HHR
Health and Human Rights Journal

Social Accountability and Legal Empowerment Initiatives: Improving the Health of Underserved Roma Communities in Eastern Europe

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Abstract

Improving the protection of the right to health of ethnic Roma people is one of the most pressing public health challenges in contemporary Europe, as their life expectancy and health status remain significantly lower than their non-Roma counterparts.[1] This paper analyzes Roma-led accountability initiatives that embrace social accountability and legal empowerment approaches to advocate for equitable fulfillment of the right to health. While these initiatives have led to the elimination of some harmful health practices (such as illegal cash bribes and violent and abusive treatment by medical professionals) and to improvements in health care, and some Roma communities have become driving forces for local and national health system reforms for advancing the fulfillment of health rights, the health inequalities affecting Roma communities remain significant. This issue also remains largely overlooked by European health research and policy experts, who are mostly reluctant to incorporate analyses of ethnicity and racialization into their research on health inequalities in Europe. The COVID-19 pandemic has further exacerbated these health inequalities.

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Competing interests: None declared.

Introduction

The quality, affordability, and inclusiveness of health care systems is determined by social practice, and structural factors such as environmental pollution and climate change, political and economic policy, access to public infrastructure, childhood development and education, poverty, and housing are fundamental determinants of health.[2] Systemic racism and discrimination mean that these factors impact particular communities inequitably, and thus they influence health, disease, and medical practice.[3] They make people less protected and more exposed to malpractice. The recent COVID-19 pandemic reinforced the impact of racism and discrimination on health.[4]

Numbering around 12 million, Roma people are the largest ethnic minority in Europe. They are also the most disadvantaged ethnic minority in the region as a result of antigypsyism.[5] Antigypsyism remains among the most conventional, unapologetic, and blatant forms of racism and ethnic discrimination in Europe.[6] Despite political commitments made by European governments and the European Union (EU), progress has been limited in reducing the avoidable and unnecessary health inequities and discrimination in health care endured by Roma people. They continue to be disproportionately burdened by chronic and preventable diseases, excluded from prevention programs, underserved by health systems, and they often die young.[7] Their life expectancy and health status remain significantly lower than their non-Roma counterparts in all European countries.[8] Their health insurance coverage has steadily worsened, as has their subjective experience of exclusion from or unequal access to health care.[9]

The scarce evidence on the effectiveness of interventions aimed at closing the gap between Roma people and majority populations in health outcomes is due to the reluctance of many European governments to collect ethnically disaggregated health data.[10] These states defy the recommendations of the United Nations and the European Commission and fail to follow up on smaller-scale studies by universities and civil society.[11] Indeed, despite the often alarming results of these studies, the health status of Roma people remains mostly ignored by European policy makers and public health professionals.[12] The relative lack of data compounds other factors determining health status, such as continuous political instability in some EU member states; austerity measures in health care, housing, and education; and ethnic prejudice and racism on the part of medical professionals. According to the World Health Organization, accountability, participation, and equality and nondiscrimination are three main principles of the human right to health.[13] This right also includes access to credible, locally generated evidence on issues with health service delivery.

In this paper, we focus on the decade-long mostly Roma-led initiatives to confront inequalities in health care provision in Romania, Bulgaria, and North Macedonia. These initiatives have led to Roma civil society's increasing voice and representation in decisions concerning the quality and availability of health care services; the affordability and accessibility of health insurance; the availability of health education and prevention programs focused on childhood vaccinations, sexual health, and reproductive health; and living environments and public infrastructure. These initiatives have been driven by a conviction that building local capacities to collect and analyze evidence on the implementation (or lack thereof) of health policies and services in Roma communities will not only limit some harmful practices but also equip these communities with skills to further advocate for their right to health. The initiatives have been clustered around two main conceptual and methodological approaches: social accountability and legal empowerment.

