

The Impact of Legal Advocacy Strategies to Advance Roma Health: The Case of Macedonia

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Abstract

Across Europe, Roma face exclusion and obstacles in access to health services, resulting in poorer health. While there are legal and policy frameworks for Roma inclusion, implementation often lags behind. Increasing the grassroots capacity of Roma to advocate for accountability in health care and against systemic impediments has been a central focus of Open Society Foundations (OSF) support. This analysis discusses the impact of an OSF-supported legal advocacy project on Roma health rights in Macedonia. The paper uses qualitative indicators to measure the capacity of nongovernmental organizations, accountability for violations, changes in law and practice, and impact on communities. The methodology for assessing the impact of legal advocacy was developed over the course of OSF's legal advocacy project and used to calculate the baseline and conduct the follow-up assessment to track progress across four strategies: legal empowerment, documentation and advocacy, media advocacy, and strategic litigation. Results show that legal advocacy has led to a notable increase in Roma awareness of their health rights. The number of lawsuits has risen dramatically, and cases are increasingly more sophisticated. Although accountability in health care is still the exception rather than the rule, blatant violations have been reduced. Some structural barriers have also been tackled. At the same time, new challenges require continuous and adaptable legal advocacy.

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Competing interests: None declared.

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Introduction

The poor state of health in Roma communities is prevalent—and ignored—across Europe. Some Roma are completely excluded from health care, while most face hostility and discrimination within health care settings. Improving the overall health of Roma communities requires addressing a host of underlying factors, some of which have already been recognized 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, devoting a special section of the European Commission's annual progress report to Roma rights in European Union accession candidate countries.

However, more work is required to breathe life into formal regulations and policies on Roma in order to see meaningful improvements in their health. While regional nongovernmental organizations (NGOs) have been working diligently 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.

The past two decades have also witnessed unprecedented attention to systemic abuses of Roma rights. In order to build on this momentum, Open Society Foundations (OSF), through its Public Health Program, has supported legal advocacy for Roma health rights by Roma-centered NGOs. This paper explores the impact of OSF-supported legal strategies, outlining the current state of legal advocacy for Roma health rights in Macedonia.

Methodology

This paper uses the methodology developed in the course of the OSF initiative. In 2010, two OSF programs—the Law and Health Initiative and the Roma Health Project—commissioned a needs assessment in several focus countries, which included Macedonia, in order to guide grant making and capacity building for the advancement of Roma rights. The assessment tailored existing initiatives on Roma human rights to a health care context and consisted

of a survey of NGO needs and donor engagement opportunities. As a result of that assessment, OSF identified two guiding objectives for future initiatives: (1) increased accountability for violations of Roma rights in health care settings, and (2) a resolution of systemic impediments to Roma access to health care. Attached to each of these objectives were concrete implementation strategies.

The initial (baseline) evaluation of 2012 took “snapshots” of the situation on the ground prior to the launch of the NGO initiatives, to establish a point of reference for subsequent evaluations.¹ A follow-up assessment in 2015 then recorded the changes that had occurred and explored the extent to which those changes could be attributed to legal advocacy interventions.

Given the lack of official statistics and other current, comparable, and reliable quantitative data, which is broadly recognized as one of the challenges in assessing the state of Roma health rights in the region, the methodology deploys a set of qualitative indicators to measure the impact of NGOs' legal advocacy initiatives (see Table 1). Specifically, it assesses impact in four categories: legal empowerment, human rights documentation and advocacy, media advocacy, and strategic litigation. The assessment is conducted on four levels: NGO capacity, accountability for violations, changes in law and practice, and effects on Roma communities.

The present analysis relies on various sources, including the following: written questionnaires and surveys that collected responses from Roma-centered NGOs in Macedonia to the questions in the methodology grid (Table 1) at the beginning of the initiative and then again after three years of implementation; semi-structured interviews conducted during two rounds of field visits with Roma community leaders, Roma health mediators, Roma paralegals, health professionals, and other key stakeholders; information gleaned from OSF grantees' annual implementation reports and publications; and secondary sources on the socioeconomic factors underlying poor health in Roma communities and rights violations against Roma in health settings.

