PRESIDENTIAL PORTFOLIO REVIEW: SOCIAL ACCOUNTABILITY FOR ROMA HEALTH

Open Society Foundations- Public Health Program

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BACKGROUND

This portfolio review looks back on the Public Health Program's (PHP) efforts to introduce and expand social accountability approaches among Roma-led and Roma-focused civil society organizations in order to advance the health rights of marginalized Roma communities in Central and Eastern Europe (CEE). Although the first efforts to introduce these approaches date to 2010, this review focuses on the period between 2013-2015 when the approach was increasingly adapted to the regional context and its expansion beyond the testing stage became possible.

By the time PHP began introducing social accountability approaches into our Roma health portfolio, we had been working in the Roma health field for approximately five years, with an emphasis on health scholarships and the development of innovative service models such as Roma health mediators. Social accountability was one of two approaches, along with legal advocacy, aimed at better aligning our Roma health portfolio with the PHP's human rights-focused goals. Two of the PHP strategic goals were relevant for this work: challenging the health establishment to promote human rights by exposing and addressing lack of access, discrimination, abuse, and torture in health care; and influencing power dynamics that led to the marginalization of Roma in the health care system, by promoting Roma participation in health related decision making. In 2013, PHP added a third new strategic focus on changing narratives about Roma in health care, promoting a new narrative that dismantled existing myths and stereotypes that perpetuated the discrimination of Roma in the health care system.

Starting in 2005, the Decade for Roma Inclusion governed the relevant policy environment in Europe, bringing Roma rights to the forefront on the EU agenda. The Decade led to the adoption of several EU and national commitments, and in many ways was the precursor to the EU Framework for National Roma Integration Strategies adopted in 2010. The EU Framework, which is still active, focused on four key areas: education, employment, healthcare, and housing. In its chapter on health, the Framework highlighted significant inequalities that required EU concerted efforts by 2020. Among these were lower life expectancy among Roma on average ten years shorter than other Europeans, high child mortality rates often two to six times higher than in the general population, and low vaccination rates among Roma children. The Framework also recognized the link between discrimination in health care and poor health outcomes.

While the adoption of these policies was a critical step in promoting political will and action across Europe, the policies' implementation lagged behind as the situation of Roma remained the same or even worsened. There were many factors that impeded their progressive implementation, including continuous political instability in some of the EU's newer Member States, the politics of austerity, and the perpetual scapegoating and "othering" of Roma in societies across Europe. PHP also believed that the policy-practice gap was partly due to the lack of grassroots

mobilization by affected communities to claim their right to health care. This included a lack of credible, locally generated evidence about issues with service delivery, and a failure to organize coordinated action by communities, health, and political stakeholders in order to bridge the gaps systemically at all levels. We assumed that equipping communities with credible information about the implementation (or lack thereof) of Roma inclusion policies related to health and putting them in constructive dialogue with local decision-makers would help to close the implementation gap.

At the same time, experiences from across the globe had demonstrated the immense potential of social accountability as a powerful vehicle for active and meaningful participation of marginalized citizens in defining health issues of concern and informing decisions about the services they need. Social accountability refers to a combination of approaches such as community monitoring, social audits, and budget monitoring used to promote civic engagement in order to hold governments accountable to their policy commitments. In marginalized communities of other parts of the world, from Dalit communities in India to indigenous communities in Guatemala, social accountability had served as a powerful vehicle to inform communities about their health rights and stimulate their involvement in advocacy to improve services in their localities.

It was the combination of the policy-practice gap in Roma health and these stories of empowerment that propelled us to explore social accountability approaches with Roma communities in CEE. From the field of social accountability, the work with Roma communities largely utilized *community monitoring* methodologies. Community monitoring entails the systematic documentation and review of the availability, accessibility and quality of services against specific government commitments or standards by the actual beneficiaries of services, for the purpose of conducting advocacy with providers and policy makers in order to improve access and quality of the services. Such monitoring assists Roma in making evidence-based arguments that demonstrate system-level failures and engage with those who hold the power to enact measures that address these failures.

