media advocacy, and strategic litigation. Then, for each area, qualitative indicators can be collected at four impact levels, moving from NGO capacity, to individual accountability, to changes in law and policy, and finally to the effect on communities at large.

<sup>48</sup>) Information from Roma SOS (on file.)

<sup>49</sup>) Romani CRISS, 2012. *Interim Grant Report* (internal OSF document, on file).

The baseline assessment of legal advocacy in Macedonia, Romania and Serbia paints a picture of the current status of legal advocacy in each of these areas and provides some preliminary results. It has already managed to capture initial changes in the power dynamic in the areas where legal empowerment projects were initiated. Particularly promising have been community-based paralegal programmes, which gradually increase awareness of Roma of their rights and of available legal remedies, leading to increased legal claims and subsequently deterring certain rights violations.

In the area of documentation and advocacy, there is still limited experience in recognising and documenting human rights violations. However, there is a marked increase in Roma-centred NGOs that have begun specialising in health rights and connecting documentation to both domestic and international advocacy, including strategic litigation. There are areas where documentation and advocacy exposing Roma rights abuses have succeeded in deterring certain violations.

In the area of media advocacy, there are considerable challenges such as widespread prejudice and lack of interest in the Roma plight among the mainstream media and general public. Although individual NGO capacities vary, most Roma-centred NGOs have yet to make proper use of media to expose Roma health rights abuses and advocate for better Roma health. There is, however, potential opportunity with local community media outlets.

Strategic litigation, in combination with other forms of legal advocacy, has also led in a few specific instances to amendments of outmoded regulations preventing Roma access to health rights. Several more cases are currently underway promising to establish important legal precedents with far-reaching implications for accountability in healthcare.

In a few years, a second rigorous assessment will be possible against this baseline, providing lessons for future efforts. Hopefully, this will bring us closer to finally closing the gap between standards and practice and lead to realisation of fundamental rights for Roma in healthcare.



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