OSF is the principal donor for legal advoca-

cy specifically focused on Roma health rights in Europe. 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—including access to documentation, insurance, housing, employment, and education—changes in access to health services among Roma populations may sometimes be byproducts of other initiatives addressing such factors. We take this into consideration when assessing the impact of the initiative.

We selected Macedonia as the case study for this paper because it was the country where the most systematic support was provided to build the capacity of Roma rights NGOs and where a substantial number of activities were carried out within the framework of the project. The Macedonian case thus offers empirical evidence of the concrete impact of legal advocacy strategies on Roma access to health care.

Background

Roma health in Europe

There is a body of research devoted to analyzing the status of Roma communities' health in Europe.

Studies have consistently found that Roma health is worse than the health of the majority populations or other ethnic minority groups. Estimated life expectancy for Roma is consistently lower—in some cases up to ten years less—than corresponding national averages. Infant mortality among Roma is estimated to exceed national averages by several percentage points.² Roma are less likely to be covered by health insurance.³ Roma do not appear to enjoy preventive health care on equal footing with non-Roma and instead are more likely to rely on emergency services.⁴

Scholars and advocates identify inadequate living conditions, poverty, limited education, and pervasive discrimination against Roma by health care professionals and the public as the key reasons for the poor health of Roma.⁵

The lack of accountability for rights abuses—due to a low awareness among Roma of their rights vis-à-vis the health system—means that neither systematic nor individual rights violations are challenged, despite legal and policy reforms over recent decades aimed at ameliorating the situation of Roma in Europe.⁶ Accordingly, the legal empowerment of Roma communities at the grassroots level appears to be a key variable to break the impasse.

TABLE 1: Assessment methodology

| 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 rights violations against Roma? | Are those responsible for health rights violations against Roma 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 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 toward Roma? | Have illegal practices in health care been reduced or deterred? |

Macedonia: The national context

The situation in Macedonia is similar to that of many other European countries where Roma have faced systematic exclusion and poor health conditions. In Macedonia, Roma are disproportionately affected by unemployment, poverty, and precarious living conditions, and they face multiple barriers in accessing health rights.⁷ Roma without formal documentation are particularly disadvantaged because they are rendered effectively and legally invisible and are denied access to public services, including health care. An estimated 4,000 internally displaced Roma from the former Yugoslavia live in Macedonia without papers. Of those who have Macedonian citizenship, as many as 50% lack health insurance.⁸

Macedonia's economy is in a dire situation, which translates into limited resources for social services, including health care, while the legal and policy framework concerning health often lacks proper implementation mechanisms and remains underutilized in practice. For example, the 2008 Patients' Rights Law lacks protocols and procedures and is thus not fully functional. Awareness of the law is limited, even among health professionals. Most patients are not aware of the law at all—and since patients do not invoke it, health professionals often conclude that there are no patients' rights violations in Macedonia.⁹ Likewise, the country's 2010 antidiscrimination law is rarely used, and even among legal professionals there is only marginal awareness of legal instruments to defend Roma rights.

Furthermore, claiming rights in Macedonian courts is difficult for most people without financial means or without a supporting organization behind them. Since its inception, the Law on Legal Aid has proved inadequate for people who could benefit from its assistance. It is now being revised, leaving people in need of free legal assistance in limbo. Although civil society organizations were invited to provide suggestions on how to improve the law, the reform process appears devoid of transparency, and there is little hope that the new law will bring significant improvement or be a useful resource for strategic litigation.

In this context of virtually nonexistent ac-

countability in health care settings, violations of Roma rights have been commonplace.¹⁰ Such violations have included the denial of health services, including for pregnant women; provision of substandard care; negligent treatment; requirement of illegal payments for services that are free; extortion of bribes; confiscation of identity documents and false imprisonment for failure to pay hospital fees; verbal and physical assaults; violations of specific patients' rights (for example, to medical information and informed consent); and racial discrimination.¹¹

OSF's approach

The legal empowerment of Roma has been a central part of OSF's strategy to use legal advocacy to advance Roma health rights in Macedonia.