As this was a concept driven by PHP, we connected with our national foundation partners in order to garner interest in testing and adopting this approach. In 2011, in partnership with the Foundation for an Open Society in Macedonia (FOSIM) we organized the first convening on social accountability in Roma health in the region, where we invited social accountability experts from India and potential partners to discuss taking this approach forward in CEE. Following training by the Public Service Accountability Monitor (PSAM) for interested NGOs at the School of Journalism and Media Studies at Rhodes University in South Africa, we made the first grants in Macedonia in 2011. These grants were made to organizations which had attended the 2011 convening, based on recommendations by FOSIM and their existing status as grantees of FOSIM and / or other PHP projects, and who had demonstrated their interest in community monitoring as a tool for advocacy. Annual convenings since then have served as a space to promote the approach, share lessons, discuss adaptations to national and local contexts, and bring other NGOs on board with this work. Consequently, we expanded the work first to Bulgaria and then to Romania. Since 2013, we have had an established portfolio on social accountability[1] in Roma health and a network of partner NGOs and experts that have successfully tested and adopted this international approach to their regional and national contexts and the experiences of Roma communities.

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[1] This portfolio was located initially within PHP's former Accountability and Monitoring in Health Initiative (AMHI), and then within the Roma Health Project in collaboration with AMHI. Since 2015, following the PHP redesign, it has been part of the Ethnicity and Health Equality Subtheme within the Health Law and Equality Division.

DEFINING THE SCOPE AND INTENDED OUTCOMES OF THE PORTFOLIO

Across the portfolio our desired outcome was that the most excluded Roma communities would be able to use community monitoring to better recognize and claim their health related rights and hold governments accountable to their health related commitments. With this as our overarching goal, we encouraged the different grantees to define the policy areas of greatest priority to them. Thus, while organizations in Macedonia chose to focus collectively on a particular issue such as immunization, those in Bulgaria chose to focus on a range of issues based on what each community prioritized. Among these issues were informal payments requested by medical professionals, access to the package of free medical services guaranteed in the law, and access to pre and post-natal care. This approach aligned with the deliberately experimental nature of this portfolio, meaning that we largely did not intend to achieve one single change in health policy or service delivery across the region, but rather to pursue different types of tactics and strategies in particular countries.

We recognized that the approach evolved differently in different national contexts and made relevant adjustments throughout the period of this review, including ending work with NGOs and communities where the approach did not gain traction, such as Roma SOS and National Roma Centrum in Macedonia, or expanding the work to more communities, and increasing the capacity of the most promising partners to serve as regional resources on this approach. An unanticipated outcome was the recognition by some NGO partners that this approach might be embraced by national governments and the EU as a formal mechanism to monitor and evaluate the implementation of national and EU policies directly by those impacted by these policies. Amalipe did the most to promote this approach as a participatory monitoring and evaluation process, and has been advocating at the EU level for its adoption as one of the official methods for monitoring the implementation of National Roma Integration Strategies. For the first time the European Commission’s Annual Communication on Roma, due to be published in June 2016, includes input collected directly by marginalized Roma communities in Bulgaria.

(I) Project grants for implementing social accountability approaches: ($1,369,805)

We used grant making as the primary vehicle to expand social accountability beyond the testing and adaptation stage of the previous years. We pursued two tactics in this regard: grants to new NGOs following their attendance at annual convenings and a formal expression of interest to develop this body of work; and support to existing partners for disseminating the approach to other NGOs and informal community groups through training and technical assistance. Grants were primarily focused on community monitoring approaches, rather than, for example, budget monitoring. Organizations used tools such as citizen report cards (participatory surveys to grade public services), community score cards (compiling information on community experiences with public services using focus group discussions) and social audits (community assessments of public records and on-site assessment of the utilization of public resources). We also adjusted our strategy depending on the opportunities and limitations presented by each country.