Conceptualizing social accountability and legal empowerment

Social accountability is an evolving umbrella concept to promote civic engagement in order to hold governments accountable to their policy commitments. It employs a combination of tools, such as community monitoring and oversight of public and private sector performance, user-centered public information systems, public complaint and grievance redress mechanisms, and citizen participation in resource allocation decision-making, such as participatory budgeting.[14] It covers strategies developed in the last two decades to pressure institutions and their governing structures and to demand fairer, more effective, and more responsive public services.[15]

Some of the key elements of social accountability are as follows:

- mobilizing and empowering people to make demands related to community priorities rather than to individual grievances;
- advocating and interacting with the state through "public space" and public deliberation;
- focusing on public goods and systemic problems, including resource distribution, failures in ensuring rights, and limited participation in policymaking;
- triggering formal sanction mechanisms and the imposition of political and reputational costs on responsible public authorities; and
- working fully with other strategies, such as policy advocacy, public planning, and cross-cutting alliances.[16]

Social accountability requires that people focus on and prioritize specific policies or programs, be trained in data collection, and be supported by experts to request and receive relevant policy documents. It also requires that public authorities be incentivized (by possibilities of formal sanctions or reputational costs) and formally committed to respond to the members of society. Social accountability approaches are often accompanied by approaches to increase the legal capacities of vulnerable communities to seek legal redress.

Legal empowerment is rooted in a human rights-based approach to development, which recognizes that poverty results from disempowerment, vulnerability, exclusion, lack of information, and discrimination.[17] It seeks to cultivate the agency and power of affected communities, provide practical and concrete solutions to legal problems, and employ paralegals and other non-lawyer professionals to support and educate lawyers about problems faced by vulnerable communities.[18] Some researchers conceptualize legal empowerment as "the transfer of power from the usual gatekeepers of the law—lawyers, judges, police, and state officials—to ordinary people who make the law meaningful on a local level and enhance the agency of disadvantaged populations."[19] The concept includes a variety of tools: legal awareness-raising, legal service provision, mediation services and dispute resolution, law reform initiatives, and litigation. These tools aim to increase legal literacy and provide individual legal capacity to understand and use the law without creating an over-dependency on lawyers.[20]

Community paralegals are often grassroots advocates who use their knowledge of the law to seek concrete solutions to local instances of injustice.[21] Equipped with legal and administrative knowledge, community paralegals—in some instances supported by lawyers—can facilitate access to government agencies and mobilize their communities to attend to the human rights issues around them.[22]

Some of the key elements of legal empowerment are as follows:

- empowering members of affected communities vis-à-vis their legal rights invoking existing legal regulations;
- focusing on rights violations and the structures that perpetuate them (the starting point is usually the individual, though systemic problems may be addressed);
- providing legal expertise and capacity to mobilize the community;
- enabling direct redress of grievances and potentially triggering changes in law and policy; and
- working with other strategies, such as policy advocacy and community organizing.[23]

The main advantages of legal empowerment approaches are that they enable people to understand and apply laws and administrative rules and procedures related to their social welfare, housing, education, and health rights, and they can lead to legal precedents that formalize and solidify policy change or that sanction an inefficient or discriminatory practice of service provision.

Social accountability and legal empowerment are also effective approaches for aligning the priorities of civil society organizations with the needs of their communities. However, the adoption of these approaches can be challenging, as it requires significant investments of human and financial resources over the long term. These approaches also presuppose that structurally vulnerable communities, while pressured by multiple deprivations, prioritize and strategically focus on a limited number of issues. Another challenge is bridging the local-national gap and translating local efforts into effective and transformative policy change. Although some studies have found that social accountability and legal empowerment can positively influence governments and other institutions, the most cited impact remains local.[24]

The public institutions most often targeted with social accountability and legal empowerment initiatives are those responsible for overseeing service provision in education, health care, infrastructure, and public works, including access to food and water.[25] Health-related social accountability and legal empowerment approaches often focus on monitoring health service delivery (e.g., informal payments requested by doctors, number of births at health facilities rather than at home, child health visits, immunizations, and community nurses) over time. The most developed body of work on social accountability approaches in health comes from Sub-Saharan Africa (specifically South Africa), Latin America, Indonesia, and South Asia. In structurally vulnerable communities—from Dalit communities in India to Indigenous communities in Guatemala—social accountability has served as a powerful vehicle to inform communities about their health rights and stimulate their involvement in advocacy to improve health services in their localities.[26] The impetus to mobilize and organize has stemmed from realizing that although the law mandates the provision of certain public health services, these services are not provided for these communities, or they are being provided in substandard or unevenly distributed ways. The goal of social accountability in vulnerable communities is to increase health care access by systematically recording malpractice and the lack of equitable access, as well as by organizing to demand compensation and improvement.