At the end of 2010, OSF assigned several pilot grants to NGOs to enable them to engage in legal advocacy for Roma health rights. As a result, the Skopje-based Association for Emancipation, Solidarity and Equality of Women (ESE), which promotes women's rights and human rights and social justice in general, started working with three Roma-centered NGOs—the Humanitarian and Charitable Association of Roma (KHAM), the Initiative for Development and Inclusion of Communities (formerly the Roma Resource Center), and the Centre for Democratic Development and Initiatives—to train paralegals. The goal of this paralegal pilot project was to empower Roma and advocate for better health services for Roma communities in several Macedonian municipalities.

Another grantee was the Prilep-based Roma SOS, whose mission is to build capacity among Roma activists, particularly Roma women. Roma SOS used its grant to establish a health advising center to promote human rights awareness among the local Roma community and advocate for Roma rights before health authorities at different levels. The organization also developed a legal department responsible for identifying strategic litigation opportunities and initiating cases. Roma SOS counts among its victories an anti-discrimination case that led Macedonia's Health Insurance Fund to amend its administrative procedures so that Roma would

no longer be indirectly excluded from obtaining health insurance.

In 2011, OSF issued a call for project proposals on legal advocacy for Roma health rights that advanced one or both of the aforementioned guiding objectives. Previous grantees saw their projects extended through further funding, and several new grants were also provided to NGOs in the focus countries.

For example, the Skopje-based Health Education and Research Association (HERA), which aims to advance Roma women's enjoyment of reproductive rights in Suto Orizari, documented and challenged violations of Roma women's reproductive rights, such as the outright denial of health care, extortion of bribes or other illicit payments, and discriminatory treatment. HERA implemented a series of initiatives, including legal submissions to the Ombudsperson's Office, the State Commission for Anti-Discrimination Law, and other human rights bodies, following up where appropriate with strategic litigation.

Another grantee, Healthy Options Project—Skopje, sought to advance the health rights of Roma 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 subsequently extended, also mapped the situation of Roma with regard to their enjoyment of the right to health.

Yet another grantee, the Skopje-based organization known as LIL—whose mission is to protect Roma women and children, particularly those who lack identification papers—focused on advocacy to help undocumented Roma obtain papers in order to access public services, including health care. LIL monitored the implementation and documented violations of Macedonia's Law on the Protection of Patients' Rights and other relevant legal frameworks and, in partnership with other Roma-centered NGOs, engaged in strategic litigation and conducted media campaigns to address systemic rights violations of and barriers to Roma access to health care, such as improper birth registration, discrimination, excessive health care fees, denials of reimbursement, and detention in health

care facilities resulting from an inability to pay.

OSF's next challenge was to develop a framework for assessing the effectiveness and impact of its support for these NGO interventions and, if necessary, revisit the strategies originally selected. A dearth of "hard" data precluded a quantitative impact assessment of Roma rights—and, in any case, the very nature of legal advocacy called for a qualitative analysis. Since the OSF initiative aimed to enable Roma communities to claim and defend their health-related rights, increased human rights reporting, viable lawsuits (even if unsuccessful), and expanded coverage of Roma health issues in public fora should be considered signs of success with regard to Roma legal empowerment and health rights advocacy. Hence, OSF developed a set of qualitative indicators to measure whether and how the Roma health rights situation would change by the next assessment as a result of OSF-supported legal advocacy (see Table 1).

As mentioned earlier, in 2012, prior to the start of the project, OSF conducted a rigorous assessment to record the state of Roma health, the relevant legal and policy frameworks, the patterns of Roma rights violations in health care settings, public attitudes, and the level of legal advocacy (or capacity for engaging in such advocacy) among Roma centered-NGOs in Macedonia.¹² This was followed by an assessment in 2015 using the same indicators and levels of evaluation. Below we discuss the outcomes of these assessments.

Results

Legal empowerment

Legal empowerment is defined as the transfer of power from the usual gatekeepers of the law—lawyers, judges, police, and state officials—to ordinary people who can make the law meaningful on a local level and engage the agency of disadvantaged populations.¹³

At the beginning of the OSF initiative, the capacity of grassroots community-based organizations to empower Roma on health rights was limited. The main challenge they faced was insufficient knowledge of health and human rights legal

frameworks among Roma-centered NGOs. After OSF supported specialized capacity building and training, the NGOs' familiarity with and ability to deploy legal redress mechanisms has improved considerably, and they have been able to impart this knowledge directly to the communities.¹⁴

In the process, Roma-centered NGOs have started to challenge legal and administrative provisions that place disproportionate burdens on Roma communities. Some organizations have advanced to the point that they have been able to start building the legal capacity of other organizations in Macedonia and abroad, ensuring the sustainability and expansion of the initiative.