In Bulgaria, we provided the most significant portion of our grant funding to Amalipe, a Roma-led NGO with strong presence in Roma communities through informal groups or established community development centers across the country. Initially, Amalipe mobilized a few communities to monitor commonly identified health-related issues every six months, tracking and documenting progress or lack thereof. It then supported the groups to engage in advocacy with local health care stakeholders to address the identified issues. Common issues were unofficial illegal payments imposed on Roma patients by medical professionals, which limited their access to health services, lack of dental care and other specialized services, and misinformation about the requirements for accessing health

insurance. The community addressed some of these issues directly, such as by identifying an eye care provider to give consultations and provide glasses at reduced prices, while other issues required more systemic engagement in terms of community awareness and sustained advocacy. Building on the success registered in the first few communities, Amalipe gradually expanded the work by providing technical assistance to two other NGOs in different locations in the country and to informal community groups in all six regions of Bulgaria. Amalipe also recognized the power of direct input from those at the receiving end of national and EU policies into shaping and revising such policies. Consequently, it has been leading on advocacy to introduce community monitoring as one of the formal monitoring and evaluation mechanisms for the National Roma Integration Strategies.

In Macedonia, a relatively small country with centralized government, we identified one national level partner, the Association for Emancipation, Solidarity and Equality of Women (ESE) to lead on the implementation of social accountability work by four other partner organizations working at the grassroots level in Roma communities. This set up allowed for better coordination of advocacy among the grantees. The groups set common priorities such as monitoring the implementation of the National Program for Active Care of Mothers and Children, with the intent of providing a stronger evidence-base for advocacy than any one NGO could have provided on its own. By documenting patterns of issues in terms of access to health services in Roma communities in different parts of Macedonia, the NGOs could justify that these were not isolated exceptions and demand systemic changes to the way the health care system addressed the needs of Roma communities. The NGOs were also able to identify key barriers within the communities to accessing benefits and services provided through national programs, and served as a bridge between the communities and the health care system.

In Romania, the work did not have the traction we hoped or expected, mainly because the interested NGOs were overwhelmed with large EU funded projects that prevented them from taking on a new body of work entailing modest financial support from PHP. Additionally, small grassroots NGOs were not confident that they could develop in-house expertise in conducting surveys and monitoring local health care budgets. When we engaged the Institute for Public Policy (IPP), a national public policy/watch dog organization to provide the needed technical assistance, other organizations relied on IPP to carry out monitoring of policy implementation at a local level and national-level budget monitoring, rather than internalizing this expertise themselves. Following an open call in 2014, we supported the NGO Together for Them to pilot community monitoring in Baia Mare. The organization operated in one of the most marginalized Roma communities in Romania, where blatant human rights abuses perpetrated by local authorities had been the subject of media exposés for the past years with no consequences. Given that this community was extremely disempowered, they relied very heavily on Together for Them to act directly on their behalf and to advocate for them, making it very difficult to engage community members as mobilizing leaders. The failure of the 2014 open call to attract more suitable organizations was also indicative of the challenges in taking this work forward in Romania.

(II) Technical assistance for testing and scaling up the social accountability approaches through consultancies, convenings, and peer exchange visits: ($193,346)

The portfolio under review was characterized by a desire to introduce to the Roma health field an approach that had been developed in other geographies and with other marginalized populations. Consequently, a significant component of support was comprised of technical assistance and capacity building. As noted, this work commenced with a convening to bring together potential implementing organizations and international experts in the field of social accountability. We continued to draw on international expertise, particularly that of Dr. Abhijit Das of the Center for Health and Social Justice in India, throughout the reviewed period. Dr. Das and others

provided remote and on-site advice to organizations and oversaw the development of their social accountability work in their own national contexts. Peer learning across implementing organizations in CEE, as well as between those organizations and international counterparts, was facilitated by multiple convenings in CEE, and by visits by CEE organizations to India and Guatemala where this work was more established. This sought to enable a continuous transfer of knowledge among practitioners in India, Guatemala, Macedonia, and Bulgaria where more experienced practitioners helped identify the appropriate community monitoring methodologies for Roma communities, and CEE organizations were eager to learn from international best practice and ambitious to apply that learning in their own communities. These relationships also contributed to developing further the international body of knowledge on community monitoring by showcasing what could be achieved through community monitoring in Roma health in international practitioners' materials, such as the Community of Practitioners on Accountability and Social Action in Health (COPASAH) newsletter.