Targeting malpractice and the absence and poor quality of health services for Roma people in Europe

Coercive treatment and other violations of patients' rights to consensual treatment and confidentiality can break people's trust in health care systems. It has been pointed out that racialized groups experience this medical malpractice and abuse more frequently.[27] Moreover, with limited awareness about health care provisions and social benefits, these communities remain sidelined from many aspects of public life, including access to quality health care services.

Since 2010, in partnership with Roma civil society, the Open Society Foundations has supported citizen-based accountability and legal empowerment initiatives designed to advance health and human rights, challenge discrimination, and improve access to quality health care services for Roma people in Eastern Europe. The initial interventions initially focused on legal empowerment. However, it was soon acknowledged that legal empowerment, in which a majority of cases deal with individual situations, needed to be complemented with community-level accountability-focused organizing.[28] The combined approach of social accountability and legal empowerment was thus piloted for the first time in the case of European Roma people.[29]

In 2011, the first convening on social accountability in Roma health was organized. At the event, social accountability experts from India trained Roma activists from the Western Balkans, Romania, and Bulgaria. Additionally, a pool of activists attended trainings delivered by experts from the Public Service Accountability Monitor Initiative of

Rhodes University in South Africa and the University of Washington. In 2013, a regional network of Roma civil society and expert partners was established to support peer learning.[30] That same year, a new strategic focus on narrative change that aimed to challenge stereotypes about Roma people by health care professionals was implemented.[31] These new relationships and networks contributed to developing an international body of knowledge on social accountability and community monitoring, such as the Community of Practitioners on Accountability and Social Action in Health, to which Roma civil society organizations and experts have actively contributed.

These initiatives supported Roma civil society organizations in determining their approaches and adjusting them to their local contexts in the emerging Roma health field. While organizations in North Macedonia chose to focus collectively on specific issues such as immunization, those in Bulgaria and Romania chose to focus on a range of issues based on the prioritization of each community. Among these issues were illegal and informal cash bribes requested by medical professionals, access to the package of free medical services guaranteed by the law, access to pre- and postnatal care, and immunization coverage.

These social accountability and legal empowerment initiatives developed differently in different national contexts. In North Macedonia, the Association for Emancipation, Solidarity and Equality of Women (ESE) provided technical and methodological support for grassroots Roma organizations, including KHAM, National Roma Centrum, Initiative for Development and Inclusion of Communities, Romano Chachipe, Sonce, Association of Citizens and Educators for the Protection of the Rights of Women and Children, Association for Legal Education and Transparency, and Health Education and Research Association (HERA).[32] In Romania, it took longer for this approach to gain traction, largely because the Open Society Foundations initiative's inflexible conceptual and methodological design had ineffectively harvested local inputs. This approach eventually antagonized some of the more established Roma civil society organizations. Moreover, after Romania joined the EU in 2007, some Roma organizations began implementing large, administratively intense, EU-funded social service delivery projects and thus complemented state services. Finally, a dozen grassroots Roma organizations collaborating with Open Society Foundations were not confident that they could develop in-house expertise in conducting surveys and monitoring local health care policies and budgets without technical support. The Institute for Public Policy, a national watchdog organization, eventually stepped in to provide technical assistance, but this collaboration was short-lived as the organization went through a leadership transition and shifted its focus to the implementation of EU projects. As a result of largely top-down approaches and insufficient investment in building trust by donors, some Roma grassroots organizations did not fully embrace the hybrid approach of social accountability and legal empowerment, even after receiving training and technical support, and returned to social service delivery. Some organizations focused on addressing immediate individual needs through legal aid assistance, while others engaged in collective action based on existing health policy. The organizations piloting these approaches in Romania were O Del Amenca and APIS, which were Roma led, and Resource Center for Public Participation, Foundation for People Development, and Together for Them, which were non-Roma led. Despite the objective to support and develop Roma leadership, the abovementioned challenges, together with rigid, top-down methodologies applied by donors, resulted in a mixed composition of partners while some established Roma organizations withdrew their participation. In Bulgaria, several Roma civil society organizations with advocates in communities across the country (e.g., Largo Association, Center Amalipe for Interethnic Dialogue and Tolerance, World Without Borders, Thirst for Life, and the Diverse and Equal Association) adopted the hybrid social accountability and legal empowerment approach. Amalipe then offered technical support for grassroots initiatives such as the World Without Borders operating in the Stara Zagora region and the Largo Association based in the Roma neighborhood of Iztok in Kystendil. These partner organizations have since become well-recognized advocates for advancing health in their regions. Each organization has conducted regular community monitoring and evidence collection on health and social status and has used these data to evaluate policy implementation.