The improved availability of legal services and increased rights awareness, in turn, have begun to deter blatant human rights violations: NGOs report that paralegal assistance and mediation, where available, have lessened the open and outright abuses of Roma rights by health professionals.¹⁵

Previously, Roma were apprehensive about filing complaints and had little faith in the system to protect them. But since the project's launch, the number of legal and administrative complaints brought by or on behalf of Roma has increased considerably. Moreover, the follow-up assessment shows that claims brought by Roma have increased in sophistication, maturing from requests for help with filling out official forms to concrete patients' rights claims.

The most dramatic effect of legal empowerment has been felt among Roma communities, with Roma increasingly seeing themselves not just as victims but as advocates speaking for their community. For example, in Prilep and Bitola municipalities, the grassroots Roma movement has evolved into an informal Roma "Civic Parliament," where Roma leaders, activists, and advocates share experiences, identify priorities, brainstorm, and formulate joint positions toward Macedonian state bodies.¹⁶

The empowerment of Roma has started to put pressure on local governments and health authorities to engage with Roma on the policy level.

Human rights documentation and advocacy

Human rights documentation refers to collecting

evidence of rights violations—in the form of victim and witness testimonials, official data, audio and video recordings, and other materials—in order to raise awareness of abuses and hold perpetrators accountable.

At the start of the project, Roma-centered NGOs had a limited ability to conduct or use documentation of rights violations, with many unable to recognize the difference between preparing legal cases and documenting human rights violations. The follow-up assessment shows improved NGO capacity for human rights documentation and advocacy. NGOs have formed collaborations to document cases and engage in domestic and international legal advocacy. Several NGOs (specifically ESE and its partners) have developed rather sophisticated documentation systems to monitor and evaluate the effectiveness of their own projects, as well as to capture the changing patterns of health-related human rights complaints.

Reports outlining patterns of Roma rights violations are now regularly presented to the national authorities in charge of health and social policy matters, as well as to international and regional human rights monitoring bodies, as recommendations and criticism coming from outside the country often carry more weight with Macedonian authorities than domestic NGO advocacy.¹⁷ Some of the NGO reports have helped address structural impediments. For example, persistent advocacy by LIL on behalf of undocumented Roma has led Macedonian authorities to recognize the lack of documentation among Roma as an institutional problem. The Ministry of Labor and Social Affairs set up a task force to build a database of undocumented persons, and up to 500 persons managed to obtain their documents.¹⁸

However, the outcomes in enforcing accountability have been mixed, and even well-documented instances of Roma rights violations have not always resulted in the perpetrators being held accountable. Reporting of discrimination cases—outside of those detected by grassroots Roma-centered NGOs—is still extremely low in Macedonia. This finding suggests that the documentation of human rights violations alone is not sufficient and that it

needs to be combined with other types of advocacy to be effective.

Strategic litigation

Strategic litigation involves “identifying and pursuing cases on critical human rights issues which if successful are likely to have a high impact at the national, regional or international level. Successful litigation can establish important legal precedents or effect changes in legislation, policy or practice. It can also positively influence public opinion.”¹⁹

The capacity of Roma-centered NGOs to engage in litigation, which was very limited at the beginning of the initiative, has improved. Initially, only a handful of NGOs had both the expertise and motivation to challenge Roma rights violations in courts. Now, each NGO engaged in legal work handles hundreds of Roma-related cases per year. Not all of the cases pertain to health or result in court proceedings, but the increase indicates a fundamental shift in attitude. For example, Healthy Options Project–Skopje observed a three-fold increase in complaints in the first few months after its legal services became available.²⁰ HERA recorded an increase from just 4 individual complaints about unlawful fees charged by gynecologists in 2015 to 24 such complaints in 2016. Roma SOS documented 340 legal complaints between 2012 and 2015, of which 4 were chosen for strategic litigation and subsequently won on behalf of Roma clients, with countrywide legal and policy implications.²¹ Roma paralegals currently deal with up to 400 cases per year; while the number of cases has stabilized, the complaints themselves show a degree of knowledge among Roma of specific patients’ rights that did not exist in the beginning of the initiative.