An additional important component of this work was connecting small grassroots implementing organizations to the larger organizations that were more proficient with the approach and could translate social accountability approaches to national and local contexts. In two of the targeted countries, Bulgaria and Macedonia, well-established national organizations, which were supported as PHP Field grantees, played a critical role in acquiring advanced expertise on social accountability and transferring it to national and local grassroots organizations in their respective countries. These organizations were also more developed in terms of their policy advocacy skills and capacity. We considered this very important as they could bring in literacy on existing laws and policies, which would form the basis for monitoring, and help connect local evidence to national policy efforts. These organizations were therefore supported by PHP in both project implementation and capacity building functions. Often, they were also the principal participants in international exchange visits, while local level organizations engaged in CEE peer-learning meetings. Efforts in Romania for IPP to act as a national resource organization were, as noted above, less successful in this regard than those in Bulgaria and Macedonia. National and grassroots organizations formed strong and mutually beneficial partnerships, engaging in joint advocacy and sharing experiences in their national context in order to help shape ongoing implementation. There was, however, a heavy reliance on the national organizations to conceptualize and lead the work, explored further below.

(III) Grants for the development of advocacy capacity and media advocacy tools ($74,755)

We used grant making to enhance the advocacy capacity of partner NGOs by supporting them to attend training and access relevant tools, as well as by developing video materials about their work that they could use in order to amplify the community voices and expand outreach. Our intention was to complement the written material generated through community monitoring with audio-visual material that included personal testimonies in order to provide a more a vivid and engaging way to present the evidence and put forward advocacy asks.

In Bulgaria, a short video that documented the social accountability work in practice served to encourage new communities to take this work on board, to promote the approach as a monitoring and evaluation tool for the implementation of the EU-mandated National Roma Integration Strategies, and in some cases to get the local government to cover the salaries of community moderators[2].

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[2] Community moderators act as the interlocutors between members of the community and the implementing NGO. They are trained on both the rights and entitlements which apply to their communities, and on how to engage community members in monitoring and mobilization activities, and also lead monitoring activities in the field to collect information for use in advocacy.

In Macedonia, we made a grant to the Youth Education Forum to develop the advocacy capacity of community monitoring partners. This included basic advocacy methods as well as more in-depth exploration of various aspects such as messaging, branding, and engagement with traditional and social media. Our intention was to introduce grantees to a range of options for pursuing their advocacy goals, and enable them to combine the most relevant tactics based on the context in their communities. This was a welcome assistance as many of the partners had no previous training in advocacy. For example, this work supported the NGO Kham to devise an effective advocacy strategy for increasing infant immunization rates in two localities, Crnik and Delchevo. Through community monitoring, Kham had identified that the main cause of low immunization rates among infants in these localities was the lack of transportation options for health professionals from the nearest clinic. Although free immunization was guaranteed in the law, the government had not made the infrastructure investments needed in order to implement this law. Doctors and nurses had no means of traveling to remote localities, and parents had no other option but wait for the medical professionals to come to the community and vaccinate their children. Using direct engagement with local stakeholders, a comprehensive community mobilization via a petition to the national government, and a radio campaign that mobilized allies regionally, Kham was successful in getting financial allocations in the budgets of the regional health department for a vehicle and fuel.

Despite important outcomes such as this, the inclusion of media advocacy as an integral part of the grantees' advocacy work was overall limited and heavily dependent on our own initiative to introduce relevant opportunities to the grantees.

REFLECTING ON OUR IMPACT

Our goal for this portfolio was that the most excluded Roma communities would be able to use community monitoring to recognize and claim their health related rights and hold governments accountable to their health related commitments. As we look back, we have been able to distill four discrete ways in which the work was able to advance this goal. We discuss each briefly before turning to lessons learned: (1) revealing and narrowing the gap between policy and implementation; (2) increasing community ownership and participation in broader issues; (3) fostering innovations in social accountability approaches for Roma health; and (4) institutionalizing and sustaining the social accountability approach.