One of the most important cross-national outcomes of these initiatives has been the development of a more intense, and in some instances positive, relationship between affected Roma communities and local health authorities, which has resulted in the elimination of harmful practices and improved delivery of routine health services. Furthermore, authorities have begun to share information with Roma communities more transparently, which has led to a decrease in freedom of information requests regarding their health status and health interventions. Finally, the initiatives' focus on relationships based on mutual recognition, evidence-based consultation, and community outreach has resulted in some public authorities adopting social accountability or legal empowerment approaches as a formal mechanism for monitoring the impact of their health policies. Below, we explore the main lessons learned from these initiatives.

Increasing accessibility and eliminating malpractice

The combined approach has been effective in challenging discriminatory and harmful practices, such as informal payments, violent and abusive treatment by medical professionals, and child pregnancy and early marriage. Community organizers and civil society organizations have documented and reported many cases of disrespect, abuse, and systemic lack of communication on the part of general practitioners, dentists, gynecologists, and other specialized medical staff when treating Roma patients. In some instances, organizers and civil society organizations have also pursued strategic litigation.[33] The most common forms of malpractice identified include illegal payments imposed on Roma patients by medical professionals, unavailable dental care and other specialized services, and misinformation and coercive requirements for accessing health insurance, all of which limit their access to health services.[34]

In North Macedonia, KHAM in Delchevo has developed a constructive relationship with the gynecologist in their area, persuading her to increase the number of patients on her roster instead of charging illegal payments. Similarly, the Roma Women Association in Shuto Orizari and HERA have logged instances of requested illegal cash bribes, pressuring doctors to stop asking for these payments, while at the same time educating and accompanying local Romani women to ensure that they are not charged. Informal payments have been reduced significantly over time as a result of these efforts. Notwithstanding these examples of progress, and despite each country declaring universal health care coverage, large numbers of Roma people lack health insurance due to administrative hurdles and payment requirements.[35] In North Macedonia, KHAM successfully challenged a state practice of disqualifying from health insurance Roma people who unknowingly did not submit information about their income, which had resulted in criminal charges against Roma and other marginalized groups.

Another example of community-led action to establish missing specialized services is the provision of a dental cabinet for rural, majority-Roma communities in an area where there had been no dental services for several decades. Amalipe has gradually expanded the initiative by providing technical assistance to other civil society organizations and informal groups in 12 communities in all six regions of Bulgaria. It has also been leading advocacy efforts to introduce community monitoring as one of the formal monitoring and evaluation mechanisms for the National Roma Integration Strategies.

Furthermore, the majority-Roma community of Crnik in North Macedonia successfully mobilized to make services available from the general practitioner (GP) in their community. They organized to enact their right based on a regulation that stipulates that a municipality of their size should have a GP available in the community at least three days per week. With the support of

KHAM, which provided health education and helped local activists analyze the legislation and collect relevant documents, they submitted a petition to local authorities, resulting in a decision to approve a visiting GP service. Similarly, the Initiative for Development and Inclusion of Communities, Romani Chachipe, HERA, and ESE successfully lobbied the government to establish a gynecological clinic in the Roma neighborhood of Shuto Orizari in Skopje.[36] However, the new gynecologist began imposing informal payments, so the community mobilized again, and the graft payment practice was abolished.[37]

In our decade-plus experience exploring the best models of mobilization of Roma communities around health rights, we have discovered that in order to bring about structural change, there also needs to be a collective focus on accountability. Without such a component, mobilization efforts risk resulting in a continuum of random unsustainable administrative fixes. There is a need for strong community ownership in defining and rectifying harmful and discriminatory health policies.

Transparency and evidence-driven action

Doctors, nurses, and pharmacists routinely fail to provide adequate explanation to Roma patients about their medical conditions, and as a result, many patients with chronic diseases are unaware of their need for regular checkups. The work of Roma community paralegals and health mediators has resulted in improvements in health education among Roma communities, as well as in cultural competence among medical professionals.[38]

The advantage of the combined approach is that paralegals are recruited from communities to which lawyers might have limited access. Evidence from Romania and North Macedonia demonstrates that the availability of paralegal services in Roma communities substantially increases their ability to pursue legal claims related to health rights.[39] The paralegal sessions have been widely attended by community members, including both Roma and non-Roma people, who face challenges in the recognition of their rights as patients. This legal mobilization effort has become a source of integration and solidarity, especially in countries where public health systems are weakening or collapsing.