NGOs also use non-court remedies—such as the Ombudsperson’s Office and specialized commissions on patients’ rights and discrimination—much more actively than before. Although not all decisions by these bodies are legally binding, they carry important political weight. In this way, NGOs can achieve the objectives of better access to health and social rights for the Roma community while avoiding the burdens inherent in the traditional legal process.

Given the inverse relationship between accountability and human rights violations, highly publicized legal victories have led not only to a marked improvement in awareness of rights and increased assertiveness among Roma but also a noticeable reduction in the blatant denial of health services and somewhat more courteous treatment of Roma by health care professionals. The change has been palpable, although localized in the areas where Roma-centered projects are implemented.

Some barriers to Roma access to health care have been removed as a result of strategic litigation. For example, in late 2014, Roma SOS successfully advocated to remove a requirement to provide an income statement from the previous year as a condition for renewing health insurance coverage.²² This provision indirectly placed a disproportionate burden on Roma since, as mentioned earlier, many Roma lack documentation, are not formally employed, or work seasonally, and therefore cannot procure an official income statement. Easing paperwork requirements has benefited not only Roma but all unemployed individuals who lack proper documentation or steady income; they can now have continuous health insurance coverage.

Furthermore, several high-profile cases have shed light on medical negligence and discrimination, establishing important precedents of compensation for victims of patients’ rights violations.²³

Media advocacy

Media advocacy is the strategic use of mass media to promote public debate and generate community support to advance changes in social norms or public policies.²⁴

The capacity of Roma-centered NGOs to engage with the media was uneven at the beginning of the project; many organizations lacked the skills to make effective use of the media. In 2013–2014, OSF provided selected NGOs with media advocacy training, including components such as communication and public relations; debate and argumentation; visualization; audio and video advocacy; internet activism; and media advocacy strategies.

The follow-up assessment revealed impressive NGO media advocacy activities. Most have excelled

in using traditional as well as new media, especially social media networks, to raise awareness of the Roma health situation and advocate for Roma health rights. For example, KHAM has produced three videos based on “storytelling” that try to discredit the mainstream media’s predominantly negative portrayal of Roma. HERA has successfully engaged journalists in raising public awareness of unlawful practices, such as making Roma women pay for free antenatal health services. Moreover, Roma-centered NGOs now regularly participate in television debates and media interviews to explain their work and educate the public on the plight of Roma communities in Macedonia.

Compared to the status quo at the beginning of OSF’s legal advocacy initiative, when media coverage was permeated with prejudice and Roma issues were covered almost exclusively in the context of criminality, there is now more coverage of Roma rights violations in health care settings, and Roma are presented as examples of vulnerable patients. This shift has been helpful in conjunction with strategic litigation efforts and indicates a gradually changing narrative.

Some advocates express concerns that in the current political climate, Roma rights are no longer a priority and that NGOs critical of the government are often presented in the official media as enemies. Despite these difficulties, the public has become more aware of corruption, extortion, and other human rights abuses in health care because of coverage in the mainstream media. Therefore, media advocacy continues to be an important tool for promoting Roma health and human rights.

Discussion

An analysis of the outcomes of OSF’s initiative supporting legal advocacy on behalf of Roma health rights shows mixed results, with greatest progress achieved in the area of rights awareness and more limited progress (and at times regression) in ensuring that the Macedonian state fulfills its legal obligations to guarantee Roma health and human rights. The positive outcomes have also been largely limited to the regions where the projects were im-

plemented. However, the example of Macedonia demonstrates that empowered Roma communities at the grassroots level are key to improving respect for Roma rights in health care settings and to removing systemic barriers to Roma health rights.