Revealing and narrowing the gap between policy and implementation

The work sought to document the gulf between progressive policy and implementation at service-delivery level for communities, including through legitimizing the experience of those communities and elevating the evidence of that experience into local and national advocacy. The extent to which this resulted in concrete measures to close that gap was varied. For example one community in Macedonia successfully used social accountability methods to demand medical services in their village. The formal basis for this demand had been a policy provision based on which certain size communities that are not located in the vicinity of a town with medical facilities, are eligible for their own medical service. Through focus group discussions held as part of the community monitoring work, the village became aware of these legal provisions. Following evidence-based engagement with the local government that included the submission of a petition to the mayor signed by all the residents of Crnik, the community convinced the mayor and the public health department to allocate a doctor to work five days per week in the village.

Through this work, we observed a distinction between cases in which there was no political will to address the issues highlighted in community monitoring, versus those where political existed or could be generated, but where there were other extenuating factors needing systemic change, such as fair resource allocation.

The situation in Baia Mare, Romania, is a clear example of the former. The NGO Together for Them had focused its monitoring on the failure of the local government to implement the national TB prevention program. Using the social audit methodology, the group worked with the community to build the evidence of the lack of access to these preventive health services. They then sought to build alliances with health institutions, but were faced with outright lack of interest by local officials who refused to institute any of the necessary changes in local service provision. Evidence and mobilization by the community, or the NGO, was ineffective in the face of political animosity towards the Roma community.

In other instances, evidence of service gaps and advocacy with local decision-makers did lead to change. In Shuto Orizari, Macedonia, for example, following the development of community scorecards and the documentation of over 130 cases of discrimination when visiting gynecologists in the main clinics, a mobile gynecological service was made available in the community. However, in both Shuto Orizari and Crnik, filling gaps in health services in particularly rural areas was hampered by the lack of interest by clinicians to work in the Roma community. This speaks to a larger challenge: while documenting the gap between policy and implementation is likely to be valuable in itself in terms of validating the experience of the community, it carries a risk of disempowerment or unmet expectations if acceptance by decision-makers of the evidence of the implementation gap does not lead to the allocation of greater human or financial resources to close the gap.

Irrespective of policy guarantees on paper, grantees tended either individually or collectively to identify changes in local health service delivery as the focus for both monitoring and advocacy at local level. Communities considered these local level services to be more relevant than regional or national services as they were most visible to them. As decision-making was highly centralized in Macedonia and Bulgaria, and the organizations were largely not national level advocates, community monitoring could identify the changes which were in fact possible at local level. Grantees could then work with their local stakeholders such as local doctors who were charging illegal fees, officials from health institutions who were making decisions about clinic opening hours or the availability of services, to advocate for service improvements. An example of success in this area occurred in Bulgaria, where the NGO LARGO used the method of community inquiry and ensuing advocacy and collaborative engagement with the local public health office to win the provision of appropriate pre and postnatal care to uninsured women. Improvements in health services proved particularly successful where local officials could be developed as allies by the organizations and where it was possible to normalize relationships between communities and decision-makers.

Where changes were identified in terms of addressing systemic gaps at the national level, organizations would typically work directly with the national or technical resource organizations like Amalipe or ESE, or with other national advocacy organizations to coordinate their advocacy with national decision makers.

Increasing community ownership and participation in broader issues

The success of any social accountability effort relies on genuine community participation and ownership, and this portfolio was no exception. In this case, taking a participatory approach meant not addressing health in isolation, but rather using *existing* community platforms to ignite interest and engagement in health issues. For example, in Amalipe's efforts to engage communities in Bulgaria on health service changes, they often used community events such as a football game or a youth club to start a conversation about engagement with health services. This helped

to foster community recognition of their stake in health issues, rather than imposing an advocacy agenda by a large NGO. In Macedonia, as the NGO Kham became more well known for its work on health, there was a growing appetite of members of the community to apply community monitoring to other issues, such as access to social benefits. In this regard, the deepening of rights literacy and community participation may have outstripped specific changes in health services as an outcome of the work. In Macedonia and Bulgaria, grantees noted that communities' perspective on what was possible slowly changed. This may have led to attitudinal change in the way Roma interacted with the health system, increasing their agency to seek services and willingness to take action when their rights were not fulfilled. This kind of attitudinal change has the potential for broader resonance beyond health services.