The focus on community-based accountability has enabled Roma communities to review how public health authorities implement formally declared commitments in their communities while at the same time placing the communities in constructive and evidence-based dialogue with authorities, often mediated by civil society organizations. When discrepancies between commitments and implementation have been identified, communities engage in evidence-based advocacy with relevant public authorities directly responsible for policy.

In Romania, Roma-led initiatives have succeeded in collecting relevant evidence on health inequalities endured by Roma people, which has been used in local negotiations with health providers and to contribute to national and European policy.[40] For example, during a measles outbreak in 2018, there were 64 deaths reported, including 58 children. All cases were from regions with large Roma communities that were insufficiently immunized. The Together for Them association, based in Cluj, mobilized the local Roma community living near a garbage dump on the outskirts of Baia Mare to demand their right to immunization. As a direct outcome of the association's work, immunization coverage, which had previously been below 50%, rose to over 60% in one year and continued rising thereafter.[41]

In Bulgaria, through door-to-door outreach, Roma civil society organizations have mobilized communities to identify and monitor health-related problems, tracking and documenting progress or lack thereof. They also support informal community-based groups in engaging in advocacy with local health care stakeholders. They have developed a system of citizen report cards (participatory surveys to grade public services), community score cards (compiling information on community experiences with public services based on focus group discussions), and social audits (community assessments of public records and on-site assessments of the utilization of public resources). Such monitoring has assisted Roma advocates in making evidence-based arguments to demonstrate system-level failures and in engaging with those in power to enact measures to address these failures. Among the most common issues that have been raised are graft payments, health insurance inaccessibility that limits access to health services, and lack of dental care and other specialized services. Organizations have addressed some of these issues directly, such as by identifying an eye care provider to offer consultations and provide glasses at reduced prices, while other issues have required more systematic engagement in terms of community awareness and advocacy.

The work of the Largo Association in the Roma neighborhood of Iztok in Kyustendil, Bulgaria, has also been acknowledged by national and international actors. Its community moderators have conducted regular community health status monitoring as a result of an annual action plan developed in partnership with the regional health inspectorate. Most of the association's outreach work has addressed sexually transmitted infections, immunization, and maternal health, as well as the implementation of a public ordinance that allows free gynecological examinations for pregnant women from socially excluded communities. These priorities emerged as outcomes of frequent community consultations and monitoring. For example, when the Largo Association uncovered the practice of Romani women being rejected from the free prenatal care appointment for uninsured women that is mandated by law, it worked together with the regional health care inspectorate to provide guidance to medical practitioners and enforce this right. It has also developed a productive relationship with the local hospital, resulting in increased satisfaction among Roma patients.[42]

In North Macedonia, ESE has developed a close working relationship with health authorities that enables channeling evidence collected by local Roma organizations, and their recommendations, directly to the North Macedonian government.

The evidence collected through community monitoring, budget monitoring, and social audits has fed into different policy monitoring and evaluation reports, including the review of the implementation of the national Roma inclusion strategies of the European Commission.[43] Consequently and quite uniquely, some EU documents and some national documents include data collected and interpreted directly by marginalized Roma communities in Bulgaria, Romania, and North Macedonia.[44]

Policy advocacy and adoption of approaches by public institutions

Roma-led initiatives have led to some cases of the institutionalization of community-led accountability efforts while preserving some degree of their watchdog capacities and professional independence.