Good practices

The empowerment of marginalized communities has been the most palpable change, as evidenced by two paralegal initiatives. The first project, led by ESE, has been implemented by several grassroots Roma organizations—KHAM, the Centre for Democratic Development and Initiatives, and the Initiative for Development and Inclusion of Communities—in Delcevo, Pehcevo, and Suto Orizari since 2010. The project’s objective is to prepare paralegals to provide appropriate and accurate information on health rights to Roma communities so that individuals themselves are empowered to assert their rights. The project has taken place on three levels: providing rights literacy to the communities and paralegal assistance in cases of health rights violations; conducting advocacy before local authorities and health care providers; and conducting national advocacy in partnership with other NGOs or state bodies.

The second paralegal project has been spearheaded by HERA, in partnership with grassroots Roma NGOs Ambrela and Initiative for Development and Inclusion of Communities. Initiated in 2014, the project focuses on supporting Roma women’s reproductive health rights. Roma women activists, trained to work as paralegals, conduct outreach to local Roma women to build awareness of reproductive health rights; collect evidence and document cases; and, when necessary, escort Roma women to local health care institutions to mediate conflicts. Paralegals also mobilize Roma women to conduct community monitoring of health services, using periodically developed community scorecards. HERA uses the scorecard results to pressure health authorities to provide missing health services to Suto Orizari, which is the only majority-Roma municipality in Macedonia. Strategic outcomes include the establishment of a community task force on reproductive and gynecological health and the

development of an advocacy action plan, which targets the National Committee for Safe Motherhood, the Ministry of Health, the Macedonian Health Insurance Fund, and associations of general practitioners and gynecologists in order to promote systemic changes.

Participants in these paralegal initiatives attest overwhelmingly to their success. For example, the ongoing evaluation by ESE shows that over 70% of Roma community members are satisfied with the paralegals' work.²⁵ This is not to suggest that Roma no longer face violations of their health and human rights. According to a recent survey conducted by ESE in ten Macedonian localities with substantial Roma populations, 34.6% of Roma still report "unkind treatment" by medical specialists, versus only 5.3% of non-Roma. In addition, 9.8% of Roma report being insulted by doctors, versus 1.6% of non-Roma. Up to 2.3% of Roma women visiting gynecologists said they were hit at least once; for the non-Roma women the number is 0%.²⁶ However, as the more aware and assertive Roma communities have begun to claim their health rights and call for accountability, power dynamics in the health system have started to shift, and Roma are no longer perceived as helpless and unaware persons. Continuous dialogue with health professionals has also resulted in greater awareness among doctors and nurses of the needs and problems faced by Roma patients.

As a way to create synergy, the NGOs have started to merge legal empowerment approaches with social accountability strategies. As a result, Roma have progressed from merely asking for access to the health system to demanding a say in the development of local policy to improve Roma health indicators. Roma paralegals from KHAM have also started providing capacity building in other countries, such as Romania, where local Roma organizations have expressed interest in adopting this initiative. Such international exchange and peer learning and mentoring fosters the continuity and sustainability not just of the paralegal pilot itself but of Roma legal empowerment more broadly.

Furthermore, engagement with local authorities has helped tackle structural barriers that previously seemed insurmountable. For example,

at the beginning of the initiative, a vast majority of Roma settlements were officially unauthorized, with the result that such settlements were excluded from urban planning and did not benefit from public investments or services. Habitat for Humanity, an international NGO with branches in Macedonia, spearheaded a project to legalize Roma settlements and provide grants to cover administrative (registration) fees, based on the 2011 Law on Proceeding with Illegally Built Objects. Several Roma-centered NGOs previously trained by OSF (specifically the National Roma Centrum in Kumanovo and Roma SOS in Prilep) have participated in this initiative by offering legal counselling and other kinds of support.²⁷

As a result, an estimated 50% of Roma settlements across Macedonia have been legalized and, following NGO advocacy, included into urban planning.²⁸ The fact that no Roma home demolitions were reported and local authorities were forthcoming can be attributed in large part to increased Roma awareness of their rights and the capacity of NGOs to support them in claiming those rights. Legalization means that residents of the formerly illegal Roma settlements can now expect and demand the provision of public services, including, but not limited to, new health centers.