Fostering innovation in social accountability approaches for Roma health

As we developed this work particularly in Macedonia, we realized that social accountability methods were being used by organizations who were also implementing legal empowerment work. A natural shift occurred towards integrating these two approaches in an effort to achieve efficiencies and mitigate the shortfalls of either approach. The two approaches indeed have much in common. Both start from the perspective that communities' agency needs to be strengthened in order to tackle systemic failures in rights protection. Such strengthening may include raising awareness about rights or what citizens ought to expect in terms of health services, mobilizing communities to monitor instances of breaches of these rights, and demanding better performance from state officials. Both approaches also seek to invest in ongoing and long-term processes of creating more active citizens, rather than just tackling specific instances of poor services.[3]

At the same time, the two approaches also differed, with legal empowerment tending to focus more on redress for individual claims, and social accountability focusing more on group issues that could be addressed through advocacy for system-level changes in policy or service provision. Blending two approaches with similar aims allowed for efficiencies in resource deployment, as the same individuals were sometimes acting as both community monitors in social accountability projects and paralegals in legal empowerment projects, as well as more coherent grant making for PHP and FOSIM. This evolution in Macedonia proved central to the thinking behind a new PHP concept on the integration of social accountability and legal empowerment across a number of geographies. The implementing organizations in Macedonia will also form part of PHP / FOSIM work on the OSF Legal Empowerment Shared Framework.

Institutionalizing and sustaining the social accountability work

We learned that the question of sustainability of social accountability approaches is a complex one, and needs to be interpreted in a number of ways. On the one hand, there may be opportunities for governments to recognize the utility of methodologies like community score cards and social audits to provide a citizen feedback loop on the provision of services, and to use such approaches to monitor how national level policy, services, and resources are executed at a local level. For example, in Bulgaria, efforts are underway to promote community monitoring as a government-recognized approach to assess the implementation of the National Roma Integration Strategy, and to secure local government funding for community moderators who would play a formal role in mobilizing the community and implementing the actual surveys that are part of the social accountability method. In this way,

[3] For further reflections on the integration of these approaches, see T.Ezer, R.McKenna, M. Schaaf, Expert Meeting on Social Accountability and Legal Empowerment: Convening Report, https://www.opensocietyfoundations.org/publications/expert-meeting-social-accountability-and-legal-empowerment

community monitoring could become part of the institutional and state-funded architecture for ensuring delivery of health services for Roma communities in a way that promotes participation of those communities.

While this approach to sustainability is an important one, valuing the community voice in the implementation of health policy may not always require the securing of funding for the particular methodologies that PHP has supported. Sustainability may also refer to the continuous involvement of communities in assessing whether their health needs are being met, normalizing the relationship between communities and decision makers and health officials, promoting dialogue about whether services are being delivered, and building acceptance of the legitimacy of community perspective on those questions. This latter outcome has been the case for work in Macedonia.

LESSONS

Below we reflect on seven initial lessons from this work, either from a programmatic or grant-making perspective.

PROGRAMMATIC LESSONS

The need to link local to national

The vast majority of this portfolio focused on local engagement with health service providers and decision-makers. In practice, this meant developing local community leaders to engage with their communities, to monitor the health experiences of those communities, to present that evidence to local stakeholders such as mayors, local health officials and clinicians, and to advocate for solutions that were within the mandate of those local stakeholders. Through negotiation between communities and those who hold power in most proximity to them, tangible changes were seen, be they preventing the charging of illegal fees by health professionals in community clinics or making services more widely available. The dialogue itself, even apart from the concrete changes that resulted from it, proved beneficial in building recognition within communities of the legitimacy of their voice and the normalizing of engagement between Roma communities and those who hold power.

At the same time, this very localized approach in the midst of problematic national policy highlighted the need to develop more national advocacy work. In Macedonia for example, monitoring and local advocacy by a number of different organizations on immunization highlighted shortfalls in the frequency of local nurses in visiting Roma families. As well as addressing this with local officials, organizations reached out to Roma and non-Roma organizations to undertake national level advocacy to address funding cuts in health prevention programs in the national budget that had undermined program performance at local level. We learned that even with successful social accountability work, there remained a need to develop the capacity of larger organizations such as ESE or Amalipe to analyze how local issues result from systemic policy, legislative, or budget deficits nationally, and act on these challenges.