In North Macedonia, several civil society groups set a common priority of monitoring the implementation of the National Program for Active Care of Mothers and Children and the National Prevention of Cervical Cancer Program. By documenting patterns of issues in terms of access to health services among Roma women and children in different parts of the country, the organizations were able to demonstrate that these are not isolated issues and to advocate for systemic health care reforms to eliminate the inequities experienced by Roma communities. The organizations identified key barriers faced by Roma people in accessing benefits and services provided by national programs and served as bridges between communities and health care professionals. One of the main outcomes of their work is that these national programs have introduced specific commitments to conduct educational sessions for vulnerable groups, including Roma women, with an associated budget allocation. The organizations have also managed to push for health budget increases for vulnerable communities. Moreover, with the support of HERA's informal group of Romani women from the Skopje neighborhood of Shuto Orizari, the National Roma Centrum in Kumanovo has focused its social accountability work on the sexual and reproductive health and rights of Romani women in North Macedonia. One of the outcomes of this work has been the inclusion of free contraception for women from marginalized groups in the Sexual and Reproductive Health Action Plan for 2010–2020.[45]

In North Macedonia and Romania, a law is under consideration to enable municipal funding for community paralegals.[46] Further, in 2018, the Ministry of Health and National Employment Agency of North Macedonia adopted social accountability approaches developed by civil society organizations to monitor the implementation of its health and employment programs. And the Open Government Partnership has trained its employees to partner with civil society in conducting social audits.[47]

In Bulgaria, some of the 12 community centers established by Amalipe have been receiving financial support from local municipalities since 2011. While this development has provided for more sustainability beyond private-donor project funding, it may have also affected their ability to hold local authorities fully accountable.

Obstacles to scaling up local-level interventions to national-level policy advocacy and the disconnect between the data gathered through community monitoring at the local level and the national policy advocacy priorities identified by civil society organizations remain the main challenges in the implementation of the combined approach to improving the health status of Roma communities. Many organizations have focused on meeting people's immediate needs through legal aid and individual trade-offs with local authorities, while refraining from striving for more systematic change. In this context, they have tactically opted for "liberal empowerment" that focuses on individual growth and the rational action of social actors based on individual interests, and have underexplored "liberating empowerment" as a process where those denied the ability to make strategic life choices acquire such an ability in terms of resources and agency for collective action and structural change.[48] This trend became evident when the COVID-19 pandemic hit Roma communities in 2020.

Community-led accountability during the COVID-19 pandemic

The impact and devastation of COVID-19 on Roma communities was twofold: the virus itself and the repressive, discriminatory, and double-standard emergency measures of the governments that ignored United Nations recommendations.[49] At the beginning of the pandemic, United Nations experts warned governments that their measures must not be used as a basis to target particular groups, function as a cover for repressive action, or be used to silence human rights defenders, and that state responses must be proportionate, necessary, and nondiscriminatory.[50] However, many Roma communities found themselves collectively quarantined by the army and police, with limited access to food, primary health care, and essential medicine. Elderly Romani people suffering from chronic diseases and pregnant women were the most severely affected. The supply of water and disinfectants provided at the entry points to the communities was often temporary and then discontinued after the emergency quarantine was lifted. Roma children were largely failed by education systems during the transition to online learning, as they were not equipped for distance learning (due to, among other things, a lack of access to internet, computers, and physical spaces for learning).[51]

Most local organizations and organizers promptly refocused their efforts to focus on the COVID-19 pandemic and reshaped part of their operations to humanitarian aid (e.g., in North Macedonia, where organizations implemented Red Cross services in Roma communities). During the early stages of the pandemic, they focused on ensuring that Roma communities had access to essential public health measures, such as disinfectants, testing, medicines, and vaccines, and that Roma outreach workers (health mediators, community nurses, and health emergency support staff) had access to adequate personal protective equipment. It became increasingly clear that in the context of their work, the largest challenges were misinformation campaigns and vaccine skepticism among Roma communities.

The latter became an overwhelming factor for community organizers and organizations practicing social accountability and legal empowerment approaches, as the high level of mistrust in medical interventions among Roma people—who have historically been subjected to unethical medical experimentation—grew ever stronger in the context of repressive and double-standard approaches from governments and public health experts.[52]

Even if there is anecdotal evidence that the communities supported by organizers responded better to misinformation campaigns and demonstrated higher vaccine uptake, organizers often withdrew from high-profile campaigning due to threats and personal assaults. On the whole, the COVID-19 pandemic deepened mistrust in medical interventions and rolled back some of the previous achievements of Roma-led initiatives in the areas of social accountability and legal empowerment.