Emerging challenges

Along with successes, the follow-up assessment noted challenges to legal advocacy for Roma health rights. If some constraints (such as limited expertise with legal frameworks and lack of technical skills with media advocacy among NGOs) have been addressed, other problems that did not receive sufficient consideration at the beginning of the initiative have come to the fore.

One of these constraints is the continuous changing of laws and administrative regulations, which can make NGO expertise obsolete if advocates are unable to keep abreast of legal developments. This factor entails the need for ongoing legal training, which places additional burdens on the already limited resources of NGOs that lack access to continuous legal capacity building.²⁹ For example, Roma-centered NGOs reported that the recent

rollout of electronic insurance cards contributed to confusion among many users of health services and placed extra burdens on Roma, especially those who lack identity documentation or who lack sufficient education to understand new requirements and procedures.³⁰

Furthermore, progress in the area of legal empowerment is often offset by the lack of progress on the part of the state to fulfill its human rights obligations, both toward minorities and toward the public at large. Legal personnel and professionals, as well as community activists, note that while the ability of persons to access health services has improved, the quality of the services offered has declined precipitously. Many qualified doctors and nurses have either left the public health sector in favor of private practice or left the country altogether. There is also an apparent shortage of equipment, medications, and supplies.³¹ But national authorities do not seem to recognize the extent of the problem and attempt to quell criticism from those who do by branding them as “subversive.” Occasionally, the state has blamed its lack of resources on the “global economic crisis,” although resources are readily available for new monuments and architecture projects, which signals that authorities may be out of touch with the real needs of the Macedonian population. Human rights NGOs that openly criticize the government for its policies, especially those that receive external funding (such as from OSF), face harassment and pressures in the form of audits and negative media coverage aimed at stifling their activism. Some Roma activists report receiving thinly veiled economic threats, such as the prospect of family members losing their jobs, and even threats of violence if they continue participating in rallies and demonstrations.³²

However, the Macedonian government has implicitly recognized the value of Roma-centered NGO initiatives.³³ Some of the most successful pilots—such as the provision of Roma health mediators—have been partially adopted by Macedonian authorities (for example, the Ministry of Health) and touted as state achievements in promoting Roma integration within the framework of the Decade of Roma Inclusion (2005–2015).³⁴ This leaves a

glimmer of hope that other good practices, such as the paralegal pilot projects, could also be institutionalized in time.

Conclusion

An assessment of legal advocacy initiatives in Macedonia shows that after just a few years of NGO interventions (from 2012 to 2015), there has been progress in bridging the gap between law and practice for Roma access to health care.

The capacity of Roma-centered NGOs to carry forward this work has increased considerably. Roma communities are more aware of their health rights and are less afraid to complain when rights violations occur. The increase in legal and administrative complaints brought by or on behalf of Roma has resulted in a reduction of violations of their rights in health care settings and has deterred some previously common abuses. Newly found assertiveness among Roma has also helped achieve cooperation with local authorities in tackling systemic problems, such as the lack of personal documentation and unauthorized housing. Although accountability in health care is still more of an exception than a norm, strategic litigation and human rights advocacy, accompanied by media campaigns, have led to a few concrete changes with regard to reducing structural impediments to accessing health care.

Therefore, on the whole, the strategies of community empowerment, human rights documentation, media advocacy, and strategic litigation continue to be valid and effective approaches in contexts where Roma and other vulnerable groups face exclusion and barriers to exercising their right to health. This finding shows promise for other countries with similar issues. Ongoing evaluation of these efforts remains important.

At the same time, new challenges have arisen that require continuous and adaptable legal advocacy. Changes in legislation strain the already scarce resources of NGOs by requiring them to retrain continuously. A deteriorating political environment and occasional hostility toward civic activism mean that Roma-centered NGOs struggle to make

their voices heard. Finally, without the political will to embrace and support civil society initiatives, the scaling up of successful pilots (such as that of Roma paralegals) is unlikely. Accordingly, the overall impact of NGOs' legal advocacy remains limited to just a few localities, and the sustainability of the progress achieved to date is far from ensured.

Despite these challenges, a national health care system that is inclusive, accountable, and respectful of patients' rights benefits all members of society, irrespective of their ethnic or other minority background. That goal is a strong argument for continued legal advocacy on behalf of Roma health and human rights.

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