The need to sharply define and understand success

While we have not done a comprehensive review of all of PHP's social accountability work, the outcomes of community monitoring work for Roma health seemed to prove different from PHP-supported work on social accountability focused on other populations. For example, budget monitoring for harm reduction services in Macedonia could be measured by the relative levels of allocation and resource expenditure on needle exchange and

substitution treatment services. This is an important and compelling metric. In relation to Roma health, the elements of success proved more difficult to measure. For example, we were interested in markers of success such as the empowerment of communities, their rights literacy, their mobilization, and the engagement of decision-makers with those communities as constituencies of interest and sources of power. Clarity about the balance between community empowerment and concrete changes in health policy, services or resource allocation is important in determining the direction and understanding of success for this work. In particular, as we look ahead to the expansion or sustainability of social accountability approaches in this field, we may not focus as much as we did earlier on indicators of implementation of National Roma Integration Strategies, or other national level health policies, but rather on whether and how power relations in communities in which we have supported this work have changed, enabling communities to engage in the long-term in definition and shaping of policy outcomes.

The need to distinguish between NGOs, leaders, and communities

While this work took place within marginalized Roma communities living in various degrees of integration with the non-Roma population, it was distinctly led and facilitated by implementing NGOs. These included NGOs who were based in those communities as well as those providing capacity and implementation support from afar. A key mode of bridging NGOs to the wider community was the identification and development of local individuals as leaders for this work, oftentimes a cadre of individuals who held influence in their communities without occupying formal leadership roles. These individuals proved critical to fostering buy-in from the wider community, to carrying out monitoring efforts, and to mobilizing communities to engage with authorities. The capacity of these individuals to be leaders in their communities will continue beyond the involvement of NGOs providing technical and financial support. While this approach generally succeeded, we also learned that it depended on the personal motivations of these leaders, and that it was unlikely that communities would remain uniformly active in claiming their health-related rights in the absence of the NGOs that had driven the work. Looking back, it would have been important to define the conditions within the communities that would enable this work to continue independently and target some of our investments in support of solidifying these.

<u>PROCESS AND GRANT-MAKING LESSONS</u>

The challenges in transferring agency and knowledge

This portfolio included a strong component of civil society support in the form of both capacity building and technical assistance from social accountability experts. It is notable in this regard that those implementing this work in the region were slow to develop their own identity as experts in this field. We observed a frequent default of turning to the established experts from other parts of the world to guide future development. Practitioners also did not pursue opportunities to establish more of a regional identity or regional coordination of this work, for example, as part of the global network of COPASAH. We attempted in 2015 to change this dynamic and to encourage regional leadership, by engaging Abhijit Das to mentor two Macedonian practitioners as resource people on community monitoring for Roma health in CEE. The success of those efforts remains to be proven moving forward, as the engagement of Dr. Das is being reduced significantly, and the regional experts have the space to act independently.

This portfolio review is also an occasion to reflect on the power dynamics which were established by the heavy reliance on one foreign, OSF-paid consultant in particular, and his prominence in the eyes of organizations as the holder of the answers on how work should be developed, as well as a privileged relationship to the funder. As this consultant was the resource person for initial workshops to introduce community monitoring to many of the organizations in the region, and was then called upon to provide technical assistance or to lead further workshops, a

power dynamic was established that consultants could provide ‘answers’ on the accountability approaches and adaptations to community monitoring that organizations should pursue, rather than them experimenting with adaptations based on their own experiences and instincts.

Efforts to broker the appropriate relationship between capacity building organizations such as Amalipe, ESE, and IPP, and those implementing community monitoring at local level also yielded lessons, with a need for the former to have credibility and legitimacy in the eyes of the latter. At both levels, knowledge and agency were seen to reside further upstream. Implementing organizations tended to see the capacity building organizations as driving the work, while capacity building organizations tended to see the international resource people as having better knowledge of how the work might evolve. The transfer of knowledge and learning was therefore limited.

A different challenge in terms of the agency to drive this work played out in Romania, where Roma-led organizations were resistant to this work being led by non-Roma IPP. That Roma-led organizations were in a position to secure significant other EU funding for other work, combined with the Roma/non-Roma dynamic, meant efforts to build community monitoring work in Romania were significantly curtailed.