Conclusion

Social accountability and legal empowerment initiatives aim at better aligning health care system priorities with human rights and right to health frameworks. These initiatives build on and highlight the work that Roma communities have been doing regarding their right to health and channel the support of non-Roma experts (including lawyers, scholars, human rights workers, and health professionals). They also challenge structural discrimination, racism, and "antigypsyism" in health care establishments, as well as incidents of malpractice and abuse in health care facilities. By promoting Roma participation and direct input in health-related decision-making and monitoring of health programs, these initiatives also help dismantle power dynamics that lead to the exclusion of Roma people. These initiatives also increase the legitimacy of professional Roma civil society organizations because they bring them closer to and make them more accountable to their communities.

However, it is also important to recognize that the application of rigid methodologies and top-down approaches in different national and local contexts has sometimes resulted in weakened trust, the imperfect harvesting of local inputs, and the withdrawal of key Roma civil society organizations.

Many Roma people live in poor and segregated neighborhoods. Spatial segregation and social exclusion are often accompanied by substandard living conditions, including poor sanitation, a lack of public utilities, and environmental hazards (such as toxic industrial waste, garbage dumps, floods, and the intermingling of waste and drinking water), all of which adversely affect their health. Beyond addressing discrimination in access to quality health care, many Roma civil society organizations and activists are working on the issues of housing, employment, and education. In fact, they were doing this before they started working on health, and thus, from the inception of these initiatives, they recognized the important role of social determinants of health.[53]

The most transformative outcome of this decade-long effort is that European health care systems have effectively become less hostile toward Roma people. The assistance of paralegals from the Roma community has lessened the open and outright abuse of Roma patients in health care settings. These paralegals have also been successful in reducing administrative barriers and providing access to personal documents, thereby fostering individuals' access to health care.

Most of the initiatives have developed specific thematic foci on improving the reproductive health of Romani women, the immunization of Romani children, and individuals' access to personal identity and health insurance documents. Perspectives related to gender and youth have thus been central to the overall framework of these initiatives. Although we can argue that reproductive health and children's health are the most developed areas when it comes to legal mobilization around Roma health, there are mixed results, with no clear trend predicting broader structural change in these areas.[54]

While these community-organizing initiatives are well endorsed and adapted to local and national contexts, more effort needs to be made to develop collective advocacy-focused and community-driven actions that tackle structural rather than individual factors affecting Roma people's right to health. Roma people continue to be described as "hard-to-reach communities" by public health and medical professionals, and they are often portrayed as being responsible for their unequal access to health care services. Although segregation in health care facilities has been legally challenged, it continues to be practiced across Eastern Europe.

Scaling up local and community-level initiatives to national policymaking and the disconnect between the evidence from community monitoring at the local level and the setting up of national-level advocacy priorities are the main remaining challenges. The focus on administrative procedures and local health care practices has been effective but has not brought about transformative change in the broader legal and policy systems. Although most organizations have developed solid skills in documenting and organizing legal cases exposing medical and bureaucratic malpractice in health care, they have yet to find a way to use this evidence to develop impactful strategic litigation and advocacy plans. In reality, grassroots organizations and community organizers have found it difficult to utilize the evidence for developing purposeful legal and policy change efforts. Moreover, focusing on meeting immediate needs through legal aid and individual trade-offs with local authorities, while refraining from striving for more systematic change, has had consequences in their communities in terms of keeping communities in a passive recipient position, while civil society organizations take on the role of service providers.

Furthermore, while community paralegals have greatly assisted individual Romani patients and been effective in helping Roma people make use of the health care system, human rights lawyers and the Roma movement more broadly have yet to capitalize on these local successes. Most of the lawsuits submitted to courts make use of criminal and not civil (antidiscrimination) laws. Most of the paralegals and health organizers prioritize mediation approaches. We argue that this is the right approach and that human rights lawyers and professional civil society organizations are structurally better positioned to engage in confrontations with the state. The paralegal work has relatively small transformative potential if strategic litigation and policy advocacy are not sufficiently employed to take up their communal work and confront the state. It is also because of the above challenges that "limited consensus remains on the effectiveness of legal empowerment interventions in optimizing health outcomes."[55]

We also recognize that limited access to quality health care services does not fully explain the gap in Roma health outcomes. The poor health status of Roma communities is significantly determined by social and environmental inequities, their living environment, and the political and socioeconomic context in which they live. Racism and ethnic discrimination would continue to determine the health outcomes of Roma people even if national health care systems were efficient. Advocates must therefore engage in efforts that go beyond the right to health and integrate all of the aspects of social, economic, and political life that determine the health of Romani people.

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