In hindsight, it would have been more appropriate to reduce Dr. Das’ involvement earlier on, in order to create more space for emerging CEE experts to come forward with their own ideas and drive the learning agenda for themselves and the organizations they were mentoring.

The value and challenges of transitioning from concept to field

While this work was originally driven by PHP as a concept aimed at applying an approach prevalent in South Asia, Eastern and Southern Africa, and Latin America to a new geography and a new population, this work subsequently became part of the core work of a number of Roma health organizations, who are now overseeing the evolution of the work in a way that is more consistent with support to the field. Consequently, we decided to adapt our grant-making posture midstream, moving some grantees to more flexible support and reducing the intensity of the substantive input and technical assistance provided. In doing so, we also learned we needed to change our expectations of organizations. It would be useful to see in particular the technical assistance organizations taking more ownership for the development of this work and to consider both what success looks like for the work to them and their local partner organizations, and the communities with whom they work, and how this work might evolve to deliver that success. For either of those components to be determined by PHP or international consultants would be problematic.

Coordination within OSF

While our default within PHP is to collaborate with our network and foundation partners, this review has given us pause to consider that perhaps we underestimated the importance of engaging OSF partners earlier on in the process, not only in information-sharing but in joint decision-making. For example, we encountered difficulties when supporting Amalipe to scale up the work in order to cover all six regions of Bulgaria at the same time as RIO was considering this organization for institutional capacity building support. Our strategy to provide increased support to Amalipe was in tension with RIO’s expectation that the organization would focus on consolidation, rather than growth.

This situation has shown us that it is too late to reconcile such expectations once a grant is already in process or in the late planning stages. In order to truly benefit from the expertise and experience of our colleagues, we would have needed to engage much earlier on in the process and agree on a common strategy that reconciled the need for programmatic growth with the focus on organizational strengthening.

In another respect, we learned from this portfolio that social accountability approaches are relevant to other aspects of Roma inclusion besides health. Further engagement with RIO and HRI will be needed in order to explore whether we could build on this work to benefit other areas of focus for OSF grantees in the Roma field, such as social services, and housing and sanitation. This portfolio review has already provided a platform for joint reflection with RIO, including in a pre-portfolio review teleconference, and we will continue this reflection and planning after the review.

Inadvertent default to one year project based support

As part of this portfolio review process, we couldn't help but notice the prevalence of one-year grants for project support despite a consciousness within the PHP about the value of flexible multi-year support. This may speak to several factors, including risk aversion when adapting a method to a new region and population, heavy engagement with grantees to define the work from year to year, and self-imposed budgetary constraints. It also links to the points above about reliance on consultants to validate the evolution of the work from year to year. Looking back, we could have moved some grantees to multi-year support and diversified our grant making earlier to move beyond project support, in order to enable grantees to run with their ideas more freely and experiment with the work.

CONCLUSION

In this portfolio we aimed to introduce a new approach to developing the agency of Roma communities in order to claim their health related rights, which had proven effective with indigenous and other marginalized communities in other parts of the world. This served as an excellent opportunity to equip Roma-led and Roma-focused organizations with novel tools and approaches to address systemic health rights issues faced by Roma in CEE.

This portfolio had many successes in terms of amplifying the influence of marginalized Roma communities whose voices had often been ignored or disregarded by policy and local decision makers; normalizing engagement between health professionals, policy makers, and Roma communities; and effecting concrete changes in health service delivery and health outcomes at local levels. It also provided the opportunity to learn key lessons that will inform the next stage of our work in this area.

Developed as a concept as first, the work became gradually an integral part of the Roma health field, especially where grantees had a long history of engagement in health. As we continue to support the building of this field, it will be critical to reflect on the level of our own operational involvement (via input during the proposal development stage and the organizing of convenings and technical assistance) and finding the most effective ways to provide the space and opportunities for established CEE leaders to consolidate, expand, and continue to innovate in this area of work. This may also align with RIO's increasing focus on organization-focused grant-making in the context of the three OSF-wide Roma goals.